‘The Going Digital Study’ – The implementation of electronic patient records in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications

Philippa Catherine Elizabeth Sipanoun
[redacted]
https://orcid.org/0000-0001-6329-645X

Doctor of Philosophy
UCL Faculty of Population Health Sciences
University College London

March 2022

This research was funded by Great Ormond Street Hospital for Children NHS Foundation Trust and GOSH Children’s Charity

This thesis is dedicated to my father, who died in April 2020 during the first wave of the COVID-19 pandemic.

Declaration

I, Philippa Sipanoun, confirm that the work presented in this thesis is my own. Where information had been derived from other sources, I confirm that this has been indicated in the thesis.

Abstract

Background: The Going Digital Study uniquely captured the experiences of all user groups before and after digital transformation of Great Ormond Street Hospital for Children (GOSH) whilst implementing an electronic patient record (EPR) system with a tethered patient portal in April 2019. This was critical and core to GOSH becoming a digital hospital, with benefits anticipated, yet challenges for all.

Aim: To investigate the practical, ethical and legal considerations of implementing an EPR in a children's tertiary hospital involving three stakeholder groups: children and young people (CYP), parents and staff.

Methods: A three phase, concurrent mixed methods, pre/post study design was utilised including both quantitative (survey) and qualitative (World Café workshops/interviews/focus group) data collection, analysis and synthesis. A systematic review of the literature was also conducted and was key to informing the examination of the experiences of users of an electronic patient record system in a children's hospital setting and interpretation of the findings.

Results: Despite the challenges experienced by all stakeholders, including ethical and legal issues associated with CYP and parents accessing health data for the first time through the patient portal, meaningful portal access can be achieved from the age of 12 years of age. Families need support accessing health information via the portal. Clinicians need to have early conversations with parents about truth-telling and sharing diagnoses and/or prognoses, supporting families through the process of disclosure. Staff need prolonged support to balance clinical demands during implementation of and adjustment to the new clinical system, whilst continuing care provision and managing families' expectations.

Conclusion: Implementation and transition to an EPR system with a tethered patient portal is complex and takes time to embed. Setting realistic expectations and involving all stakeholders at all stages is paramount if benefits for all are to be fully realised. Managing this change process well, with prolonged engagement over time with all stakeholders, is essential if future utility is to be achieved. This requires an inclusive culture, in which the voice of all children and young people and parents is valued, and enabled through investment of appropriate resources, with equity of access a key priority.

Impact Statement

There is wealth of evidence concerning EPR and patient portal implementation in the adult context, yet very little was known or reported on the specific considerations required for implementation and use in the context of children and young people (CYP). This was demonstrated by the systematic review, which also highlighted that CYP's views are not always considered. Taking into consideration their needs and preferences is essential to increasing their understanding of their condition(s), increasing their independence, and for prolonged healthcare engagement with a patient portal. This study has sought to understand the complexities involved in implementing an EPR system along with a patient portal in this context, where CYP are able to have access to their health information, which was unique to this children's hospital. More specifically, this research aimed to investigate the practical, ethical and legal considerations of implementation, focussing on three stakeholder groups: CYP, parents and staff.

The findings of this study are complex, and heterogeneous. The overwhelming message is that all those who will be affected by system implementation require targeted, individualised preparation pre-implementation, and support for a prolonged period post-implementation. This will help to promote satisfaction and facilitate long-term engagement. Important considerations exist related to CYP and parents accessing health data via the portal including the following: early collaboration from all those involved in care; open discussions about granting portal access; and a need for a coordinated approach to portal access when commencing the transition journey from children's/adolescent's services into adult services. Due weight and consideration must be given to the views of CYP, with co-design advocated, incorporating their continued feedback to promote portal utility, and engagement. Furthermore, the study's findings illustrated that complex tensions exist in relation to the parental role and responsibilities and their child's developing autonomy.

Children and young people, parents and staff have already benefitted, and will continue to do so from this work. Timely and consistent dissemination of findings has underpinned this work from the outset. Due to the rapidly evolving digital health context, accelerated by the pandemic, early and wide dissemination of the study findings occurred with each phase of research. Local, national, and international audiences were reached, which included CYP, parents, staff members, healthcare professionals, researchers, ethicists, funders and the public. Two manuscripts have been published in peer-reviewed journals, with further publications planned. The overall aim of this wide dissemination was to raise awareness of the CYP-specific considerations of digital health implementation to not only help healthcare professions in navigating this arena, but, moreover, to promote the rights and interests of CYP.

Involving CYP in the management of their own health may lead to better health outcomes through the following: increasing their understanding, enabling them to take a more active role in making decisions about their care, increasing their confidence and independence, and preparing them for transition into adult services. A patient portal, that CYP are supported to access ‘when ready’, has a significant role to play. Parents and staff are instrumental in providing this support to CYP, throughout their healthcare journey.

Acknowledgements

There are many whom I need to thank for supporting me during the period of my doctoral studies. Firstly, thank you to my supervisory team, Dr Kate Oulton, Professor Jo Wray and Professor Faith Gibson for their ongoing support, guidance, expertise, and encouragement. Thank you for believing in me! I would like to acknowledge members of Clinical Academic Faculty and Research Faculty, and my fellow doctoral students from the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability for the invaluable peer-support, and for tirelessly promoting research excellence. I would also like to thank Deborah Ridout for her support in the statistical analysis of the quantitative aspects of the study, and Heather Chesters from the UCL Great Ormond Street Institute of Child Health Library for librarian support during the systematic review.

I wish to thank Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) and GOSH Children's Charity for kindly funding this research, and Helen Vigne from the electronic patient records (EPR) team for supporting this project, which was essential to help evaluate and shape the delivery of EPR and its tethered patient portal for the future benefit of all those who will use it.

My thanks and appreciation go to the participants of this research: the inspirational young people from GOSH's Young People's Forum, children and young people who are patients at GOSH, their parents, and staff at the hospital. Without their vital contribution this research would not have been possible. Furthermore, I wish to thank the Patient Involvement and Experience team for their support throughout the study.

Lastly, my thanks go to my children, Sofia, Isabella, and Madeleine, for their patience and understanding during my studies.

Although no direct funding has been received, this work is supported by the National Institute of Health Research Biomedical Research Centre at UCL Great Ormond Street Institute of Child Health.

Abbreviations

AHP	Allied Health Professional
ANOVA	Analysis of Variance
BRC	Biomedical Research Centre
CAF	Clinical Academic Faculty
CDS	Clinical Decision Support
CI	Chief Investigator
CM	Committee Member
CINAHL	Cumulative Index to Nursing and Allied Health Literature
CNS	Clinical Nurse Specialist
COVID-19	Coronavirus 2019
CPOE	Computerised Physician Order Entry
CQC	Care Quality Commission
CYP	Children and Young People
DRE	Digital Research Environment
ED	Emergency Department
EMBASE	Excerpta Medica Database
EPR	Electronic Patient Records
FCR	Family Centred Rounds
GOSH	Great Ormond Street Hospital for Children NHS Foundation Trust
HCP	Healthcare Professional
HCT	Healthcare Team
HIMMS	Healthcare Information and Management Systems Society
HPs	Health Professionals
HRA	Health Research Authority
ICF	Informed Consent Form

ICH	Institute of Child Health
ID	Identification
IT	Information technology
IRAS	Integrated Research Application System
I-SEE	Information Systems Expectations
LD	Learning Disabilities
MAD	Microsoft Access Database
MCA	Mental Capacity Act
MEDLINE	Medical Literature Analysis and Retrieval System Online
MeSH	Medical Subject Headings
MMAT	Mixed Methods Appraisal Tool
m-PHR	Mobile Personal Health Record
MyChart	MyChart Patient Portal
MyGOSH	MyGOSH Patient Portal
NICU	Neonatal Intensive Care Unit
NHS	National Health Service
NHS R&D	National Health Service Research and Development
NIB	National Information Board
NIHR	National Institute of Health Research
ORCHID	The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability
OPD	Outpatient Department
P	Parent Participant
PBC	Paediatric Bioethics Centre
PhD	Doctor of Philosophy
PHR	Personal Health Record
PI	Principal Investigator

PICU	Paediatric Intensive Care Unit
PPIE	Patient and public involvement and engagement
PR	Parental Responsibility
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PROSPERO	The International Prospective Register of Systematic Reviews
QI	Quality Improvement
REC	Research Ethics Committee
REDCap	Research Electronic Data Capture
RDF	Researcher Developmemt Framework
RF	Research Faculty
RR	Response Rate
SD	Standard Deviation
SEND	Special Educational Needs and Disabilities
SME	Subject Matter Expert
SOPs	Standard Operating Procedures
T_1	Time point 1
TAM3	Technology Acceptance Model3
TTM	Treatment Team Members
UCL	University College London
UCL GOS ICH	UCL Great Ormond Street Institute of Child Health
US	United States of America
Wi-Fi	Wireless Fidelity
YP	Young People
YPF	Young People’s Forum

Ethical Permissions

Phase one

Staff World Café Workshops

Due to the fast pace of this research and the need to be in-keeping with the EPR team’s time frame for implementation, ethical permission to conduct the phase one Staff World Café workshops was sought from UCL Research Ethics Committee, in the form of a Chair’s review. Due to the low-risk nature of the staff workshops, this approach was deemed feasible. The staff workshops were held in October 2018, only 6 months after commencing the Doctor of Philosophy (PhD). This staged approach to approval meant that the workshops were conducted in a timely manner so that surveys could be developed from the workshop’s findings for Trust-wide distribution during phases two and three of the study. UCL REC ID: 13707/001 (Appendix 1).

Young People / Parent World Café Workshops

Health Research Authority approval was sought for both the young people and parent World Café workshops in the form of proportionate review, due to its low-risk nature. IRAS ID: 252222 (Appendix 2).

Phases two to four

Health Research Authority approval was sought for phases two to four in a full application for ethical review by a Research Ethics Committee. IRAS ID: 248793 (Appendix 3).

Table of Contents

Signed Declaration……………………………………………………………..2

Abstract………………………………………………………………………..3

Impact Statement………………………………………………………………4

Acknowledgments………..…………………………………………………….5

Abbreviations…………………………………………………………………..6

Ethical Permissions……………………………………………….…………10

Table of contents……………………………………………………….…...11

Table of Tables…………………………………………………………………22

Table of Figures……………………………………………………………….24

1 Background and Introduction...23

1.1 Introduction..23

1.2 Global digitalisation and implications for worldwide healthcare .27

1.3 Influence of legislation and policy on National NHS Strategy......27

1.4 Impact on individual Hospital Trusts at local level........................28

1.5 Influences on GOSH's decision to 'Go Digital' 29

1.6 Justification for studying pre- and post-implementation of EPR.30

1.7 Ethical and legal context...32

1.7.1 The EPR Applied Ethics Framework 34

1.8 Personal reflections on the need for this research 37

1.9 Organisation of the thesis 38

1.10 Summary 41

2 Research Aims and Design..42

2.1 Introduction..42

2.2 Aims of the research 42

2.3 Patient and Public Involvement and Engagement.........................43

2.4 Research design 44

2.5 Sampling and setting 46

2.6 Recruitment, data collection and informed consent 49

2.6.1 Children and young people and their parents..............................49

2.6.2 Hospital Staff 50

2.7 Early dissemination..51

2.8 Summary 52

3 Systematic Review 53

3.1 Introduction..53

3.2 Background and context...53

3.3 Aim of Systematic Review 54

3.4 Methods..55

3.4.1 Primary outcomes..55

3.4.2 Inclusion and exclusion criteria...55

3.4.3 Search strategy 56

3.4.4 Data extraction 58

3.4.5 Quality assessment 58

3.5 Results..58

3.5.1 Study selection 58

3.5.2 Quality assessment results..61

3.5.3 Findings..96

3.6 Discussion 103

3.7 Strengths and limitations..105

3.7.1 Strengths 105

3.7.2 Limitations 106

3.8 Implications for practice 106

3.9 Implications for future research...106

3.10 Implications for the Going Digital study.................................107

3.11 Conclusion 107

4 World Café workshops (phase one)...110

4.1 Introduction..110

4.2 Aim......110

4.3 Methodology......111

4.4 Methods......113

4.4.1 Participant inclusion and exclusion criteria......113
4.4.2 Sampling strategy......113
4.4.3 Participant recruitment and consent......113
4.4.4 Sample size......115
4.4.5 Data collection......115
4.4.6 Data analysis......116

4.5 Results......117

4.5.1 Participants......117
4.5.2 Findings from young people's workshop......118
4.5.3 Parent and staff findings......134

4.6 Survey development from the themes......140

4.6.1 Piloting the surveys......141

4.7 Informing the interview schedule......143

4.8 Summary......144

5 Children's and young people's survey (phases two and three)......147

5.1 Introduction......147

5.2 Aim......147

5.3 Methods......147

5.3.1 Study setting and design......148
5.3.2 Survey development......148
5.3.3 Participant inclusion and exclusion criteria......149
5.3.4 Survey distribution......150
5.3.5 Data collection......151
5.3.6 Sample size......151
5.3.7 Statistical analysis......151
5.3.8 Duplicate data......152
5.3.9 Missing data......152

5.4 Results......152

5.4.1 Demographic characteristics......152

5.4.2 Response rate 156
5.4.3 Survey findings 157

5.5 Discussion 168

5.5.1 How the key findings relate to the hypotheses and literature 168

5.6 Summary 173

6 Parent survey (phases two and three) 176

6.1 Introduction 176

6.2 Aim 176

6.3 Methods 176

6.3.1 Study setting and design 176
6.3.2 Survey development 177
6.3.3 Participant inclusion and exclusion criteria 177
6.3.4 Survey distribution 178
6.3.5 Data collection 179
6.3.6 Sample size 179
6.3.7 Statistical analysis 179
6.3.8 Duplicate data 179
6.3.9 Missing data and not applicable responses 180

6.4 Results 180

6.4.1 Demographic characteristics 180
6.4.2 Response rate 184
6.4.3 Survey findings 186

6.5 Discussion 202

6.5.1 How the key findings relate to the hypotheses and literature 202

6.6 Summary 208

7 Staff survey (phases two and three) 211

7.1 Introduction 211

7.2 Aim 211

7.3 Methods 211

7.3.1 Study setting and design 211
7.3.2 Survey development 212

7.3.3 Participant inclusion and exclusion criteria 212
7.3.4 Recruitment and survey distribution 212
7.3.5 Data collection 213
7.3.6 Sample size 213
7.3.7 Statistical analysis 213
7.3.8 Missing data and not applicable responses 214

7.4 Results ***215***

7.4.1 Demographic characteristics 215
7.4.2 Representativeness to the GOSH staff population 216
7.4.3 Response rate 216
7.4.4 Survey findings 218
7.4.5 Family involvement in care 219
7.4.6 Support families 221
7.4.7 Managing families' expectations 226
7.4.8 Managing appointments 227
7.4.9 Communication 228
7.4.10 Barriers to accessing MyGOSH. 234

7.5 Discussion ***235***

7.6 Summary ***239***

8 Parent interviews **242**

8.1 Introduction ***242***

8.2 Context and setting ***242***

8.3 Aim ***242***

8.4 Methods ***243***

8.4.1 Interview schedule development 243
8.4.2 Participant inclusion and exclusion criteria 243
8.4.3 Sampling strategy 243
8.4.4 Participant recruitment and consent 243
8.4.5 Sample size 244
8.4.6 Data collection 244
8.4.7 Data analysis 244

8.5 Results ***246***

8.5.1 Participants........246
8.5.2 Themes........247

8.6 Discussion........275

8.7 Summary........280

9 Focus Group Discussion........283

9.1 Introduction........283

9.2 Context........283

9.3 Aim........284

9.4 Methods........284
9.4.1 Focus group methodology........284
9.4.2 Why choose to conduct a focus group?........284
9.4.3 Topic guide development........285
9.4.4 Participant inclusion and exclusion criteria........286
9.4.5 Participant recruitment and consent........286
9.4.6 Data collection........286
9.4.7 Data analysis........287

9.5 Results........288
9.5.1 Participants........288
9.5.2 Theme development........288
9.5.3 Granting access........288
9.5.4 Inequalities resulting in inequities........293
9.5.5 Responding to change........295
9.5.6 Engagement, empowerment and understanding........296

9.6 Discussion........299

9.7 Summary........302

10 Synthesis, implications, and conclusions........304

10.1 Introduction........304

10.2 Summary of the research........304

10.3 Key findings........305
10.3.1 Integration........306

10.4 Unique contribution of the study........329

10.5 Recommendations for clinical practice when implementing an EPR system with a patient portal..331

10.6 Recommendations for future research.......................................333

10.7 Strengths of this research 335

10.7.1 World Café workshops 335

10.7.2 Parent interviews..336

10.7.3 Focus group 336

10.8 Limitations of this research...337

10.8.1 World Café workshops 338

10.8.2 Parent interviews..338

10.8.3 Quantitative data collection 339

10.9 Dissemination..342

10.9.1 Engagement in research and priorities during COVID-19..........349

10.10 Conclusion 350

11 Reflections and future directions...352

11.1 Reflecting on challenges 352

11.2 Professional, educational, and personal growth 357

11.3 The impact of COVID-19 on the study...362

11.4 Future directions 362

11.5 Final thoughts..363

References..364

Appendix 1 – Ethical approval for phase one (staff)................................383

Appendix 2 – Ethical approval for phase one (young people/parents)....385

Appendix 3 – Ethical approval for phases two to four 390

Appendix 4 – Study Gantt chart...396

Appendix 5 – Substantial amendment – virtual data collection................397

Appendix 6 – PROSPERO registration of systematic review protocol 399

Appendix 7 – Example search terms (EMCARE).......................................404

Appendix 8 – Systematic review data extraction tool...............................406

Appendix 9 – Mixed Methods Appraisal Tool (version 2018)....................408

Appendix 10 – Invitation letter to YPF members.......................................409

Appendix 11 – Invitation letter to parents of YPF members......................410

Appendix 12 – Phase 1 participant information sheet 10-15 years 411

Appendix 13: Phase 1 participant information sheet ≥16 years..............413

Appendix 14: Phase 1 participant information sheet parent/carer for child 415

Appendix 15 – Phase 1 assent form 10-15 years 418

Appendix 16 – Phase 1 informed consent form ≥16 years 420

Appendix 17 – Phase 1 informed consent form parents for their child....422

Appendix 18 – Phase 1 email invitation to parent/carer 424

Appendix 19 – Phase 1 participant information sheet parent/carer 425

Appendix 20 – Phase 1 informed consent form parent/carer....................427

Appendix 21 – Phase 1 staff recruitment information 429

Appendix 22 – Phase 1 participant information sheet staff 431

Appendix 23 – Phase 1 informed consent form staff.................................433

Appendix 24 – World café workshop topic guide 435

Appendix 25 – World café workshop scenarios/ questions......................438

Appendix 26 – Children’s and young people’s baseline survey...............440

Appendix 27 – Children’s and young people’s follow-up survey 447

Appendix 28 – Parent baseline survey...454

Appendix 29 – Parent follow-up survey 462

Appendix 30 – Staff baseline survey..471

Appendix 31 – Staff follow-up survey 479

Appendix 32 – Parent interview schedule 487

Appendix 33 – Missing data table (CYP)..489

Appendix 34 – Substantial amendment – survey demographics 491

Appendix 35 – Missing data table/number of N/A responses (parents)...494

Appendix 36 – Parent survey collection – location/number......................498

Appendix 37 – Who signed the parent up to MyGOSH..............................499

Appendix 38 – Example of screensaver and banner 500

Appendix 39 – Missing data table/number of N/A responses (staff) 501

Appendix 40 – Phase 3 parent interview participant information sheet ..504

Appendix 41 – Phase 3 informed consent form 507

Appendix 42 – Substantial amendment – focus group..............................509

Appendix 43 – Focus group topic guide..511

Appendix 44 – Phase 3 focus group participant information sheet 516

Appendix 45 – Phase 3 focus group informed consent form....................518

Appendix 46 – 2018 GOSH conference digital poster...............................520

Appendix 47 – Published abstract...521

Appendix 48 – ‘Roundabout’ entry..522

Appendix 49 – 2019 RCN International Research Conference..................523

Appendix 50 – Tweet from GOSH Conference oral presentation 524

Appendix 51 – Published abstract...525

Appendix 52 – Institute of Medical Ethics Postgraduate Bioethics conference abstract...526

Appendix 53 – 2021 RCN International Research Conference poster and UCL Doctoral School poster competition...527

Appendix 54 – 2021 RCN International Research Conference..................528

Appendix 55 – UCL Doctoral School poster competition..........................529

Appendix 56 – Published abstract...530

Appendix 57 – Submitted manuscript – focus group 531

Appendix 58 – 2021 GOSH conference poster 532

Appendix 59 – Published abstract...533

Appendix 60 – 2021 GOSH conference poster 534

Appendix 61 – Published abstract..535

Appendix 62 – Systematic review publication...536

Appendix 63 – Showcase for research impact...537

Appendix 64 – Published abstract..538

Appendix 65 – Formal Doctoral training and additional development activities 539

Appendix 66 – Associate Fellowship Award 547

Appendix 67 – Legal implications for critical care publication.................548

Appendix 68 – Published abstract..549

Appendix 69 – Service evaluation publication 550

List of Tables

Table 1-1: National strategic objectives informing healthcare digitalisation 24

Table 2-1: Sample strategy and size for phases two and three 47

Table 2-2: Inclusion and exclusion criteria phases two and three 48

Table 3-1: Summary of quality assessment 62

Table 3-2: Study characteristics...64

Table 3-3: Study outcomes 75

Table 4-1: World Café methodology core principles and application 112

Table 4-2: Practical application of Framework analysis 117

Table 4-3: Workshop participants 118

Table 4-4: Specialities represented at the staff workshops (x2)......................118

Table 4-5: Young People’s views on expected benefits of EPR/MyGOSH 120

Table 4-6: Mapping of parent/staff data onto YPF data 135

Table 4-7: Excerpt from thematic framework – Barriers to accessing MyGOSH 140

Table 4-8: Examples of feedback from survey pilot 142

Table 5-1: Respondent demographics 153

Table 5-2: Sample compared with GOSH population 155

Table 5-3: Baseline survey distribution and response rate 156

Table 5-4: Follow-up survey distribution and response rate...........................157

Table 5-5: Satisfaction with aspects of care...158

Table 5-6: CYP’s views – age limits/feeling informed about MyGOSH 165

Table 5-7: Barriers to accessing MyGOSH 167

Table 5-8: Hypotheses, key findings and whether each hypothesis was supported..169

Table 6-1: Respondent demographics 181

Table 6-2: Sample compared with GOSH population 183

Table 6-3: Baseline survey distribution and response rate 184

Table 6-4: Follow-up survey distribution and response rate............................185

Table 6-5: Satisfaction with aspects of care..187

Table 6-6: Parents' views – age limits/feeling informed about MyGOSH........196

Table 6-7: Parent responses – their child accessing health data/sharing on social media...199

Table 6-8: Barriers to accessing MyGOSH 201

Table 6-9: Hypotheses, key findings and whether each hypothesis was supported...203

Table 7-1: Respondent demographics...215

Table 7-2: Representativeness..216

Table 7-3: Survey distribution and response rate across three time-points 217

Table 7-4: Staff confidence in their ability to support families 222

Table 7-5: Hypotheses, key findings and whether each hypothesis was supported...236

Table 8-1: Demographic details of interview participants................................247

Table 9-1: Overview of topic guide...285

Table 10-1: Going Digital study metamatrix – Expectations............................308

Table 10-2: Going Digital study metamatrix – Benefits and challenges 311

Table 10-3: Going Digital study metamatrix – Information and support needs315

Table 10-4: Going Digital study metamatrix – Ethical and legal considerations 319

Table 10-3: Dissemination throughout the Going Digital study 344

Table 11-1: Challenges encountered, reason, remedy, and resultant learning 354

Table 11-2: Additional dissemination activities 360

List of Figures

Figure 1-1: Worldwide phenomenon of global digitalisation to the advent of the Going Digital study 27

Figure 1-2: Electronic Patient Record (EPR) applied ethics framework 35

Figure 2-1: Going Digital mixed methods plan 45

Figure 3-1: Hierarchy of evidence 55

Figure 3-2: PRISMA Flowchart showing study selection process 57

Figure 3-3: Detailed breakdown of the focus of included studies 59

Figure 3-4: Participant groups for each study 60

Figure 4-1: Themes from the YPF World Café workshop 119

Figure-4-2: Example from workshop notes 141

Figure-4-3: Formulation of the survey question 141

Figure 5-1: Satisfaction with care at T_1 and T_2 159

Figure 5-2: Expectations and perceptions of improved aspects of care 160

Figure 5-3: Information and support needs 161

Figure 5-4: Additional information and support needs 162

Figure 5-5: Worries about using MyGOSH 163

Figure 5-6: Additional worries 164

Figure 5-7: Social media/health app use 166

Figure 6-1: Parent sign up/intention to sign up for MyGOSH 186

Figure 6-2: Satisfaction with care at T_1 and T_2 189

Figure 6-3: Expectations and perceptions of the benefits of MyGOSH 190

Figure 6-4: Expectations and perceptions of improved aspects of care 191

Figure 6-5: Information and support needs 192

Figure 6-6: Additional information and support needs 193

Figure 6-7: Worries about using MyGOSH 194

Figure 6-8: Additional worries 195

Figure 6-9: Parental social media/health app use 197

Figure 6-10: Parental perception of their child's social media/health app use 198

Figure 6-11: Parent responses from Table 6-7 at T_1 and T_2...........................200

Figure 7-1: Keeping families informed of care plan..218

Figure 7-2: Increased family involvement in decisions about care 219

Figure 7-3: Results release onto MyGOSH enabling family involvement........220

Figure 7-4: Staff confidence in their ability to support families 223

Figure 7-5: Results release via MyGOSH and family anxiety 224

Figure 7-6: Family support when accessing results via MyGOSH 225

Figure 7-7: Managing families' expectations..226

Figure 7-8: Ease of changing appointments via MyGOSH, and whether MyGOSH use reduces missed appointments 227

Figure 7-9: Improvements in communication and collaboration......................229

Figure 7-10: Improvements in communication via InBasket messaging 230

Figure 7-11: The messaging function via the portal (InBasket messaging).....231

Figure 7-12: Staff worries about families posting on social media 232

Figure 7-13: Staff perceptions of whether MyGOSH use makes it easier for families to share health data on social media 233

Figure 7-14: Staff perception about whether patients will be unable to access MyGOSH 234

Figure 8-1: Parent interview findings...248

Figure 9-1: Thematic map: themes and subthemes.......................................289

Figure 10-1: Adapted EPR Applied Ethics Framework 329

Figure 10-2: Dissemination strategy 343

Figure 11-1: What does it take to do a PhD? 357

Figure 11-2: Illustration of the Going Digital study journey.............................359

1

1 Background and Introduction

1.1 Introduction

The global phenomenon of digitalisation is transforming society worldwide, nationally and locally. The digital health revolution is upon us, and currently at its most crucial stage due to the Coronavirus 2019 (COVID-19) pandemic. Accelerated digital pathways will influence healthcare going forward, with benefits to be had, but also considerations of equity requiring deliberation and action to ensure fair and equal access to healthcare. Global digitalisation and the impact on healthcare worldwide has cascaded down to influence legislation and policy on the National Health Service (NHS) strategy. Key national strategic objectives and guidelines informing the need for digitalisation of healthcare are presented in Table 1-1. Those which informed the need for Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) to implement an electronic patient record system (EPR) with a tethered patient portal, and which led to the advent of the Going Digital Study, are presented in blue. Important strategic objectives have continued to emerge since the start of the Going Digital study in 2018 (presented in green), further emphasising the need for healthcare digitalisation, and reinforcing the importance of this research. The cascade effect from global digitalisation and its impact on healthcare, legislation and national policy, local impact, GOSH’s decision to Go Digital and the advent of the ‘Going Digital’ study is represented in Figure 1-1.

The motivation behind, and the importance of the ‘Going Digital’ study will be made clear in this chapter, including the significance of its timing, which became even more pertinent during the COVID-19 pandemic. Anticipated ethical and legal considerations of implementing an EPR system are also highlighted.

Table 1-1: National strategic objectives informing healthcare digitalisation

Strategic objective/guideline	Date published	Objectives identified/advocates for/recommendations
Five Year Forward View [1]	October 2014	• NHS transformation is required to address three widening gaps: health/wellbeing gap; care/quality gap, funding/efficiency gap • New technologies/ways of working advocated/harnessed to improve the quality of care and patient experience [2] • Unacceptable variations in patient outcomes should be reduced • By 2020, the NHS will have 'fully interoperable electronic health records so that the patients' records are largely paperless' (p.34) [1]
Personalised Health and Care 2020 – Using Data and Technology to Transform Outcomes for Patients and Citizens – The National Information Board [3]	November 2014	• Better use of data and technology has the power to improve health, transform the quality, reduce cost of healthcare services • EPR's rich data source and data analytics supports clinical decision making and clinical decision support, clinical diagnoses, continuous performance management and comprehensive transparency of performance data
National Health Service Digital's Strategy key objectives for 2015-2020 [4]	March 2015	• Vision of providing all members of the public/healthcare professionals with access to health data • Allow patients to make informed choices about their care • Support healthcare professionals in clinical decision making • Support research organisations and policy makers

Strategic objective/guideline	**Date published**	**Objectives identified/advocates for/recommendations**
Safe Data, Safe Care report – Care Quality Commission (CQC) reviewed effectiveness of current NHS data security [5]	July 2016	• "Good information underpins good care" (p.2) [5] • Information that is accessible assures patient safety • Ensure confidentiality is maintained; integrity is protected against loss/damage • All staff should be provided with the right information, tools, training/support to do their jobs effectively/meet their responsibilities for handling/sharing data • Information technology (IT) systems and all data security protocols should be designed to meet the needs of patients and frontline staff; the need for workarounds, which risks data security breaches, should be removed [2] • As a matter of urgency, computer hardware/software that can no longer be supported should be replaced
The Wachter Review [6]	September 2016	• Returns on investment from digitisation = improvement in quality/safety plus financial • Following digitalisation short-term slowdown of activity/unanticipated consequences should be expected • Successful health IT requires both technical *and* adaptive change; leadership *and* front-line staff using the system must be supported and engaged with for success • All NHS Trusts should have achieved a high degree of digital maturity by 2023 • Not achieving digitisation by 2023 = non-compliant on quality and safety
Healthy Children – Transforming Child Health Information [7]	November 2016	• Transformation programme – child health information can be used to support families in providing high quality care for children • Development of Digital Child Health Hub • Replace current organisational child health information services

Strategic objective/guideline	Date published	Objectives identified/advocates for/recommendations
NHS Long Term Plan [8]	January 2019	Improved care for patients over the next 10 years is proposed by: making sure everyone gets the best start in life; by delivering world-class service for major health problems; and supporting people to age well. Among other improvements, digital health is highlighted as one aspect that will help deliver the NHS Long Term Plan by: • Making better use of data and digital technology: providing patients with more convenient access to services and health information including the new NHS App as a digital ‘front door’, and better access to digital tools/patient records for staff. Service planning and delivery will be based on the analysis of patient and population data [8]
The Topol Review: Preparing the healthcare workforce to deliver a digital future. An independent report on behalf of the Secretary of State for Health and Social Care [9]	February 2019	• The UK has the potential to become a world leader in digital healthcare technologies (which include digital medicine, genomics, artificial intelligence and robotics) [9] • Evidence suggests technologies will augment healthcare professionals’ skills (rather than replacing them), giving more time for patient care • Three principles were proposed to support the deployment of digital healthcare technologies throughout the NHS: informing and involving patients especially vulnerable/marginalised groups (promoting equitable access); expertise/guidance to enable healthcare workforce to evaluate new technologies; implementation of new technologies ought to enable staff to have more time to care [9]
Data Saves Lives [10]	June 2022	• Improving trust in the health/care system’s use of data • Giving health/care professionals the information they need to provide the best possible care • Improving data for adult social care • Supporting local and national decision-makers in data • Empowering researchers with the data they need to develop life-changing treatments, diagnostics, models of care and insights • Working with partners to develop innovations that improve health and care • Develop the right technical infrastructure [10]

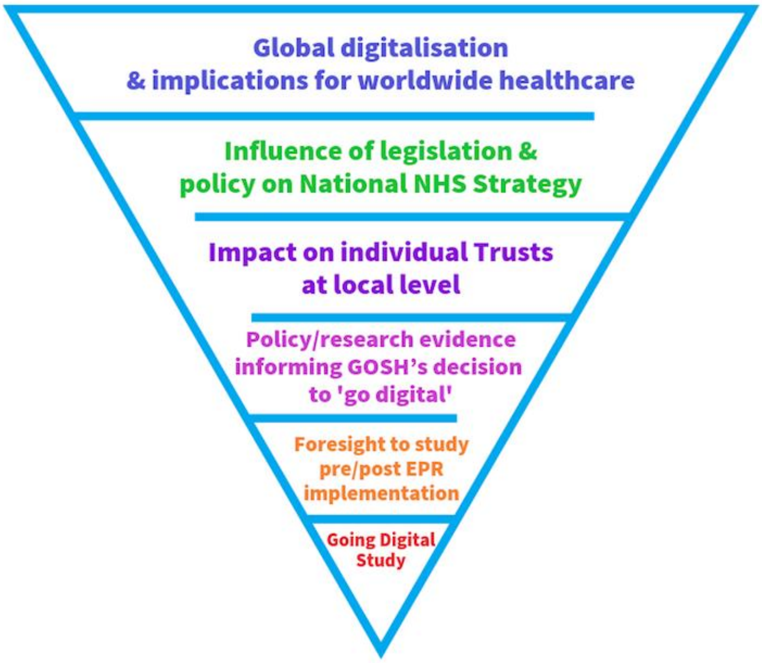


Figure 1-1: Worldwide phenomenon of global digitalisation to the advent of the Going Digital study

1.2 Global digitalisation and implications for worldwide healthcare

Digitalisation is a phenomenon that is transforming our world rapidly, affecting us all in numerous ways, from governance, rights, and business, to the law, justice, and healthcare. Numerous healthcare centres around the world are deploying EPR systems to respond to the demands of digitalisation. The rapid development of personalised digital healthcare, including apps and portals, aims to respond to the changing landscape of healthcare. Currently, in an age of instant gratification with an immediacy that is prevalent due to digitalisation [11], healthcare will soon be driven by the patient rather than the current traditional paternalistic model, as Topol so eloquently discusses in his book 'The patient will see you now' [12]. Social media use has also exploded with global digitalisation, creating avenues for people to seek health advice and support from one another with the same or similar conditions, with a worldwide reach [12].

1.3 Influence of legislation and policy on National NHS Strategy

When considered together, the strategic objectives outlined in Table 1-1, proposed that introducing pan-NHS digitalisation will facilitate electronic health record access for patients, promoting and supporting self-management of their health and care, and greater control their personal digital health information [2]. National Health Service digitalisation has the potential to transform the way care is provided through better clinical decision support and evidenced based treatment that promotes best practice [2]. By improving engagement with patients and their families, healthcare digitalisation ought to respond to the health and wellbeing gap, and the care and quality gap, as documented in the Five Year Forward View strategic objective [1, 2]. In addition, realisation of operational effectiveness and efficiencies, and cost savings which address the funding and efficiency gap become tenable with this approach [2]. Furthermore, compliance with the General Data Protection Regulation requirements necessitate that health and personal data is managed in a safe and secure manner, which an EPR system would help to facilitate [13].

1.4 Impact on individual Hospital Trusts at local level

Global digitalisation, legislation, and policy impact individual Trusts at local level. Trusts need to be pro-active in joining the digital revolution. Internationally renowned children's hospitals such as Boston Children's Hospital, Children's Hospital of Philadelphia, Cincinnati Children's Hospital and The Royal Children's Hospital in Melbourne, had already invested in EPRs at the time this study began. More locally, University College London Hospitals, Addenbrooke's Hospital in Cambridge, Bradford Teaching Hospitals, and Calderdale and Huddersfield NHS Foundation Trust were also using or introducing EPRs. Alder Hey Children's NHS Foundation Trust in Liverpool was the first children's centre to be named as a global digital exemplar [14]. Great Ormond Street Hospital for Children was fortunate to receive charity funding to enable the implementation of EPR [15], and has since achieved Healthcare Information and Management Systems Society (HIMMS) Level 7, the highest attainable international digital maturity benchmark, following EPR and patient portal implementation [16]. Other hospital Trusts may not be so fortunate, making compliance with the Wachter Review and other strategic objectives, for example, to achieve digitalisation by 2023, a greater challenge and, for some, potentially impossible.

1.5 Influences on GOSH’s decision to ‘Go Digital’

Evidence from literature and the strategic objectives and guidelines, presented in Table 1-1, suggest that EPRs have the potential to address many of the current challenges healthcare systems face. This, in turn, informed GOSH’s decision to ‘Go Digital’. Benefits of implementation are expected for patients, healthcare professionals, and organisations [17]. It is reported that EPRs can enhance quality of care as patients have their essential health data accessible to their different clinicians. Electronic patient record systems can also provide relevant, timely, and up-to-date information that contributes to increased knowledge exchange for collaborative decision-making across specialities and among multidisciplinary teams. This is essential when caring for the complex needs of the patients often seen at GOSH, who may be under multiple specialities, including some patients who stay well beyond the age of 18, even above 25 years within some speciality services such as genetics and cardiac [18-21]. The use of an EPR system is also reported to support empowerment of the patient and parent, enabling partnerships in care and involvement decision-making, contributing to creating both a safer and more efficient healthcare system [22]. All of which are essential if GOSH is to comply with strategic digitalisation objectives by 2023, as recommended in the Wachter Report [6].

The magnitude of the task of digital transformation in a hospital that cares more often for very complex patients, with a wide geographical reach (national and worldwide), with numerous specialities, and a large staff group is acknowledged. We grasped the opportunity to study the experiences of all stakeholders in real time, so that all learning, whether from planned or un-planned activities, could be achieved. This organisational learning could then support not only the ongoing development of digital health services in our hospital, but also other hospitals could learn from our experience, providing national and international evidence on the implementation of EPR and a patient portal in a children’s hospital setting.

After two years of preparation, this digital transformation began in April 2019 at GOSH, when an EPR system was implemented. This replaced paper medical notes and numerous (over 500) separate patient management/clinical systems, giving one overarching integrated system – Epic (Epic Systems Corporation) EPR. Included in this new EPR system was a patient portal called 'MyGOSH' (hereafter MyGOSH) which is accessed by parents and children and young people (CYP) from electronic devices. MyGOSH enables patients and families to have direct access to some of their health data for the first time. Patient profiles can be personalised; appointments, after visit summaries (formerly clinic letters) can be accessed. Families can also view some health results, in addition to being able to message their clinician, with the view to include video-link capacity (the term clinician pertains to the medical, nursing, and allied health professional members of the clinical team involved in the CYP's care, hereafter 'clinician'). Furthermore, it was aimed that 'MyGOSH bedside' would be accessible for each inpatient, and a 'Kiosk' would be accessible in out-patient clinics enabling self-check-in for appointments, both of which link with the EPR system. The deployment of this innovative EPR system was a critical and core requirement of GOSH moving towards being a digital hospital, seen as potentially enabling the following: improvements in quality of care; operational efficiencies; development of new models of treatment and care; improved communication with patients and families; and implementation of a platform to enhance innovative research and enhanced analytics (Aridhia).[i]

1.6 Justification for studying pre- and post-implementation of EPR

Great Ormond Street Hospital for Children is the first dedicated children's tertiary centre in the UK to introduce an EPR system with a patient portal in a one-step, Trust wide approach. Alder Hey introduced EPR in a staged approach over a number of years [23], and Addenbrooke's hospital have yet to grant CYP access to the patient portal, despite implementing EPR in 2014 and launching the portal in 2016, with parents accessing their child's health information as a proxy instead [24]. It is essential to move *with* healthcare digitalisation, to embrace the changes facing society and the NHS so that we can help shape its future. With this philosophy in mind, this research presented a unique

---

[i] The scope of this project does not extend to examining the research platform but gives rise to the need for further evaluation of this at a later date.

opportunity to observe, examine and analyse a children's tertiary centre's transition to an EPR system.

Current literature explores specific aspects of EPRs adoption: by certain professional groups [25, 26]; specific uses of EPR for admissions monitoring [27]; pharmacological evaluation [28]; and patient portal access in specific patient populations [29, 30]. However, there is an absence in the literature of large-scale studies, such as the Going Digital study, involving all relevant stakeholders spanning the period from pre to post EPR implementation in any children's tertiary hospital setting, despite EPR implementation in some of the world's other leading children's centres. The EPR implementation process is also both lengthy and costly, so it is important to get it right, to ensure the hospital delivery is as expected, and to be able to inform other healthcare providers who may embark on the journey of digital transformation.

Despite the numerous expected benefits, such a large-scale change inevitably poses challenges for patients, parents, and staff practically, ethically and legally, and these needed to be understood prior to the implementation phase. Gaining perspectives of all relevant stakeholders impacted by EPR transition will enable a thorough and comprehensive examination of expectations, and whether these have been met. Wide inclusion of stakeholder experiences validates *everyone's* experience with the recognition that what works for one group may not work for another. This is especially important when involving CYP, whose voices are not always heard.

The timing of this research and PhD is of significance. Keeping in-line with the schedule for 'Going Live' with EPR was crucial to being able to conduct this study at the appropriate time-points. Conducting the study too early would have meant that stakeholders would not be aware of EPR and would, therefore, be unable to make a valuable contribution. Being too late would have meant that the opportunity had been missed: this study has been able to maximise on learning in advance of and in-action.

1.7 Ethical and legal context

An essential component of EPR and MyGOSH is to enable patients and their parents to become ‘real’ partners in their care, facilitating joint decision-making and enhancing patient experience.

Access to MyGOSH is in accordance with the Mental Capacity Act (MCA) 2005; however, this raises a number of ethical and legal issues when thinking about determining competence and, with those aged 16-17, establishing capacity [31]. Determining competence in those under 16 is often described, under Gillick competence, as task-specific competence - meaning a child may be competent in making certain decisions but not another [32].

Questions arise such as, how will competence to understand the specific information within MyGOSH be assessed and who is going to assess it? Furthermore, how often will competence be assessed, because competence or capacity can fluctuate, particularly in patients who have complex illnesses or needs such as those with learning disabilities, mental health conditions and/or a life-limiting or terminal illness [33]? In addition, difficulties may arise for those whose first language is not English, especially for children who often translate for their non-English speaking parents.

Conversely, young people aged 16 or over must be presumed to have capacity unless proven otherwise (as with adults). This is referred to as the rebuttable presumption of capacity [31]. It may be that some parents who have been on the journey with their child throughout their illness or disease may struggle at not having access to their son’s or daughter’s medical records when their child turns 16 and does not want them to have access, despite this being prescribed by the law [34].

To summarise, MyGOSH access will be granted to:

<u>0-15 years</u>:

- Proxy automatically offered (parents with parental responsibility)
- Children aged 12-15 years will their parents’ consent (if deemed competent by their consulting physician)

16-18 years:

- Patients with capacity automatically offered access
- Proxy granted only with consent of patients
- Patients without capacity can have proxy granted with clinicians' consent (can be time limited)

Over 18 years:

- Patients with capacity automatically offered access
- Proxy granted only with consent of patients
- Patients without capacity could be granted partial/appropriate access
- Proxy access only with a court order

A potentially significant ethical dilemma is where parents or carers who have not previously divulged aspects of their child's diagnosis to them may not wish to engage with an EPR system or MyGOSH for fear of them finding out previously undisclosed information. This dilemma is a cause of great concern. It may be that clinicians ought to liaise with families about these issues pre-Go-Live, but there may also be a concern that families would then completely disengage with the clinical team, potentially putting the young person with the illness or disease at more risk if they are not accessing the treatment or care that they need.

Another ethical consideration is that some people do not trust the internet, or simply do not have access despite MyGOSH being accessible from numerous electronic devices including smartphone, tablet, laptop, and desktop computer. Literacy levels may also hinder access to the EPR system. Inevitably some people will not be able to engage, or engage fully, possibly leading to inequitable access to healthcare. This is referred to in the literature as the 'Digital divide' [35-37]. These considerations have the potential to risk the integrity of distributive justice, the principles of which are embedded in medical ethics, and are represented by the fair distribution of healthcare [38]. Health policy makers face challenges addressing these issues which conflict with the ethical principles of ensuring equitable access to services and care to *all* patients [39]. The importance of exploring these issues in this study is highlighted.

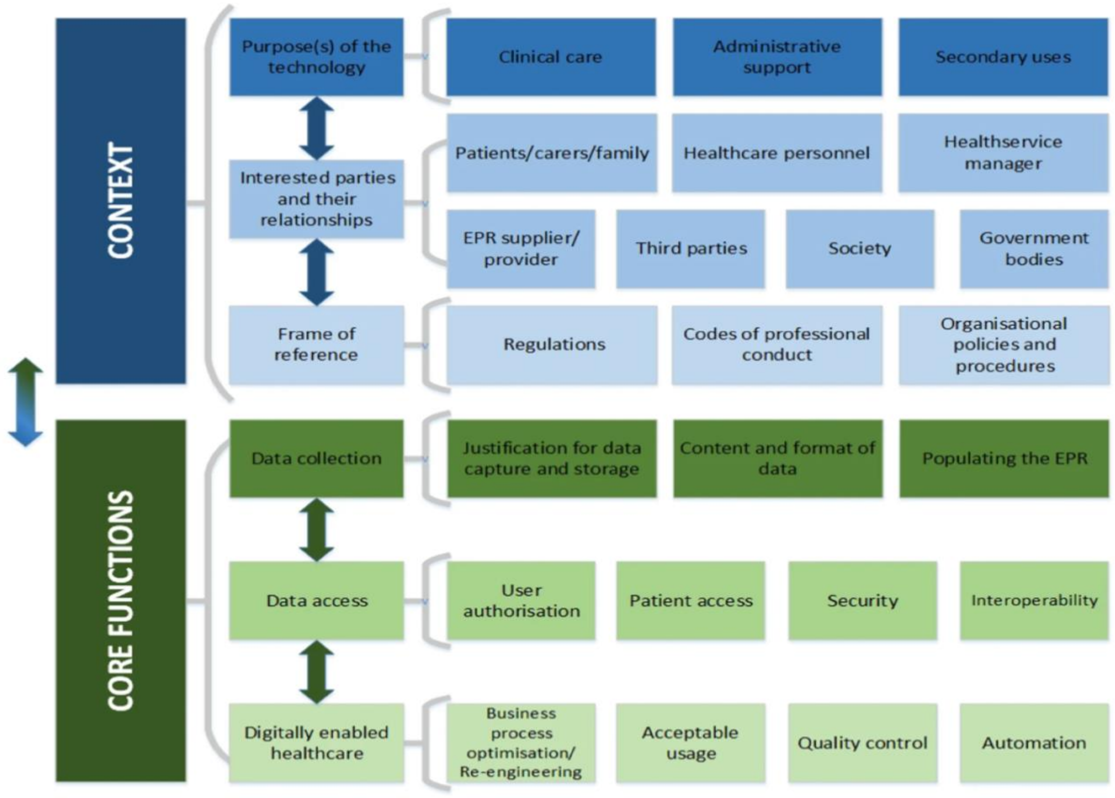
1.7.1 The EPR Applied Ethics Framework

Jacquemard et al. (2021) argue that ethical values can inform all stages of the EPR-lifecycle [40]. This includes from the design phase, trough development and implementation, to the practical application of EPRs [40]. Consequently, Jacquemard and colleagues developed the EPR Applied Ethics Framework to guide the identification and assessment of EPR-related ethical considerations and potential challenges [40]. Their intention was for the framework to be used to help positively steer EPR implementation, rather than simply as a tool to prevent ethically-related risks [40].

The EPR Applied Ethics Framework (Figure 1-2) was developed following a scoping review which mapped the literature related to the ethics of EPR technology [40, 41]. The framework encompasses two components: context and core functions. The importance of understanding the context prior to understanding EPR's core functions is advocated. Within 'context' it is seen as essential to clarify:

- The purpose(s) within which the EPR exists/will exist,
- The interested parties and their relationships,
- Codes of professional conduct, organisational policy frame of reference and regulatory requirements [40].

Core functions are concerned with health data collection, data access and digitally-enabled healthcare and the related topics within these themes [40].



Jacquemard et al. (2021)[40].

Figure 1-2: Electronic Patient Record (EPR) applied ethics framework

1.7.1.1 Review of the framework

The authors advocate the framework as an adaptable and iterative tool, applicable to a wide range of EPR categories with the ability to cater for new and evolving EPR-enabled healthcare priorities [40]. It is proposed by Jacquemard et al. (2021) that to apply the framework “an EPR of interest is assessed against each of its elements (sections, categories, and attributes) in order to identify any ethical considerations determine the associated benefits and/or risks” [40]. Appropriate measures are then implemented to address the identified issues [40].

A strength of the framework is that it is derived from an extensive scoping review which included 123 eligible articles, following an inclusion criteria where articles needed to be in the English language; presented normative arguments and not solely empirical research; included an abstract for software analysis; and discussed EPR technology [41]. Upon examination of the review to determine which CYP-related ethical issues were considered, the review briefly mentions the evolving decision-making competence of CYP, and identified the EPR-related privacy interests of children due to them being vulnerable patient populations [41]. However, the review does not go into detail of either of these points. The review also does not discuss the child or young person’s developing autonomy, the intricacies related to granting system access, or take account of the child’s voice, wishes, preferences or considerations required when engaging with CYP in the digital health context. Nor does it recognise any of the tensions and potential conflicts between the parent and the developing child [42], or the sense of responsibility the parents feels over their child’s health and wellbeing, and as the child’s advocate [43], or any potential challenges health professionals may have related to this [44, 45]. Consequently, the aspects relating to the CYP in the digital health context are not sufficiently considered, and a more in-depth understanding of the related issues are required.

Aspects related to CYP that were highlighted in the scoping review, albeit insufficient and brief, did not translate across to the framework. Furthermore, although the framework incorporates patients, carers and families, the interests of CYP in the digital health context are not represented further than a brief mention about potential privacy implications of parental access to their child’s records, and generic reference to inequalities that may arise as a result of the digital divide.

Although it was unlikely that it was intentional of the authors to omit the rights and interests of CYP in their framework, the voice of this patient group is absent. Children and young people’s voices, “often remain unheard, not because the context of what they have to say is insignificant, but simply because they are children” (p.61) [46]. It is argued by Mohr Ione (2019) that a failure to listen, “solely on the basis of age … constitutes a form of epistemic injustice” (p.53) [46]. As seen in Chapter 3, this was also evident in the findings of the systematic review conducted during this study on the experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting, where CYP’s views were often not considered [47]. Importance should be placed on the value of the child’s/young person’s voice in healthcare as the inclusion of CYP is an increasingly pressing need in the digital health context, with additional considerations required for those with physical, intellectual, or sensory disabilities [48-50]. This is due to the rapidly changing landscape of digital health, and the prospect of more CYP accessing their health data via patient portals. By not including CYP, this directly contradicts ‘No decision about me, without me’ which promotes shared decision making, patients being supported in taking more responsibility for maintaining and improving their health and self-care abilities, and joint care planning with the clinician [51]. Patient choice in who and where patients receive care is also advocated [51]. These aspects of care should be routine, promoting effective, active partnerships in care, which are also increasingly recognised as key to improving the design, delivery and organisation of health services and policy [52].

The authors acknowledge that the framework may fail to address legal concerns around EPRs. Nevertheless, consideration of the ethical and legal complexities relating to CYP’s health in the digital health context is an area in need of exploration, clarification, and inclusion in the framework for it to be applicable to this patient group. The Going Digital study presented a unique opportunity to evaluate and shape the delivery of this component of the digital system at GOSH, and the study’s findings are also an important contribution to understanding CYP’s needs, rights and interests in this context. Importance was placed on voices, views, and experiences of CYP. This study has an important contribution to make on the inclusion of children and young people in digitally enabled healthcare.

1.8 Personal reflections on the need for this research

I have almost 30 years’ experience as an adult and children’s nurse, with extensive experience predominantly in the paediatric critical care environment. Over the years, I have experienced numerous iterations of paper charting and medical notes, hybrid models of electronic charting and paper medical notes, and the use of numerous different systems to be able provide the holistic care to the patient. Challenges existed in using multiple different approaches and systems to deliver patient care. These included duplication of documentation, time-inefficiencies as a result, and from needing to log on to numerous different systems. This also led to a disjointed overview of the patient’s status and clinical needs. As a healthcare professional, I could see the huge potential and benefit of having one overarching clinical information system.

Clinically I have cared for, and within my research have strived to include, diverse and vulnerable groups, as I am acutely aware of the inequities they can experience in healthcare. I have become attuned to the need to actively involve hard to reach or under-researched populations, and a diverse range of participants. This is important given the diversity of patients, parents, and staff populations at GOSH. Furthermore, from working in sensitive situations in both the research and clinical context, I also have experience of solving complex issues and concepts, including controversial or difficult issues, as well as promoting best practices, which would be highly applicable to conducting this fast-paced and demanding study. Through studying Medical Ethics and Law at master’s level, and from being an active member in the area of clinical ethics and research ethics, this expertise was essential to this research topic due the presence of ethical and legal considerations within this study.

I acknowledge my previous clinical and research experience as beneficial, but embarked on this study and developmental journey with an open mind. I am especially mindful of my personal and professional interest in ethical and legal issues and that this could lead to bias in the way that the data is captured, analysed, and reported. I was open to new ideas and processes, aiming to gain a rich understanding of the experience of those affected by the hospital’s digital transformation, and through ongoing discussions with my supervisory team and the use of a reflective diary to capture my thoughts as the study progressed, a true representation of stakeholder experiences is presented.

1.9 Organisation of the thesis

This thesis is comprised of 11 chapters and is inclusive of a systematic review that has informed the study, both the quantitative and qualitative aspects of the study, synthesis and interpretation of the study findings, conclusions, reflections, and my personal and professional development throughout the PhD.

Chapter 1 – Background and Introduction

This introductory chapter has set the scene for the study by highlighting how existing literature, legislation and policy has influenced NHS strategy for the digitalisation of healthcare, GOSH's decision to go digital, and the unique research opportunity this presented.

Chapter 2 – Research aims and design

The research aims, patient and public involvement and engagement, design and methodology are outlined in Chapter 2, including a justification for the decision to utilise a mixed methods approach.

Chapter 3 – Systematic review

The systematic review, presented in Chapter 3, was conducted to understand the experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting. The findings provided a theoretical underpinning to inform the subsequent phases of the study.

Chapter 4 – World Café workshops

In Chapter 4, the World Café workshop findings held with each stakeholder group (young people, parents, hospital staff) during phase one of the study are presented. The workshops were essential to understanding stakeholder expectations of the new system, what their information and support needs might be, and whether they considered there to be any ethical or legal dilemmas we, as a Trust, needed to consider. The findings were used to formulate the surveys for all stakeholder groups for phases two and three of the study.

Chapter 5 – Children's and young people's survey findings

The quantitative findings from the phase two and three CYP surveys are presented in Chapter 5. This was crucial to understanding CYP's perceptions and experiences of the hospital transitioning to an EPR system and the use of the MyGOSH patient portal for managing aspects of their care.

Chapter 6 – Parent survey findings

In Chapter 6, the quantitative findings from the phase two and three parent surveys are presented as it was essential to understand parental perceptions and experiences of the hospital transitioning to an EPR system. This included the use of MyGOSH patient portal for managing aspects of their child's care.

Chapter 7 – Staff survey findings

In Chapter 7, the quantitative findings from the phase two and three staff surveys are presented. The aim was to understand staff perceptions and experiences of the hospital transitioning to an EPR system and MyGOSH, with the focus on how EPR and MyGOSH impacted the provision of care for families, and staff perceptions of their ability to provide care.

Chapter 8 – Focus group discussion

The qualitative findings from the focus group held with members of the GOSH Paediatric Bioethics Centre during phase three of the study are presented, focused on the ethical and legal considerations of CYP and their parents accessing their digital health data and using a patient portal. This was a critical ethical debate on important issues that had been raised during the study.

Chapter 9 – Parent interview findings

The focus of this chapter is on phase three qualitative parent interviews. The aim of the interviews was to understand participants' perceptions and experiences of GOSH's transition to EPR and MyGOSH patient portal, and how this affected the care of their child, including communicating and interacting with healthcare professionals, their involvement in decision-making, viewing results, and managing their child's care.

Chapter 10 – Synthesis, implications, and conclusions

A synthesis of the quantitative and qualitative findings is presented. This includes identifying any convergence or divergence of the results, and ethical and legal analysis. Recommendations for clinical practice and for future research are presented, and the strengths and limitations of the research are described. Finally, conclusions are drawn, summarising the research. The results of this unique research will add to the limited body of evidence on the implementation of electronic patient records and patient portal, and CYP and parents accessing their digital health data in a children's hospital setting.

Chapter 11 – Reflections and future directions

In this final chapter, dissemination of the study's findings, the impact COVID-19 had on the study, and professional and personal development throughout the PhD journey are presented. Future directions, and overall reflections following the conclusion of the PhD are highlighted.

1.10 Summary

This chapter outlined the implications of the global phenomenon of digitalisation, its impact worldwide, nationally and locally on healthcare. The motivation behind and the importance of the Going Digital study has been highlighted, including the significance of its timing. Anticipated ethical and legal considerations of implementing an EPR system have also been discussed, and a plan of the thesis has been presented.

The research aims, design, and different phases of the study are presented in the next chapter. The aim of this is to give the reader an overview of the Going Digital study.

2

2 Research Aims and Design

2.1 Introduction

The aim of this chapter is to give the reader an overview of the Going Digital study through a presentation of the aims, design, and the detail of the three phases of data collection, then a final phase of integration and synthesis.

Due to the use of a mixed methods approach to this study, the structure of each chapter reporting data includes the methods relevant to that chapter (4-9), for ease of reading.[ii]

2.2 Aims of the research

To understand from the perspective of patients, parents, and staff:

1. Their expectations regarding the introduction of electronic patient records (EPR) and MyGOSH patient portal, and whether these were met,
2. The benefits and challenges of transitioning to an EPR system and the use of MyGOSH,
3. Their information and support needs when accessing EPR and MyGOSH,
4. The ethical dilemmas and legal implications associated with the implementation and use of EPR and MyGOSH.

[ii] Please note that the ‘numbered’ referencing style has been used throughout this thesis. After discussion, this was decided as the least cumbersome approach to take due to the inclusion of a large systematic review. Utilisation of an alternative referencing style would be more arduous for the reader.

2.3 Patient and Public Involvement and Engagement

Prior to commencement of this research, patients, parents, and hospital staff were involved in helping to shape the study. Through patient and public involvement and engagement (PPIE), stakeholders were consulted on the study design, methodology, how best to manage the research, how to recruit participants, and who to recruit to ensure that the viewpoints of all stakeholders were considered. The practicalities of performing the research, and any barriers that might prevent participation were also considered with each stakeholder group. Patient and public involvement and engagement has continued throughout the study. Activities related to PPIE included:

- PPIE session with the members of the Young People's Forum (YPF) to gain their ideas about the proposed study, and their potential interest in participating in the World Café workshops
- PPIE meetings with parents
- PPIE meetings with hospital staff members
- Presentations prior to commencement of the study at the hospital's Open House event in 2018, involving staff members, board members, and lay members of the public in attendance
- EPR Showcase session and presentation of the Going Digital Study at GOSH Children's Charity Staff Event in 2018
- Presentation of the proposed study to the MyGOSH patient portal Steering Committee for feedback and input. Regular progress updates continued throughout the study
- All stakeholders were involved in phase 1 World Café were invited to pilot the survey they helped to develop prior to the survey going live
- Presentations at the hospital's Open Day event in 2019, involving CYP, parents and hospital staff
- Presence at a weekly lunchtime EPR staff event throughout the first six months of the study

2.4 Research design

This was a single site, single arm pre-post study with data collected from a sample of all relevant stakeholders before and after the implementation of EPR and MyGOSH [53]. A concurrent mixed methods design was utilised with qualitative (workshops/interviews/focus group) and quantitative (surveys) data collected simultaneously over three phases and analysed discretely before a final stage of synthesis and interpretation, including ethical analysis [53, 54]. The study's mixed methods plan is presented in Figure 2-1, reporting target recruitment. Subsequent mixed methods plans at the start of each chapter will report actual recruitment. A mixed methods approach was utilised to enable multi-faceted investigation, and deeper understanding of the complexities of stakeholder experiences and perceptions that would not have been achieved through single method research [55].

Data was collected at four times points:
T0: Pre Survey development (Phase 1)
T1: Pre Go Live (Phase 2)
T2: Post Go-Live follow-up (Phase 3)
T3: Post Go-Live repeated follow-up (Phase 3)

Phase one comprised World Café workshops with each stakeholder group, one workshop with young people (*n*=24), one with parents (*n*=24), and two with hospital staff (*n*=48; T0 on the mixed methods plan). The workshop findings informed the content of surveys for Trust-wide distribution during phases two and three (B1-B4 on mixed methods plan).

Phase two comprised pre Go-Live surveys with all stakeholders, as well as exploratory interviews with staff (T1; A1/B1).

Phase three comprised follow-up surveys with all stakeholders post Go-Live (T2; B2/3), as well as repeated follow-up surveys with staff (T3; B4). Phase three also included a focus group with members of the GOSH Paediatric Bioethics Centre (A2) and post Go-Live interviews with parents and staff (A3).

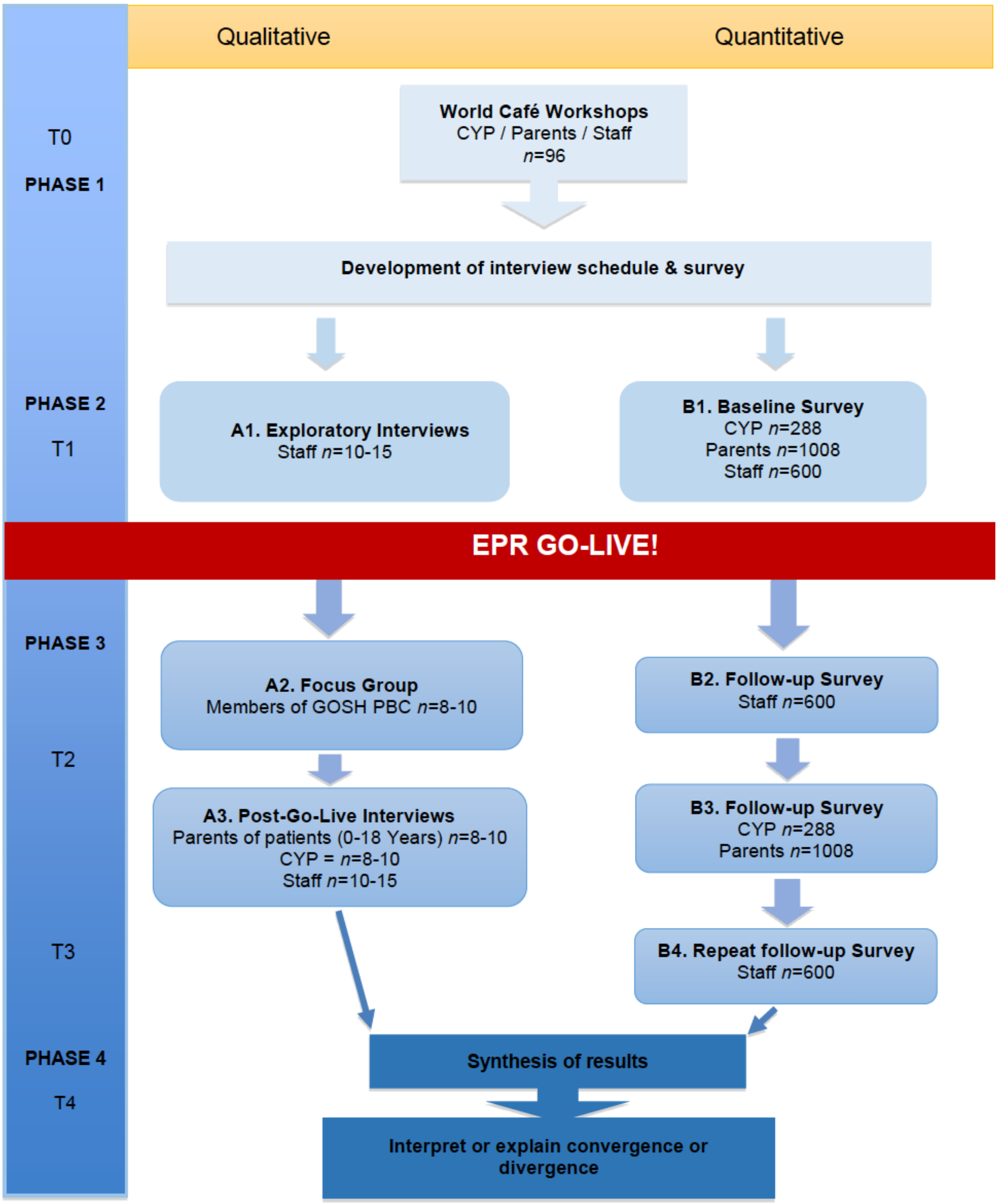


Figure 2-1: Going Digital mixed methods plan[iii]

[iii] Staff interview data was collected in real time, due to risk of recall bias, but data was not utilised in this thesis. No CYP came forward for interviews. These points will be discussed further in the thesis.

The final phase consisted of data integration and synthesis (T4). Please see Appendix 4 for the study's Gantt Chart, which set out a comprehensive plan for the research and PhD.

2.5 Sampling and setting

The research took place across all departments in a children's tertiary hospital. The study sample included three key stakeholder groups – patients, parents, and hospital staff.

For phase 1, the study sample included three key stakeholder groups to inform the relevant survey – Members of the Young People's Forum (YPF), parents from an existing hospital wide special EPR interest group, and hospital staff. All those who wished to participate were included in the workshops.

For phases 2-3, the sampling strategy applied varied for each participant group and method of data collection as described in Table 2-1; and inclusion/exclusion criteria is presented in Table 2-2.

Table 2-1: Sample strategy and size for phases two and three

Participants	Method	Time point	Sampling strategy	Anticipated sample size
CYP 12-25 years	**Survey**	T1/2	The required representative sample (GOSH patient population) comprised 288 responses for each time point. Calculated prior to the start of the Going Digital study based on total number of patients predicted to be attending the hospital during the expected data collection period. Sample size was based on a predicted number of *n*=2000 CYP aged 12-25 years attending in a 2-week period, assuming 20% (*n*=400) ineligible, 60% of the eligible *n*=1600 will be approached (*n*=960), with a predicted response rate of 30%, resulting in *n*=288 minimum number of anticipated responses	288 at each of 2 time-points
	Interviews	T2	A purposive sampling strategy using a sampling matrix to ensure a range of CYP of different ages, with a variety of clinical needs	8-10
Parents of CYP **0-25 years**	**Survey**	T1/2	The required representative sample (parents of GOSH patient population) comprised 1008 parent respondents. Calculated in the same manner as the CYP's survey, based on a predicted number of *n*=7000 parents of CYP 0-18 years attending in a 2-week period (in- and out-patient), assuming 20% (*n*=1400) would be ineligible, 60% of the eligible (*n*=5600) would be approached (*n*=3360), with a predicted response rate of 30%, resulting in *n*=1008 minimum number of anticipated responses	1008 at each of 2 time-points
	Interviews	T2	A purposive sampling strategy using a sampling matrix to ensure a range of parents (mothers and fathers) caring for children of different ages, with a variety of clinical needs.	8-10
Hospital staff	**Survey**	T1/2/3	Sample size was based on an estimated 20% response rate from a total of 3000 clinical staff members.	600 at each of 3 time-points
	Interviews	T1/2	A purposive sampling strategy using a sampling matrix to ensure inclusion of a range of staff from different professions, levels of seniority and working in different specialities.	10-15 at each of 2 time-points
Members of the GOSH PBC	**Focus group**	T2	All members of the GOSH Paediatric Bioethics Centre were invited to participate.	8-10

*It was unfeasible to distribute just to clinical staff or only those who had contact with patients (as initially intended), due to needing to complete an all-user email via the Trust email system. Furthermore, the decision to send to all staff was informed by the systematic review conducted as part of this study, in which it was identified that some staff groups were under-represented or absent from the research.

Table 2-2: Inclusion and exclusion criteria phases two and three

	Inclusion criteria	Exclusion criteria
CYP	• Age 12 years of age* Attending hospital for out-patient appointment	• CYP <12 years of age* • CYP 25 year or older** • Moderate/severe learning disability • CYP who do not speak English
Parents	• Accompanying child/young person aged 0-18 years for outpatient appointment	• Parents who do not speak English
Staff	• All staff • Members of the GOSH Paediatric Bioethics Centre (focus group only)	• None

*MyGOSH portal is only accessible to CYP aged 12 years and over therefore CYP <12 years of age were not eligible for survey or individual interviews regarding portal use.
**CYP 25 years of age or over were not eligible to participate. This was to prevent adult patients, who remain under the care of the hospital due to its specialist nature, participating and to ensure the voices of CYP were captured.

Non-English speaking children and parents were not able to be included in this study. This was designated by the hospital due to the initial roll-out of EPR being in English only, with system functionality only to facilitate translation of after-visit summaries into Arabic. Permissions were also not granted by the hospital to include private patients due to these limitations.

The implications of this on non-English speaking potential participants is acknowledged. This gives rise to the need for further research in the postdoctoral phase on a larger scale, to include research materials translated into different languages to gather family's perspective. Those with moderate to severe intellectual disabilities were also unable to participate due the in-depth nature of the topics covered, however, those with intellectual disabilities who were thought to be able to contribute to the study were actively encouraged to participate. Guidance was sought from the clinical team and parents of the child or young person.

2.6 Recruitment, data collection and informed consent

2.6.1 Children and young people and their parents

Baseline data collection with families was completed at Go-Live when families were approached for MyGOSH sign up. This is described in more detail in Chapters 5 and 6. The invitation to complete the surveys was open to those in the hospital at the time of data collection (T1), and those who had signed up to MyGOSH patient portal (T2). This meant that CYP and their parents could complete the survey at one or both time-points, depending on their hospital activity. The content of the surveys was developed and piloted following the phase one World Café Workshops, and this is presented in Chapter 4.

A pre-identified group of clinical staff distributed paper copies of baseline surveys within their clinical area, to be returned by families upon completion to sealed post boxes on the ward. Post-Go-Live surveys were completed electronically. At all stages, the survey was accompanied by information about the study with contact details of the research team. All surveys were anonymised. Return of completed surveys was taken as consent to participate. All surveys included an invitation for parents/patients aged 16 years or above to leave their contact details if they were interested in participating in other aspects of the study.

Parents were invited to participate in in-depth interviews after they had expressed in their survey response (this will be discussed further in Chapter 8). Parents were sent an email inviting them to participate in the interviews. Those who responded were sent a participant information sheet. Parents with CYP wishing to participate would be sent the age-appropriate information and consent forms to enable their child to take part. Written informed consent was obtained from parents prior to data collection. Through in-depth interviews parents and CYP were able to ‘tell their stories’ about their experiences as experts in their own thoughts, commitments, and feelings. The purpose of the interviews was to understand participants’ experiences, either as an in-patient or out-patient, including communicating and interacting with healthcare professionals, their involvement in decision-making, and managing appointments. Where relevant, expectations were also be sought about what MyGOSH could offer them/their child, as well as any challenges or concerns they had. With participants’ permission, interviews were audio-recorded for transcription accuracy and transcribed verbatim, and were expected to last 30-60 minutes. The parent interviews are presented in Chapter 8.

Due to the impact of the pandemic affecting our ability to conduct face-to-face data collection, a substantial amendment was made to include virtual data collection methods (Appendix 5).

2.6.2 Hospital Staff

Staff throughout the Trust were invited to take part in a baseline survey pre-Go-Live (T1; B1 on mixed methods plan) and follow-up surveys at 6 months (T2; B2) and 18 months post Go-Live (T3; B4). The content of the staff survey was developed and piloted following the World Café Workshops undertaken during phase one. All surveys were anonymised but included information such as profession or role, and area of work, to aid understanding of the impact, challenges, and benefits of the implementation of EPR throughout the Trust and what it means to each person. The survey was available electronically, in the form of REDCap at both time-points, and also on paper pre-Go-Live. Staff were invited to complete the online survey via Trust-wide emails containing information about the study and a direct link to the survey. The return of completed surveys were taken as consent to participate.

Staff were also invited to take part in interviews pre-Go-Live (T1; A1) to gain more in-depth understanding of their views and expectations of EPR and MyGOSH prior to implementation. They were recruited via a range of internal communications such as the Trust Monthly Newsletter, EPR Newsletter (which will also be accessible via ‘GOSHweb’ Intranet), posters, a Trust screensaver, and through the EPR ‘Roadshow’ (a weekly event located in the hospital to enable staff members to access and enquire about EPR) as well as through information provided at departmental meetings and via Head of Department emails. The staff survey (described above) also had a section for staff to leave their contact details if they wished to receive information directly about the interviews. All interested staff received an information sheet about the study prior to taking part and had the opportunity to ask questions. They were also asked to provide written informed consent before the interview took place and consent was re-confirmed verbally at the start of the interview. Interviews were expected to last 30-60 minutes and were conducted in person at T1 in a quiet room in the hospital, and virtually at T2. With permission interviews were audio recorded and transcribed verbatim.

As the data collection evolved, the primary focus of this study was determined to be on CYP and families and their experiences. Views of staff do feature in this thesis, but their experiences, as told by staff members do not. This data will feature in a companion publication, as a separate piece of work outside the remit of this thesis. This is to ensure that justice is done to each stakeholder groups' experiences, as it became evident that they are too complex to be presented sufficiently within the context of this thesis.

A focus group was held with members of the GOSH Paediatric Bioethics Centre (PBC) post-Go-Live to explore the ethical and legal considerations of the introduction of MyGOSH patient portal (see T2; A2). The GOSH PBC is made up of members from a variety of specialisms and backgrounds including clinicians (medical and allied healthcare professionals), academics (including a Philosopher and Ethicists), and lay members with expertise in clinical ethics, who between them had sufficiently varying perspectives to encourage debate [56]. This research activity is presented in Chapter 9.

2.7 Early dissemination

> *"Research is of no use unless it gets to the people who need to use it"*

Professor Chris Whitty (2016) [57].

Throughout this study, thought has been given to ensuring the principles of good dissemination have been followed. This included consideration of stakeholder engagement to determine primary, secondary and other important audiences to engage with, involving them throughout, from the planning phase to dissemination [58]. The format of dissemination was crucial to ensure outputs were appropriate for the target audience, which included CYP, parents, staff members, healthcare professionals, researchers, ethicists, funders and the public, at local, national, and international level [58]. Opportunities were grasped to build partnerships with established networks; face-to-face and virtual conferences and events were utilised to exchange knowledge and raise awareness of the study, sharing emerging findings during each phase of the research [58]. Dissemination of the study's findings will be presented in-depth in Chapter 10.

2.8 Summary

This chapter has presented an overview of the study's aims, design, and phases of the research, relating each research activity to the Going Digital mixed methods plan and the related chapter, for clarity.

This next chapter will present the systematic review that was conducted at the outset of the Going Digital study.

3 Systematic Review

3.1 Introduction

The focus of this chapter is presentation of the methods and findings from the systematic review which focused on the experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting. The findings provided a theoretical underpinning to inform the subsequent phases of the study.

3.2 Background and context

Having a first class, well-funded healthcare system is a fundamental premise to health. Integral to this is the worldwide transition to digital health, including utilisation of EPR[iv] systems to promote effective healthcare. However, implementation, acceptance and utility of EPRs and patient portals vary throughout the world. Although there is an increasing body of literature on EPR use in the adult setting, especially adoption related to financial incentives in the United States (US), the experiences and perceptions of users of an EPR system within the paediatric hospital setting are less well understood. Furthermore, the advent of patient portals that CYP and their parents can access bring new promises of benefits but pose challenges for them and healthcare professionals (HCPs) alike. Gaps in the literature on this topic were evident, requiring further investigation.

[iv] Electronic patient records may also be termed electronic health records or electronic medical records but for the purposes of this review the term electronic patient records will be used.

It should be noted at the outset that terminology related to, and the function of electronic health-related systems varies around the world. In the UK, the EPR relates to the patient's systematised digital health and care record that can be shared across different healthcare settings. Outside of the UK, this is often referred to as an electronic health record. The electronic medical record is usually the longitudinal health record within a specified organisation. The personal health record usually refers to patient-maintained health documentation and differs from patient portals in the UK insofar as patient portals are maintained by both the healthcare team and the patient. Furthermore, outside of the UK, health-related digital systems also comprise billing information. To the best of our knowledge, no systematic review has been completed on this topic, which was important because it demonstrates the widespread lack of knowledge and understanding about EPR implementation in the paediatric hospital setting. With EPR implementation about to take place in our paediatric tertiary hospital, we wanted to understand best practice approaches to implementation and to learn from other centres about their experiences to help facilitate successful digital transformation, and ongoing utility in our centre. Without evidence from an existing systematic review and meta-analysis, it was clear that this was necessary as an integral component of the Going Digital Study. Systematic reviews and meta-analyses are recognised as the highest level of evidence in the hierarchy of evidence [59-61] (see Figure 3-1), synthesising research from multiple studies and enabling increased and efficient access to evidence [62].

3.3 Aim of Systematic Review

The aim of the systematic review was to understand the experiences and perceptions of *all* relevant stakeholders (CYP, parents, HCPs) using an EPR system in the paediatric hospital setting, including the use of an EPR-linked patient portal.

(Greenhalgh, 1997) [60].

Figure 3-1: Hierarchy of evidence

3.4 Methods

3.4.1 Primary outcomes

The primary outcomes were the experiences and perceptions of all relevant stakeholders using an EPR system in the paediatric hospital setting, including the use of an EPR-linked patient portal. The protocol was registered on PROSPERO (CRD42020152099)[63] and can be found in Appendix 6.

3.4.2 Inclusion and exclusion criteria

3.4.2.1 Inclusion criteria

- Use or experience of using an EPR system implemented in a hospital setting where paediatric patients (children from 0-17.9 years) were cared for, with/without EPR-linked patient portal

3.4.2.2 Exclusion criteria

- Patient populations other than children - i.e., exclusively adults
- Paediatric data could not be determined/not clearly specified
- Primary care setting

- Other out of hospital care e.g., community or hospice care
- Commentaries/editorials
- Title or abstract not in English
- Computerised physician order entry (CPOE), clinical decision support (CDS) or medication management system only studies, EPR linkage/use not mentioned

3.4.3 Search strategy

A systematic search was conducted using the following electronic databases: EMBASE, EMCARE, MEDLINE, Cochrane Library, Web of Science, Scopus, CINAHL, and PsycINFO to identify literature published 2010–January 2020, in addition to manual searching of conference abstracts, and research reports searched via the Health Research Authority (HRA)website [64]. Results were limited to studies relating to EPR system use or implementation, and the experiences and perceptions of EPR users, in a paediatric hospital setting from 2010, to incorporate the current incarnation of EPR systems. A broad search strategy was utilised, with Medical Subject Headings (MeSH) and free text searching using title or abstract keywords. Reference lists of identified articles were hand-searched for other relevant studies for inclusion. Difficult to find, unpublished and ongoing study details were obtained wherever possible via correspondence with authors. Provided the abstract was in English, non-English studies were included in the review. This review was inclusive of all study designs. An example of the search terms can be found in Appendix 7.

Following duplicate removal, the title and abstract of 27377 records were screened independently by two researchers (PS/JW). The full text papers of 278 studies were then reviewed independently for inclusion by three researchers (PS/KO/FG), ensuring each full text paper was reviewed by two researchers. Discussion with the full research team resolved any uncertainties regarding inclusion of a paper (PS/JW/KO/FG). This review was conducted according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [65](Figure 3-2).

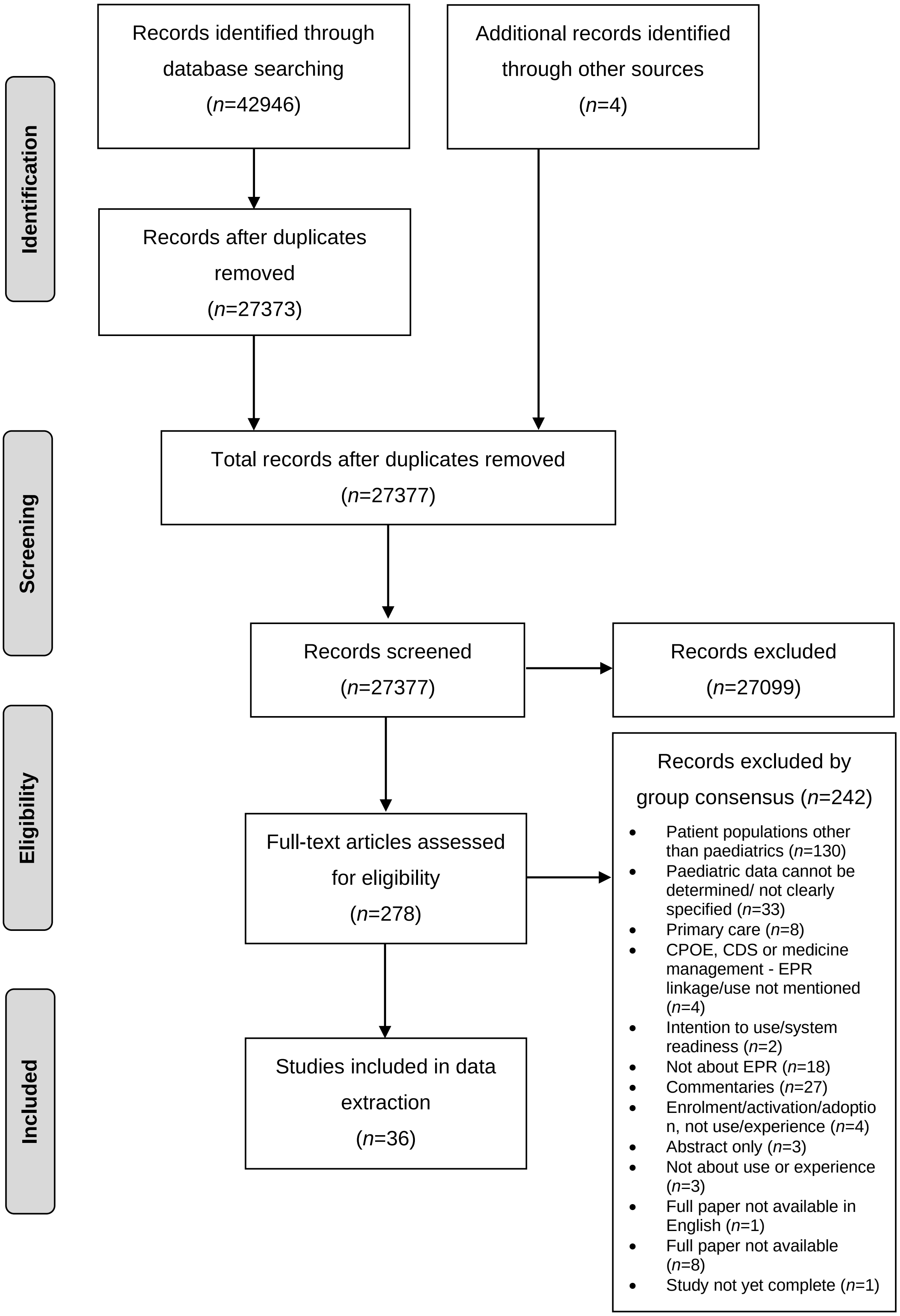


Figure 3-2: PRISMA Flowchart showing study selection process

3.4.4 Data extraction

A data extraction form was developed and piloted. Extracted data were entered into Microsoft Excel (2021; Excel version 16.54) by PS and verified by JW. Information collected included study design, population, diagnosis, and outcomes. Topic-specific information included whether the study was pre/post system implementation, an EPR system/patient portal/both and included outcomes specifically related to user experiences/perceptions, benefits or challenges, user information/support needs and ethical or legal issues encountered. A copy of the data extraction tool can be found in Appendix 8.

3.4.5 Quality assessment

Critical appraisal of the included studies was performed using the Mixed Methods Appraisal Tool (MMAT); version 2018 [66], which permits methodological quality appraisal of five study categories: qualitative research; randomised controlled trials; non-randomised; quantitative descriptive; and mixed methods studies [66]. The MMAT can be found in Appendix 9.

3.5 Results

3.5.1 Study selection

Thirty-six studies were eligible for inclusion from ten countries, predominantly from the United States (*n*=23), but studies were also from Canada (*n*=4), Korea (*n*=2) and Australia, the Netherlands, Norway, Iraq, Jordan, the United Kingdom and Saudi Arabia (one per country).

The review included 26 quantitative studies which comprised of 22 cross-sectional analytic studies [25, 67-87], two quantitative descriptive studies [88, 89], one retrospective observational cohort study [90] and one non-randomised controlled trial [91]. Also included in the review were six mixed methods studies [92-97] and four qualitative studies [98-101].

A detailed breakdown of the focus of the 36 included studies can be seen in Figure 3.3. This includes whether the studies were conducted pre or post implementation of an EPR or linked portal, or related intervention, and whether user experience was studied. Participant groups for each study are presented in Figure 3.4.

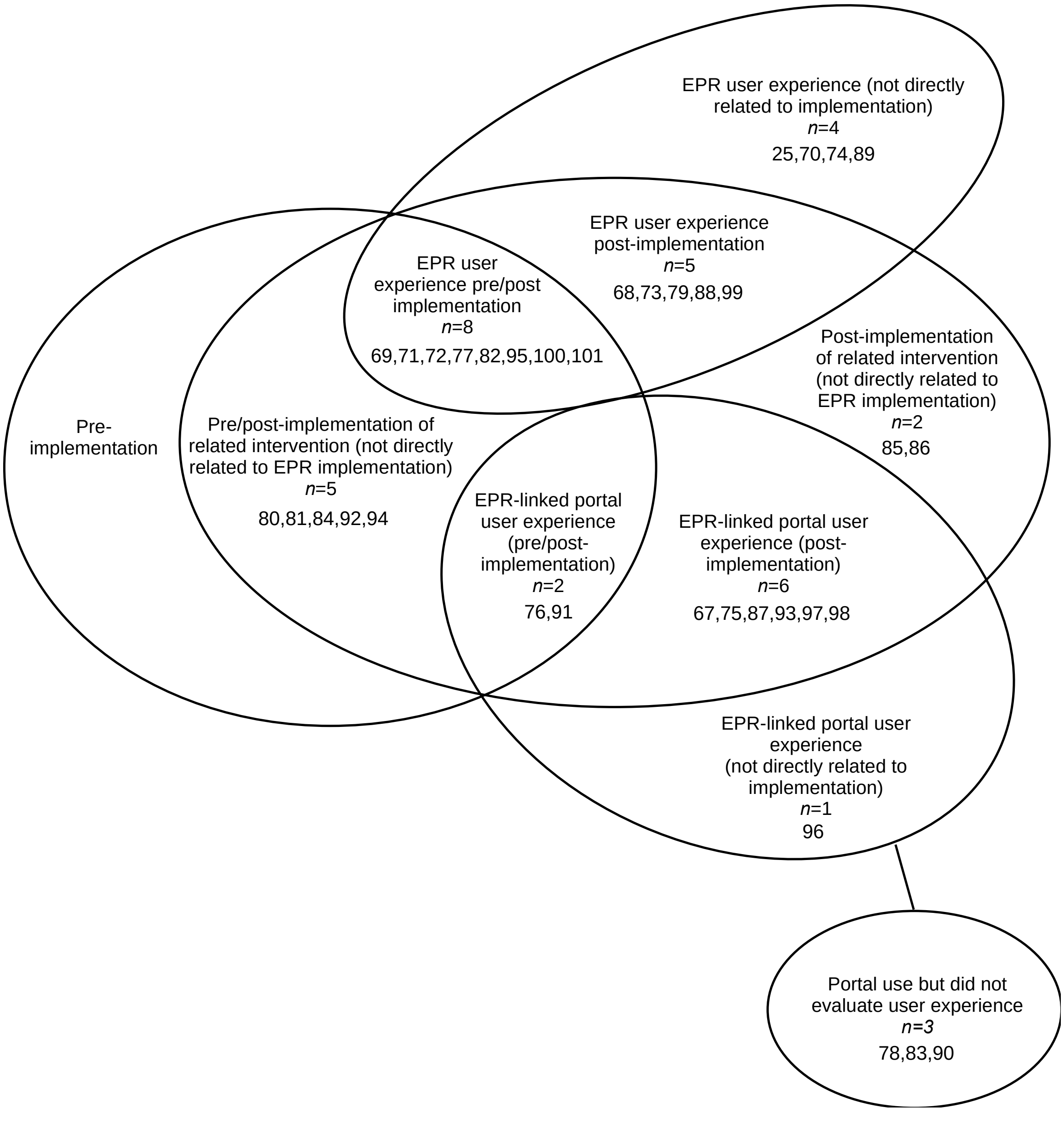


Figure 3-3: Detailed breakdown of the focus of included studies

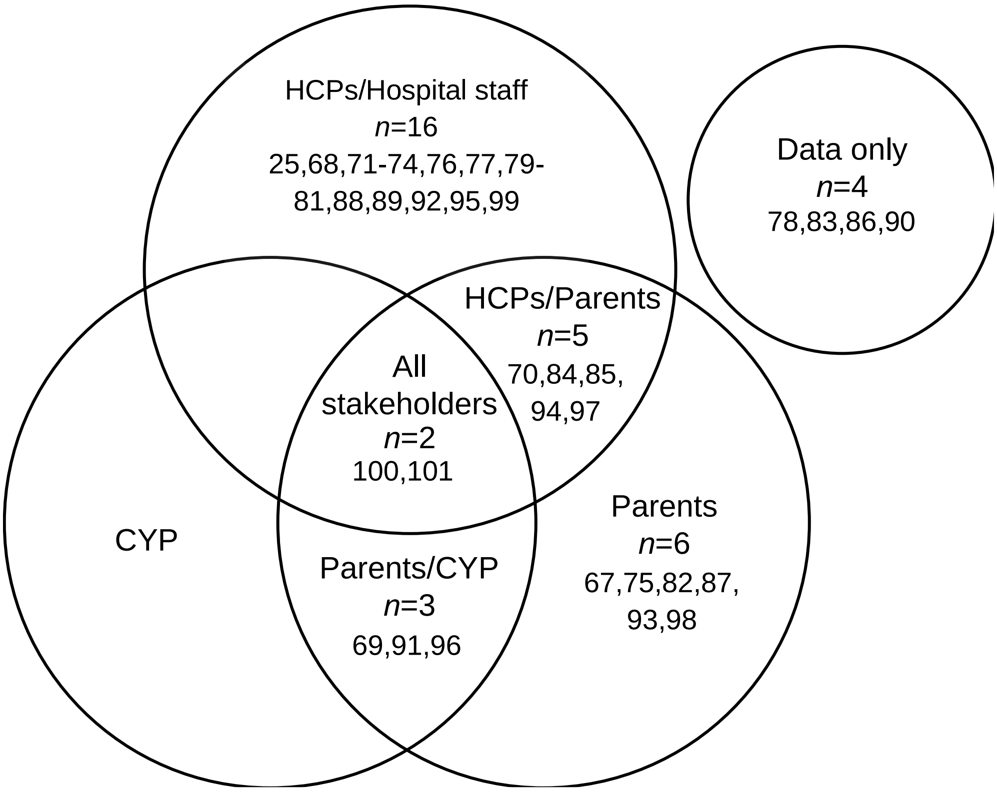


Figure 3-4: Participant groups for each study

One study reporting inclusion of patient participants utilised EPR data only, with no direct participation from CYP, and was therefore included under 'HCPs and/or hospital staff' [72]. Tethered portal implementation evaluation in a single US institution was reported in three articles, presenting different aspects of the study, different participants groups and/or different methodologies with distinct datasets [75, 76, 98]. Similarly, the transition from paper charts to vendor EPR in another US institution was described in two articles, presenting clinician experiences in one, and the impact EPR implementation has on clinical reasoning and interprofessional collaborative practices in the other [100, 101].

Due to widespread heterogeneity, it was not possible to conduct a meta-analysis. Heterogeneity was seen in terms of study methods, participant groups, and outcomes. Studies examined different aspects of EPR/portal implementation and use. Huge diversity was seen in what was studied, the questions that were asked, and how they were asked, with some studies using surveys developed within their institution, making meta-analysis impossible.

3.5.2 Quality assessment results

Table 3.1 presents the quality assessment results. Overall, three issues stand out as potentially raising the risk of bias for many studies in this review. First, failing to or being unable to tell if confounding factors were addressed [67, 68, 73, 75, 76, 78, 81, 82, 87, 91]. Second, lack of clarity as to whether the participants were representative of the target population [67, 69, 70, 72, 74, 87-89]. Third, having incomplete data [25, 71, 74, 83] or lack of clarity on this issue [79, 81, 87]. In two studies the measures could not be administered as intended [69, 77]; one study did not appear to adhere to the quality criteria for methods within a mixed-methods study [95], with divergencies between qualitative and quantitative not being fully presented. Table 3.2 summarises the included studies and Table 3.3 presents outcomes for the included studies.

Table 3-1: Summary of quality assessment[v]

Qualitative studies							
First author	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**	**1.1. Is the qualitative approach appropriate to answer the research question?**	**1.2. Are the qualitative data collection methods adequate to address the research question?**	**1.3. Are the findings adequately derived from the data?**	**1.4. Is the interpretation of results sufficiently substantiated by data?**	**1.5. Is there coherence between qualitative data sources, collection, analysis, interpretation?**
Kelly et al. [98]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Tubaishat [99]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Varpio et al.[100]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Varpio et al. [101]	🟩	🟩	🟩	🟩	🟩	🟩	🟩

Non-randomised studies							
First author	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**	**3.1. Are the participants representative of the target population?**	**3.2. Are measurements appropriate regarding both the outcome/intervention (exposure)?**	**3.3. Are there complete outcome data?**	**3.4. Are the confounders accounted for in the design and analysis?**	**3.5. During the study period, is the intervention administered (or exposure occurred) as intended?**
Ahlers-Schmidt et al. [67]	🟩	🟩	🟧	🟩	🟩	🟧	🟩
Alsohime et al. [68]	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Cavuoto et al. [69]	🟩	🟩	🟧	🟩	🟩	🟩	🟥
Chung et al. [70]	🟩	🟩	🟧	🟩	🟩	🟩	🟩
Cillessen et al. [86]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Colligan et al. [71]	🟩	🟩	🟩	🟩	🟥	🟩	🟩
Copley et al.[25]	🟩	🟩	🟩	🟩	🟥	🟩	🟩
Ghazi Al-Shammari et al. [72]	🟩	🟩	🟧	🟩	🟩	🟩	🟩
Hollenbeck et al. [73]	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Johansen et al. [74]	🟩	🟩	🟧	🟩	🟥	🟩	🟩
Kelly et al. [75]	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Kelly et al. [76]	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Kirkendall et al. [77]	🟩	🟩	🟩	🟩	🟩	🟩	🟥
Lee et al. [78]	🟩	🟩	🟩	🟩	🟩	🟧	🟩

---

[v] S = screening questions; No-randomised studies in review hence no 2.1-2.5 boxes

First author	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**	**3.1. Are the participants representative of the target population?**	**3.2. Are measurements appropriate regarding both the outcome/intervention (exposure)?**	**3.3. Are there complete outcome data?**	**3.4. Are the confounders accounted for in the design and analysis?**	**3.5. During the study period, is the intervention administered (or exposure occurred) as intended?**
Lee et al. [91]	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Matton et al. [79]	🟩	🟩	🟩	🟩	🟧	🟩	🟩
Palma et al. [80]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Raval et al. [81]	🟩	🟩	🟩	🟩	🟧	🟧	🟩
Rosen et al. [82]	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Selvadurai et al. [87]	🟩	🟩	🟧	🟧	🟧	🟧	🟩
Shenson et al. [83]	🟩	🟩	🟩	🟩	🟥	🟩	🟩
Singh et al. [84]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Wieck et al. [85]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Zhou et al. [90]	🟩	🟩	🟩	🟩	🟩	🟩	🟩

Quantitative descriptive studies

First author	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**	**4.1. Is sampling strategy relevant to address the research question?**	**4.2. Is the sample representative of the target population?**	**4.3. Are the measures appropriate?**	**4.4. Is the risk of non-response bias low?**	**4.5. Is statistical analysis appropriate to answer the research question?**
Cross et al. [89]	🟩	🟩	🟩	🟧	🟧	🟧	🟩
Williams et al. [88]	🟩	🟩	🟩	🟥	🟩	🟩	🟩

Mixed methods studies

First author	**S1. Are there clear research questions?**	**S2. Do the collected data allow to address the research questions?**	**5.1. Is there an adequate rationale for using a mixed methods design to address the research question?**	**5.2. Are the different components of the study effectively integrated to answer the research question?**	**5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?**	**5.4. Are divergences and inconsistencies between quantitative and qualitative results adequately addressed?**	**5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?**
Aylor et al. [92]	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Byczkowski et al. [93]	🟩	🟩	🟩	🟩	🟩	🟧	🟩
Byrd at al. [94]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
Hanauer at al. [95]	🟩	🟩	🟩	🟩	🟩	🟥	🟥
Hong et al. [96]	🟩	🟩	🟩	🟩	🟩	🟩	🟩
King et al. [97]	🟩	🟩	🟩	🟩	🟩	🟩	🟩

Yes	🟩	No	🟥	Can't tell	🟧

Table 3-2: Study characteristics

Study/year/ region (*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Studies relating to EPR *n*=17					
Healthcare professionals/hospital staff only as participants					
Alsohime et al. [68] (2018) Saudi Arabia	Tertiary teaching hospital	Satisfaction and perceived usefulness with newly implemented electronic health records system among paediatricians at a university hospital	• To identify paediatricians' satisfaction/perceived usefulness of EPR	• Cross sectional analytic study (survey); Likert-style questions • Demographics; quantitative: regression analysis; means/standard deviations; Pearson's correlation	• Paediatric physicians: all physicians invited to training; survey sent within 2 months post-training: *n*=194 approached; *n*=112 completed survey
Colligan et al. [71] (2015) US	Paediatric hospital - academic tertiary care healthcare system (NICU/inpatient ward)	Cognitive workload changes for nurses transitioning from a legacy system with paper documentation to a commercial electronic health record	• To assess the paediatric nurses' cognitive workload changes during routine information entry and retrieval of data during legacy/paper to EPR transition	• Cross sectional analytic study • The NASA-TLX validated instrument at baseline (pre-; t0), 1 (t1), 5(t2), 10 shifts (t3) and 4 months (t4) post-implementation • Demographics: computer attitude/skills scores obtained • Quantitative: repeated measures ANOVA	• Paediatric nurse participants *n*=74 (NICU *n*=50; ward *n*=24) at baseline (t0) and t1; Complete data obtained from 82% of participants. No difference to conclusions when analyses re-run excluding t4 missing data
Copley et al. [25] (2019) US	Pediatric Orthopedic Society of North America (POSNA)	Electronic medical record use and satisfaction among pediatric orthopedic surgeons	• EPR Meaningful Use regulatory framework review • To assess paediatric orthopedic surgeons EPR utilization	• Cross sectional analytic study (survey); Likert-style questions	• POSNA) members (Pediatric orthopedic surgeons); distributed by POSNA Practice Management Committee (PMC) to *n*=1100; *n*=324 respondents

Study/year/ region (*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Cross et al. [89] (2016) UK	UK hospital's where paediatric ophthalmologist clinicians practice	The experiences and perceptions of paediatric ophthalmic clinicians using electronic medical records in the United Kingdom	• Investigation of paediatric ophthalmic clinicians' experiences/perceptions of EPR use - a national survey	• Quantitative descriptive study; one-off online survey (with reminders) • Univariate statistical tests	• Paediatric ophthalmologists (*n*=90) across 42 UK hospitals • E-mail invitations to those on paediatric ophthalmologist mailing list
Ghazi Al-Shammari et al. [72] (2018) Iraq	Maternity and children hospital (PICU)	Application of electronic medical record at intensive care unit in maternity and children hospital	• To identify factors affecting PICU staff EPR acceptance – TAM3 model • Evaluation of time spent calculating completeness of documentation pre/post-implementation	• Cross sectional analytic study (survey; data gathering tool) • Limited demographics; descriptive statistics/inferential analysis; quantitative: Cronbach's α/paired-samples T test	• Paediatric patients admitted to PICU (convenience sample) pre (*n*=60); post (*n*=60) (total *n*=120) • PICU staff (purposive sample) 3 months post-implementation (*n*=30)
Hanauer et al. [95] (2017) US	Academic medical centre (paediatrics/ family and internal medicine)	Two-year longitudinal assessment of physicians' perceptions after replacement of a longstanding homegrown electronic health record: does a J-curve of satisfaction really exist?	• To identify if results followed a J-curve pattern whereby perceptions dropped at first, but subsequently rose above the baseline measures	• Mixed methods; 2-year prospective, longitudinal survey plus free text fields of pre/post transition to commercial EPR: 1-month pre; 3, 6, 13, 25 months post-implementation • Quantitative: Pearson-Klopper method, R; qualitative: free-text quotes	• Family medicine/paediatrics/internal medicine attending physicians • RR ranged from 76% for general paediatricians at +13-month stage to 23% for internal medicine at the -1-month stage
Hollenbeck et al. [73] (2017) US	Academic medical centre; paediatric orthopedic patient care (outpatient setting)	Electronic medical record adoption: the effect on efficiency, completeness, and accuracy in an academic orthopedic practice	• To investigate EPR's impact on: orthopedic surgeon attitude; efficiency; and note completeness and accuracy	• Single centre retrospective comparative study (chart comparison; survey) • Paper charts (*n*=60); EPRs (*n*=60) • Pre-EPR/post-EPR billing data determined outpatient volume/number of patients seen per provider per month; Note completeness/accuracy evaluated	• Orthopedic surgeons *n*=10; sent to all at academic medical centre (RR 100%)

Study/year/ region (*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Johansen et al. [74] (2019) Norway	Four hospitals in Northern Norway	Health professionals' experience with patients accessing their electronic health records: results from an online survey	• To evaluate the experience of hospital professionals (HP) including their attitude towards patients who access their own EPRs	• Cross sectional analytic study (survey); multiple choice questions; follow-up questions; free text fields • Demographics; quantitative analysis: descriptive statistics; use of R; qualitative: content analysis	• HPs from four hospitals in Northern Norway; survey sent via common email list • *n*=457 survey responses; *n*=332 from HPs, *n*=125 from administrative staff members
Kirkendall at al. [77] (2013) US	Tertiary children's hospital	Transitioning from a computerised provider order entry and paper documentation system to an electronic health record: expectations and experiences of hospital staff	• To investigate perceptions, experiences and expectations of healthcare worker's when transitioning from CPOE to full EPR • Assessment includes the effect on work processes, patient care and patient-related safety	• Cross sectional analytic study (I-SEE survey); pre (T1)/1 year post EPR implementation (T2) • Demographics; descriptive statistics, Cronbach α	• All staff members at hospital sent survey *n*=7213; responses T1 *n*=377; T2 *n*=983
Matton et al. [79] (2016) Canada	Tertiary children's hospital (medical/ surgical PICU)	Electronic medical record in paediatric intensive care: implementation process assessment	• To examine the satisfaction of caregivers at a stage 7 EPR, at EMR Adoption Model stage 3 during the first 6 months of implementation • Evaluation includes assessing patient safety and PICU caregivers' comfort levels.	• Cross sectional analytic study (critical incident forms/survey) • Medical incidents reported during study periods were recorded/classified/analyzed • All-user survey 1 wk./2 months/6 months post-implementation • Quantitative: ANOVA	• PICU caregivers: survey: *n*=10 physicians; *n*=10 fellows/residents; approx. *n*=100 nurses; *n*=40 respiratory therapists
Tubaishat [99] (2019) Jordan	Hospitals in Jordan (*n*=10)	The effect of electronic health records on patient safety: a qualitative exploratory study	• To evaluate nurses' perceptions of EPRs on patient safety	• Qualitative exploratory study (semi-structured interviews/field notes during interviews/thematic analysis)	• Staff nurses from ten hospitals working in various wards/units using the same EPR system for 1-5 years: *n*=32 recruited; *n*=17 chosen at random to participate

Study/year/ region (*n*=36)	Setting	Title	Aim of study	Method/design	Participants, sample selection
Williams et al. [88] (2019) US	Quaternary care academic hospital	Physician use of electronic health records: survey study assessing factors associated with provider reported satisfaction and perceived patient impact	• To identify clinical practice/provider factors associated with physician satisfaction with EPR/perception of patient impact	• Quantitative descriptive study (survey) • Demographics; quantitative: Kruskal-Wallis test/linear regression	• Physicians (incl. residents/fellows: random number generator sampling: *n*=160 approached; *n*=157 were sent survey; *n*=111 completed survey (Paediatrics *n*=22/19.8%)
Healthcare professionals/hospital staff and parents as participants					
Chung et al. [70] (2018) US	Tertiary children's hospital (NICU)	Differing perspectives on parent access to their child's electronic medical record during neonatal intensive care hospitalisation: a pilot study	• To explore parent/medical professional opinions regarding independent parent access to their child's EPR during NICU hospitalisation	• Cross sectional analytic study (survey); Likert-style questions • Demographics	• Parents of NICU patients who are able to visit *n*=85 • Medical professionals working in NICU (physicians/ nurses/nurse practitioners/respiratory therapists) *n*=133
Healthcare professionals/hospital staff, parents and paediatric patients as participants					
Varpio et al. [100] (2015) Canada	Tertiary children's hospital (PICU)	The impact of adopting EHRs: how losing connectivity affects clinical reasoning	• To investigate how the loss of connectivity affects clinical reasoning (CR) • Evaluation of clinician experience during transition from paper to EPR • How do paper v EPR present conceptions of time/data interconnections and their effect on CR?	• Qualitative longitudinal study over two phases (field observations, think-aloud/think-after sessions/interviews/document retrieval): Phase 1 = pre; Phase 2 = during/after transition from paper to EPR • Constructivist grounded theory: NVivo	• Purposive sampling: *n*=300 HCPs (staff physicians/residents/medical students/ nurses/AHPs); *n*=22 patients; *n*=32 parents; 146 hours of field observations; think-aloud (*n*=13); think-after (*n*=11) sessions; interviews (*n*=39); document retrieval (*n*=392)

Study/year/ region (*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Varpio et al. [101] (2015) Canada	Tertiary children's hospital (PICU)	The EHR and building the patient's story: a qualitative investigation of how EHR use obstructs a vital clinical activity	• To evaluate the impact of EPR implementation on clinician and teams' documentation and care practices • Investigation of complexity/boundaries of 'Building the patient's story' and how transition to EPR impacts on this	• The same design and methodology as above were used	• The same sampling as above was used
Parents and paediatric patients as participants					
Cavuoto et al. [69] (2016) US	Tertiary children's hospital	The impact of the transition to an electronic medical record on patient perceptions in a paediatric ophthalmology practice	• To evaluate the impact of paper-based medical records transition to EPR • Evaluation includes: parent/patient satisfaction/waiting time/time spent with clinician/impact on interaction during appointment	• Cross sectional analytic study (survey); pre/post-implementation; Likert-style questions; plus, free text fields • Demographics	• Consecutive patients (adult/children) recruited: Phase 1: *n*=137 surveys; Phase 2: *n*=54; Phase 3: *n*=143
Parents only as participants					
Rosen et al. [82] (2011) US	Paediatric rheumatology practice at a tertiary children's hospital	Parent satisfaction with the electronic medical record in an academic pediatric rheumatology practice	• To investigate the impact of EPR implementation on families.	• Cross sectional analytic study (survey); Likert-style survey: 1-month pre/3 months post-implementation	• Convenience sample of parents of patients • All those approached agreed to participate: pre *n*=99; post *n*=107 (participants were the patients' parents of two of the authors)

Study/year/ region(*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Studies relating to a patient portal/personal health record *n*=12					
Healthcare professionals/hospital staff only as participants					
Kelly et al. [76] (2017) US	Tertiary children's hospital (paediatric general medical/ surgical unit)	Healthcare team perceptions of a portal for parents of hospitalised children before and after implementation	• To examine perceptions of HCTs pre/post inpatient portal implementation • To investigate perceptions of HCTs on the impact portal use has communication with and on questions received from parents • Study the effect on workload, satisfaction, and care provision's quality and safety	• Repeated cross-sectional study; Likert-style survey pre/6 months post-implementation • Tablet computer given to hospitalised children's parents to facilitate portal access • Demographics; quantitative: chi-squared/ Mann-Whitney/Kruskal-Wallis tests	• HCT members (nurses/physicians/ancillary staff): Survey: pre *n*=94; post *n*=70
Healthcare professionals/hospital staff and parents as participants					
King et al. [97] (2017) Canada	Paediatric rehabilitation hospital	Connecting families to their health record and care team: the use, utility, and impact of a client/family health portal at a children's rehabilitation hospital	• To investigate the use of a patient portal providing access to EPR including secure, 2-way messaging with clinicians • To assessment portal utility • To examine its impact caregiver-provider communication and participation in care	• Prospective, concurrent mixed-methods study (caregivers' portal usage information/ survey/focus groups/interviews) • Demographics; quantitative: Cronbach α; qualitative: content analysis	• Parents/service providers: parents survey *n*=18; parent focus group/interviews *n*=6; service providers focus groups/interviews *n*=5
Parents and paediatric patients as participants					
Hong et al. [96] (2017) US	Tertiary children's hospital (paediatric cancer care setting)	Adolescent and caregiver use of a tethered personal health record system	• To explore adolescent cancer and blood disorder patients (ages 13-17) and their parents' experiences of using a tethered PHR system called MyChart	• Mixed-methods study: MyChart usage analysis, survey, and interviews • Likert-style questions; quantitative: descriptive statistics; usage analysis; qualitative: inductive coding	• Patients/parents recruited in pairs: *n*=30 pairs approached; *n*=23 pairs consented/ assented; *n*=16 pairs signed up to MyChart; *n*=10 patients/*n*=15 caregivers completed survey; *n*=4 pairs completed individual interviews

Study/year/ region (*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Lee et al. [91] (2017) **Korea**	Hospital setting (paediatric plastic/ reconstructive surgery (PPS) department	Beneficial effects of two types of personal health record services connected with electronic medical records within the hospital setting	• To assess benefits of a designed/developed/integrated system connected with EPR to ensure accurate health information delivery via comparison of users' knowledge/ information needs satisfaction/overall satisfaction pre/post use	• Quasi-experimental, pre/post survey design before/after approx. 30 mins participant use; Likert-style questions • Two types of consumer-centric open PHRs: a pan-disease PHR for all users; a disease-specific mobile application (app) for cleft lip/palate patients • Demographics: analysis not described	• Patients/parents who visited PPS department who used a smartphone recruited, *n*=50 assigned to the portal; *n*=52 assigned to the app
Parents only as participants					
Ahlers-Schmidt et al. [67] (2013) **US**	Paediatric clinic	Parent intention to use a patient portal as related to their children following a facilitated demonstration	• To report feedback from parents and their intention to use a patient portal to access their child's health records	• Cross sectional analytic study (survey); Portal demo in outpatients, participants asked to complete REDCap survey • Demographics	• Parents of children attending paediatric clinic *n*=316 approached; *n*=171 participated in demo; *n*=64 completed survey
Byczkowski et al. [93] (2014) **US**	Tertiary children's hospital	Family perceptions of the usability and value of chronic disease web-based patient portals	• To understand parent perceptions of patient portal usability/value to access their child's electronic health records, and any concerns raised • Focus is on children with - diabetes mellitus (DM), juvenile idiopathic arthritis (JIA), cystic fibrosis (CF)	• Cross-sectional survey vie telephone; semi-structured interviews; Likert-style questions plus free text fields • Demographics; quantitative: chi-square/Mann-Whitney U, logistic regression; qualitative: content analysis	• Parents of children CF/DM/JIA at disease-specific outpatient clinics • All portal users invited to participate (*n*=215); *n*=126 parents recruited. Interviews *n*=15 (5 from each disease-specific group)
Kelly et al. [75] (2017) **US**	Tertiary children's hospital (paediatric general medical/ surgical unit)	Using an inpatient portal to engage families in paediatric hospital care	• To understand parental use of/perceptions of a patient portal during their child's inpatient stay via tablet computer	• Cross-sectional study (tablet metadata; Likert-style survey completed on discharge • Demographics; quantitative analysis: descriptive statistics; chi-square/ Mann-Whitney U test; qualitative: content analysis	• English-speaking parents (convenience sampling) of children <12 years of age • Parent portal users *n*=296, sending *n*=176 requests; *n*=36 messages; *n*=90 survey respondents

Study/year/ region (*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Kelly et al. [98] (2019) US	Tertiary children's hospital (paediatric general medical/ surgical unit)	Parent perceptions of real-time access to their hospitalised child's medical records using an inpatient portal: a qualitative study	• To explore reasons for parental use of a patient portal during their child's inpatient stay via tablet computer • To seek parental perspectives on how best to optimise the patient portal	• Semi-structured interviews • Limited demographics; qualitative: inductive, content analysis	• Parents given tablet computer with patient portal access for use throughout their child's stay in hospital • English-speaking parents (convenience sampling) interviewed *n*=14
Selvadurai et al. [87] (2019) Australia	Paediatric asthma clinic at a tertiary children's hospital	An online patient portal to enhance clinical communications for patients with chronic asthma	• To understand the experiences of chronic asthma patients and their families who use the 'My Health Memory' app	• Cross sectional analytic study (online survey); 10 months post-implementation	• Parents of asthmatic children *n*=25
Data only					
Lee et al. [78] (2016) Korea	Large tertiary hospital (children and adults)	Which users should be the focus of mobile personal health records? Analysis of user characteristics influencing usage of a tethered mobile personal health record	• Usage pattern analysis of 'My Chart in My Hand' - a hospital-tethered patient portal (m-PHR)	• Non-randomised controlled trial (access logs collected 18 months/usage pattern analysis - those with/without a patient ID/patient ID users: light/heavy user groups • Demographics; quantitative: descriptive statistics, correlations, stepwise multiple linear regression	• Access logs/usage patterns of m-PHR selected for analysis during study period
Shenson et al. [83] (2016) US	A private, academic non-profit institution - adult and paediatric primary/regional referral care	Rapid growth in surgeons' use of secure messaging in a patient portal	• To investigate surgeons' secure message use in the first 3 years post patient portal utilisation • A cross-surgical subspecialties secure messaging use comparison • An analysis of surgical OPD encounters to identify the contribution of secure messaging	• Cross sectional analytic study Quantity of secure messages and clinic visits • Quantity of outpatient encounters conducted via messaging • Demographics; quantitative: descriptive statistics; logistic regression/chi-square/Wilcoxon rank-sum	• Unique patient portal users *n*=20,484 (96 % patients; 3 % surrogates; 1 % delegates) • Surgical providers were sent *n*=83,912 secure message threads between January 1, 2008 – December 31, 2010

Study/year/ region (*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Zhou et al. [90] (2015) US	Kaiser Permanente Hawaii and Northwest Regions	Personal health record use for children and health care utilisation: propensity score-matched cohort analysis	• To explore relationships between PHR use and utilisation of healthcare services by paediatric patients and their caregivers from two Kaiser Permanente regions.	• Retrospective observational cohort study: paediatric patient data 2007-2011: analysis of telephone encounters/OPD/ED visits • Demographics; quantitative: propensity score/chi-square; ANOVA	• Data from 2286 paediatric members: 6 months – 2 1/2 years of age from designated regions enrolled in EPR before 31 days of age, continuously enrolled for 2 years with ≥1 adult caregiver registered
Studies relating to another EPR-related intervention *n*=7					
Healthcare professionals/hospital staff only as participants					
Aylor et al. [92] (2017) US	Tertiary children's hospital	Resident notes in an electronic health record: a mixed-methods study using a standardised intervention with qualitative analysis	• To explore resident perceptions of EPR documentation • Comparison of electronic residents' inpatient progress notes pre/post deployment of standardised note templates	• Mixed methods QI study (resident progress notes examined pre/post-implementation/ survey/focus group)	• Paediatric residents/family medicine residents. All in dept invited to participate (*n*=39); survey *n*=9; focus group *n*=8
Cillessen et al. [86] (2017) The Netherlands	A university-based Dutch medical center	A hospital-wide transition from paper to digital problem-oriented clinical notes. a descriptive history and cross-sectional survey of use, usability, and satisfaction	• Implementation of problem-oriented note application (app) • Exploration of: usage and satisfaction, and factors affecting satisfaction	• Retrospective cross sectional analytic study (survey/log files); post-implementation of problem-oriented note app • Demographics	• *n*=1,793 physicians recorded progress notes for *n*=219,755 patients across all specialties • *n*=700 selected physicians, *n*=258 survey responses (after five excluded - incomplete)
Palma et al. [80] (2011) US	Tertiary children's hospital (NICU)	Impact of electronic medical record integration of a handoff tool on sign-out in a newborn intensive care unit	• To identify provider reported sign-out accuracy/satisfaction with: sign-out information process; sign-out printed document; time required for updating sign-out information (impact on workflow, plus time taken transcribing EPR information for sign-out purposes)	• Cross sectional analytic study (survey) • Demographics, quantitative: descriptive statistics; Wilcoxon rank sum/Fisher's exact	• NICU clinicians/care providers: pre: *n*=52; post *n*=46

Study/year/ region (*n*=36)	Setting	Title	Aim of study	Method/design	Participants, sample selection
Raval et al. [81] (2015) US	Quaternary care children's hospital (paediatric surgical service)	Development and implementation of an electronic health record generated surgical handoff and rounding tool	• To evaluate accuracy, patient safety and efficiency improvements during transition from a Microsoft Access Database (MAD) tool to an EPR-generated handoff/rounding list	• Cross sectional analytic study (handoff/rounding list review/survey) • Error quality/quantity compared pre/post-implementation: *n*=5 MAD lists/*n*=5 EPR-based lists (random samples) • Serious safety events compared: 6 months MAD list use/6 months EPR-based list use • Demographics	• Interns/residents/fellows/nurse practitioners at the hospital: MAD list *n*=21; EPR-based list *n*=29
Healthcare professionals/hospital staff and parents as participants					
Byrd et al. [94] (2018) US	Tertiary children's hospital	Integration of mobile devices to facilitate patient care and teaching during family-centered rounds (FCR)	• To demonstrate mobile devices integration ↑access to patient data/educational resources at the point-of-care during FCR. • Aim 50%↑ usage of mobile devices within 6 months; determine if ↑use/access during FCR ↑efficiency/explore perceptions regarding impact on clinical teaching	• Mixed methods QI study; surveys pre/post-implementation; direct observations of FCRs; 3 rapid cycles of continual QI: Plan-Do-Study-Act framework	• Paediatric physicians/physician assistants *n*=7, residents *n*=33, patients' parents (selected at random) *n*=76
Singh et al. [84] (2016) US	Tertiary children's hospital (paediatric hospital medicine service - PHM)	Who's my doctor? Using an electronic tool to improve team member identification on an inpatient paediatrics team	• To evaluate the impact of EPR-linked tool which communicates treatment team members (TTMs) identity (photo plus name/title/role) in inpatient setting • To assess importance of being able to identify TTMs and evaluate the impact on trust, communication and satisfaction	• Cross sectional analytic study (survey); pre/post over 17-month period • Demographics; descriptive statistics; Fisher exact test	• Parents of children admitted to PHM (emergency admission, no prior admission); Phase 1: *n*=61; Phase 2: *n*=59 • Physicians surveyed during Phase 1 only: *n*=63

Study/year/ region (*n*=36)	**Setting**	**Title**	**Aim of study**	**Method/design**	**Participants, sample selection**
Wieck et al. [85](2017) US	Tertiary children's hospital (surgery)	Utilising technology to improve intraoperative family communication	• To evaluate an EPR integrated system designed to optimise family communication during surgery • To evaluate staff and family satisfaction with the use of the communication system and its effectiveness	• Cross sectional analytic study (survey/ Press-Ganey data) • Customised or standardised text pages function built into nursing navigation screen • Families received text pagers preoperatively including: instructions, and hospital map	• Parents of children having surgery/nurses/ surgeons • Surveys: *n*=50 families selected at random (*n*=5 families selected at randomly daily for 10 days over a period of two-weeks • All intraoperative nurses (*n*=36); attending surgeons (*n*=25) were given survey

Abbreviations: AHP – Allied Health Professional; ANOVA – Analysis of variance; CPOE – Computerised Physician Order Entry; ED – Emergency department; EPR – Electronic patient record; FCR – Family Centered Rounds; HCPs – Healthcare professionals; HCT – Healthcare team; HPs – Health Professionals; ID – Identification; I-SEE –Information Systems Expectations; MAD – Microsoft access database; m-PHR – Mobile personal health record; NICU – Neonatal intensive care unit; OPD – Outpatient department; PHR – Personal health records; PICU – Paediatric intensive care unit; QI – Quality improvement; RR – Response rate; SD – Standard deviation; TAM3 –Technology Acceptance Model3; TTM – Treatment team members

Table 3-3: Study outcomes

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Studies relating to EPR *n*=17					
Healthcare professionals/hospital staff only as participants					
Alsohime et al. [68]	Cross sectional analytic study (survey) Post Internally branded EPR ‘eSiHi’	Paediatric physicians *n*=112	Perceived usefulness of EPR system; physician satisfaction; positive/negative system feedback/previous EPR experience/training received/time efficiency/ease of use/PC access/quality overall	• EPR's ability to ↑quality of care and ↓errors ranked highest; followed by EPR improved work environment and promotes hard work • Participant familiarity with EPR’s functions/benefits ranked lowest	EPR has ability to: • ↑care quality and ↓errors • ↑practice quality (work environment) • Encourages hard work
Colligan et al. [71]	Cross sectional analytic study (survey) Pre/post Unnamed commercial EPR	Paediatric nurse participants t0 and t1: *n*=74 t2 and t3 *n*=71 t4 *n*=63	Serial cognitive workload analysis for routine information entry and retrieval of data/documentation tasks pre/post EPR implementation	• The majority of nurses who participated experienced significant ↑cognitive workload at first two time-points post go-live (1/5 shifts) • ↑cognitive workload reduction varied, predicted by participants’ computer attitudes scores ($p = 0.01$)	• Nurses’ cognitive workload ↑ significantly early post-EPR implementation (1–5 shifts) • Workers’ adaptability to the new EPR will vary • “One-size-fits-all” strategies for training may not be applicable for everyone • Technical support may be required for longer

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Copley et al. [25]	Cross sectional analytic study (survey); Not directly related to implementation Commonly utilised systems: Epic (81 sites/646 providers); Cerner (35 sites/378 prov.); GE Centricity (15 sites/132 prov.); Allscripts (10 sites/107 prov.)	Pediatric Orthopedic Society of North America (POSNA) members (Pediatric orthopedic surgeons) *n*=324	Analysis of participants' satisfaction/dissatisfaction with EPR	• Overall satisfaction with vendor or practice type demonstrated no significant differences • Five specific parameters of satisfaction demonstrated significant differences: IT support provision; template usefulness; practice workflow efficiency and system speed; number of logon events	• Substantial effort required to ↑subspecialty specific EPR documentation, clinical workflows, order entry, and research tools to enhance provision of care • Collaboration and networking between those using common EPR systems advocated to ↑future EPR functionality
Cross et al. [89]	Descriptive study (survey) Conference abstract Not directly related to implementation EPR systems not specified	Paediatric ophthalmologists (*n*=90) across 42 UK hospitals	Documentation practices on routine basis; perceived benefits and barriers of routine EPR use; additional questions exploring the participant experience	• Almost 17% routinely use EPR documentation methods • Over 60% reported some previous EPR experience • Perceptions varied depending on EPR experience/use • Those with previous experience (*n*=58) were significantly more likely to identify barriers/challenges preventing routine EPR use: 'difficult-to-navigate system designs' (p=0.013); 'poor user interface' (p=0.015) • Most frequently identified barrier preventing EPR use: 'software functionalities not meeting clinical needs' (1/4 of respondents)	• EPRs do not meet the needs of UK paediatric ophthalmologists • Those with previous EPR experience are more likely to identify barriers related to use: usability is a challenge when transitioning to electronic system • In order to produce a usable system, a full understanding of EPR users' specific clinical requirements is required during all phases of implementation, including any limitations

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Ghazi Al-Shammari et al. [72]	Cross sectional analytic study (data gathering tool, questionnaire) Pre/post The Medical Records System (EMR NEXT™) app for Windows 8	PICU staff *n*=30 (post only) Data from paediatric patients *n*=120 (pre *n*=60; post *n*=60)	To establish effectiveness of system, analysis of the attitude toward usage of the system (TAM3) including: usefulness/ease of use/ease to learn/satisfaction	• Faster documentation time (10.25 min ±0.38sc vs 23.9 min ±0.43 sc; p < 0.001) • Significant ↑documentation completion post-implementation • All PICU staff recorded high attitude scores towards EPR system use	• Electronic charting in PICU was faster and showed significantly ↑documentation completion • PICU staff demonstrated a positive attitude towards EPR system adoption
Hanauer et al. [95]	Prospective, longitudinal mixed methods (survey with free text (qualitative) comments) Pre/post Epic	Attending physicians (*n*=985) from paediatrics/family and internal medicine	To identify if results followed a J-curve pattern whereby perceptions dropped at first, but subsequently rose above the baseline measures	• The findings did not demonstrate a J-curve • A U-curve was seen in reminders and alerts measures where perceptions dropped, then returned to baseline • An L-curve was seen for most measures, where perceptions dropped, remaining below baseline • Exam room documenting alongside the patient was the only measure to remain above baseline	• This study highlights the need for further research on whether user perceptions eventually rise above the baseline, and the requirement for more exploration of how to best facilitate effective EPR use

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Hollenbeck et al. [73]	Retrospective comparative study (survey, paper charts/EPR charts, billing data) 3 years post EPR system not specified	Orthopedic surgeons *n*=10 Plus, paper/EPR charts *n*=60 each	User attitude toward the EPR, its effect on efficiency and documentation completeness and accuracy	• Pre/post-EPR showed no difference in monthly volume • Pertinent clinical information x1.3 more likely in EPR over paper charts but both modalities deemed highly accurate • Surgeons highlighted the need for out of hours charting, ↓clinic efficiency/teaching	• Confirmation EPR is important, and essential to patient care • Both modalities demonstrated similar accuracy and completion rates • Patient visits per clinician ↓19% as ↑clinicians needed to attend to patient • EPR record-keeping during clinic detracts from patient interaction, and teaching junior team members
Johansen et al. [74]	Cross sectional analytic study (survey) Not directly related to implementation EPR system not specified but hospital's EPR accessed via the national health portal Helsenorge.no (for x2 regions)	HCPs across 4 hospitals *n*=332 Administrative staff *n*=125	HCP's attitude towards and experience with patients accessing their own EPRs/assess differences between hospitals/between doctors/ nurses/psychiatry/somatic care	• 25% of administrative staff reported patients/relatives had identified errors or missing information in the EPR • Over 2/3 of HCPs expected more patients in the future to have a basic understanding of their health status • 21.4% found patients already gained better knowledge about diagnosis/treatment/follow-up • Challenges exist, especially for those HCPs in psychiatric specialism, questioning suitability of EPR for their most vulnerable or sickest patients	• Patients identified mistakes in the EPR • Better informed about diagnosis, treatment, or follow-up than before • Differences in experiences/attitudes based on differing practices are minor at different hospitals, and between professions • However, major differences were seen in psychiatric/somatic care: HCPs in this specialism queried the appropriateness of EPR use for their most vulnerable patients

Study (*n*=36)	Design, pre/post-implementation, EPR system	Participants	Focus of measures	Range of outcomes	Conclusions
Kirkendall at al. [77]	Cross sectional analytic study (Information Systems Expectations and Experiences (I-SEE) survey) Pre/post Epic	All hospital staff members T1 *n*=377; T2 *n*=983	Participants' expectations pre/changes in perceptions post EPR implementation: • Communication • Impact of working life • Improvements in care • Resources and support • Patient care provision	• The majority were favourable about transitioning from CPOE to EPR and understood goals of doing so • Nurses were respondents with the least +ve outlook • Overall ratings ↑over time • Baseline expectations were +ve for all participant groups, experience scores mostly demonstrated ↑at 1-year post-implementation	• Favourable perceptions reported pre- and post-implementation of a full EPR, with ↑in most areas examined • The modified I-SEE survey proved to be a useful tool to examine participants' expectations pre/post EPR transition
Matton et al. [79]	Cross sectional analytic pilot study (critical incident forms, survey) Post ICCA	Physicians *n*=10 Fellows/residents *n*=10 Nurses *n*=100 Respiratory therapists *n*=40	Evaluating staff satisfaction with the PICU EPR, safety and comfort	• 6 months post-implementation: nonsignificant ↓severe clinical incidents compared to previous year • PICU staff were mostly 'very' or 'completely' comfortable with EPR, but EPR only satisfied a third of all staff (which included non-regular users such as external staff) and almost 42% of in-house staff	• Successful implementation was achieved due to a long preparation period and ongoing change management strategies • However, caregivers' satisfaction was not significantly increased in the first 6 months
Tubaishat [99]	Qualitative exploratory study (semi-structured interviews, interview field notes) Post 'Hakeem Project'	Staff nurses *n*=17	Hospital, department and participant characteristics Participant perception of EPRs impact on patient safety (positive/negative) Medication errors	• Two major themes: perceived ↑patient safety; concerns raised through system use • Subthemes: EPRs ↑patient safety by minimising medication errors; documentation and completeness of data, and data sustainability all improved • Interviewees: concern patient safety may be jeopardised due to: data entry errors, technical issues, minimal clinical alerts, improper communication use via system	• Nurse opinions ranged from full support of EPRs to reluctance to agree that EPRs ↑patient safety • Poor system design or improper system use may be associated with concerns raised • Involving nurses throughout the design process, incorporating specifications that support safety may ↑nurse perception that EPRs ↑patient safety

Study (*n*=36)	Design, pre/post-implementation, EPR system	Participants	Focus of measures	Range of outcomes	Conclusions
Williams et al. [88]	Quantitative descriptive study (survey) Post Epic	Physicians, including residents/fellows *n*=111 completed survey (Paediatric residents *n*=22/19.8%)	Provider demographics, level of training, and their overall experience with EPR	• EPR super-users: 12.6% (14/111) of the total sample • Satisfaction with EPR, and perceptions on how EPR impacts the patient rated above neutral survey anchor point • Physician's clinical role/level, age, and perceived efficiency were associated with EPR satisfaction/dissatisfaction • Participants who perceived ↑efficiency reported ↑satisfaction/patient impact overall	• Participant satisfaction/perception of impact of EPR on patient care was mostly positive • Greater age/clinical experience level linked to worse EPR satisfaction • Participant satisfaction most associated with perceived efficiency • Targeting of technology resources through understanding physician perceptions of EPRs may ensure satisfaction with EPR system and its efficiency during clinical care
Healthcare professionals/hospital staff and parents as participants					
Chung et al. [70]	Cross sectional analytic study (survey) Not directly related to implementation EPR system not specified	NICU medical professionals *n*=133; Parents *n*=85	Perceived benefits/harms of independent parent EPR access Parental EPR access from home Timing of information release to parents	• Medical professionals: perceptions that parental access would complicate their work, ↑documentation time/time spent updating families, worries about being ↑liable to litigation – resulting in reluctance to record sensitive information • Parents desired direct EPR access, reporting a lack of control over their child's care • EPR access would ↑parental understanding of their child's condition, ↑advocacy, and ↑medical record accuracy	• Perspectives of NICU parents/medical professionals differ on whether parents should access their child's EPR independently • Common goals prevail, promoting family-centered care • Giving parents such access can: encourage ↑parent involvement, ↑communication between professionals and parents • Improved professional–parent relationship provides overall benefit the infant, enhancing care/transparency

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Healthcare professionals/hospital staff, parents and paediatric patients as participants					
Varpio et al. [100]	Longitudinal qualitative study (field observations, think-aloud and think-after sessions, interviews, document retrieval) Pre/post Sunrise Clinical Manager	Patients/family members/ HCPs purposive sampling: *n*=300 HCPs (staff physicians/ residents/medical students/ nurses/AHPs), *n*=22 patients; *n*=32 parents	HCP's responses to and interaction with flowsheets in both paper and EPR formats To examine (i) how both modalities present time/data interconnections, and (ii) how these conceptions impact HCP's clinical reasoning (CR)	• Paper: patient data was viewed/recorded in chronologically organised displays, emphasising data interconnections • EPR: patient data was viewed/recorded via individual data points that were deemed contextually/ chronologically isolated • As a result, HCPs reported a lack of knowledge about the evolving state of the patient; ↑cognitive workload, and loss of mechanisms supporting CR when using EPR	• CR requires an understanding of how patient data are interconnected • Paper flowsheet emphasises chronology/interconnectedness • EPRs often deconstruct data interconnections • EPR flowsheets emphasise independent data values that are mostly separate from other patient data/chronology • Education on connectivity required to prepare trainees to work with EPRs, ensuring chronologically framed data interconnections are understood to support CR
Varpio et al. [101]	Longitudinal qualitative study (observations, interviews, document analysis, and think-aloud/-after sessions) Pre/post Sunrise Clinical Manager	Patients/family members/ HCPs purposive sampling: *n*=300 HCPs (staff physicians/ residents/medical students/ nurses/AHPs), *n*=22 patients; *n*=32 parents	What is the patient's story, how is it built, and why is it important? What impact does EPR have on building this? How does the restrictive narrative note space affect building the patient's story and what is the impact of having disjointed information?	• EPR use inhibited HCP's ability to build the patient's story through disjointed patient information • EPR has restrictive narrative note space, inhibiting HCP's ability to interpret clinical information from other professionals, resulting in a loss of shared interprofessional understanding of the patient's status • ↑time needed to build the patient's story whilst using EPR	• In order to fully support HCPs to provide patient care there are still improvements to be made to EPRs, including the crucial function of building the patient's story

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Parents and paediatric patients as participants					
Cavuoto et al. [69]	Cross sectional analytic study (survey) Pre/post EPR system not specified	Parents/paediatric patients Phase 1 *n*=137 Phase 2 *n*=54 Phase 3 *n*=143	Parent/patient satisfaction with/impact of EPR in paediatric ophthalmology practice	• 382 surveys collected: Phase 1: 158; Phase 2: 68; Phase 3: 156 • All 3 time-points demonstrated high patient satisfaction • No significant difference seen during all phases in patients' wait time estimations compared to actual wait time • Phase 1 saw significant underestimations of patients' estimates of time spent with physicians (20 vs 25 minutes, *P* = .04) • Phase 3 estimates were accurate or overestimated	• Patient satisfaction with service with both paper charts and EPR • Patient waiting times were not improved through EPR system use, but the impact on the perception of time spent with the physician was significant
Parents only as participants					
Rosen et al. [82]	Cross sectional analytic study (survey) Pre/post Cerner	Parents Pre *n*=99/Post *n*=107	To determine satisfaction with the visit, the quality of care received, computer usage/skill and patient safety during EPR transition	• Families received EPR well • parents agreed EPR ↑quality of doctor care compared with the paper chart (55% or 59/107 vs 26% or 26/99, P < .001) • Parental preference was for their child's physician to use EPR (68% or 73/107 vs 51% or 50/99, P = .01)	• Family satisfaction with practice visit can be increased through EPR implementation in the paediatric rheumatology setting

Study (*n*=36)	Design, pre/post-implementation, EPR system	Participants	Focus of measures	Range of outcomes	Conclusions
Studies relating to a patient portal/personal health record *n*=12					
Healthcare professionals/hospital staff only as participants					
Kelly et al. [76]	Cross sectional analytic study (survey) Pre/post Tethered portal (MyChart Bedside) linked to Epic EPR	HCT members (nurses/ physicians/ancillary staff) Pre: *n*=94/Post: *n*=70	HCT perceptions pre/post-implementation of MyChart bedside	• Pre: General optimism about portal benefits for parents • Challenges when using portal were anticipated by all participants • Post: HCTs worries from pre-implementation were significantly↓ (all p<0.001), including: the notion that parents will ask a lot of questions or know test results before the clinical team, skepticism from staff, and worries around the level of IT support	• Although challenges were anticipated by all HCT respondents in the provision of a portal for parents which their children were in hospital, post-implementation saw that these concerns were minimal

Study (*n*=36)	Design, pre/post-implementation, EPR system	Participants	Focus of measures	Range of outcomes	Conclusions
Healthcare professionals/hospital staff and parents as participants					
King et al. [97]	Prospective, concurrent mixed-methods study (portal usage information, survey, focus groups and interviews) Post 'Connect2care' online portal	Service providers: Focus groups or interviews: *n*=5 Parents: Total *n*=18 Survey: T1 *n*=15; T2 *n*=11* *6-8-week interval between surveys Focus group or interviews *n*=6	Survey: portal and messaging utility/satisfaction; impact of messaging via portal on service providers; involvement in care process; overall satisfaction with portal Focus groups/interviews: portal (satisfaction/extent of portal use/for what purposes); portal improvements; most valuable portal functions; any portal-related challenges with utility or access; whether the portal met expectations and increased efficiency	• Average usage 2.5 times a month over 9 months), ↑reported use • Most frequented portal pages: home page, medical record, appointment/reports pages • Survey: Moderate portal satisfaction/utility of its functions but no change over time, slow improvement in care engagement and communication between parents/service providers • Focus group/interviews: Parents/service providers saw considerable information advantages, providing suggestions to ↑portal use/utility • Parents concentrated on breadth of portal utilisation across the organisation, offering suggestions for future • Service providers focused on how best to manage preparing reports or messages via portal in a client-friendly manner considering time and effort	• The promise of the portal is demonstrated • The findings demonstrate a requirement for continued appraisal to demonstrate the portal's future potential in improving communication with professionals and engagement in care

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Parents and paediatric patients as participants					
Hong et al. [96]	Mixed-methods study (portal usage analysis, survey, interviews) Not directly related to implementation Tethered PHR (MyChart), EPR system not specified	Parents/adolescent patients *n*=16 pairs signed up to MyChart *n*=10 patients and *n*=15 caregivers completed survey *n*=4 pairs completed interviews	To understand adolescents'/parental experiences of using MyChart patient portal — exploring divergence or alignment of experiences, and electronic information and communication needs	• Parents/patients: demonstrated the importance of MyChart use immediately before/after their clinical encounters • Survey: Portal messaging was utilised more by parents, but adolescents expressed ↑confidence in managing their health whilst using MyChart • Although MyChart information plus the internet clarified information in their records, most parents were the adolescents' main source for information about their health • Adolescent patients reconcile who is an authority on their health during their transition to adulthood • Challenges for health portal designers include maintaining adolescent patients' confidentiality whilst also meeting caregivers' needs	• Patient portals can provide an age-appropriate means for accessing health data • To ensure patient portals are of value to adolescent patients, and their parents, system design must incorporate user-specific communication preferences, as well as accommodating the varied assessments of illness-related measures

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Lee et al. [91]	Quasi-experimental, pretest-posttest design (survey) Pre/post Consumer-centered Open Personal Health Record Portal (CoPHR) portal and Cleft Lip/Cleft Palate App (CLCP) app, linked with the hospital EPR	Paediatric patients/their guardians *n*=50 assigned to portal *n*=52 assigned to application (app)	Objective knowledge/subjective knowledge/information needs/overall satisfaction for each group	• Post: Both portal/app participants showed significantly ↑objective and subjective knowledge • ↑information needs satisfaction post-implementation for both portal and app participants, but app group showed significantly ↑satisfaction • Participant characteristics in the app group linked to greater knowledge changes • Findings may be influenced by the app's provision of disease-specific information/individualised plan of care based on participant or other users' data	• Individualised, disease-specific EPR-linked health services are advocated in the hospital setting

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Parents only as participants					
Ahlers-Schmidt et al. [67]	Cross sectional analytic study (survey post portal demo) Post eClinical Works	Parents *n*=171 participated in demo; *n*=64 completed survey	Feedback on portal/future intention to use	• Most parents had no prior knowledge of/experience in using portal • Ease of use and satisfaction with offered features reported • Benefits of viewing medical records, getting laboratory results, and sending messages outweighed concern for the security and lack of symptom checker • 69% would continue to use portal • 1/3 felt kiosk access was important	• Facilitated demo of patient portal in clinic is advocated to raise awareness, aid understanding and promote portal use • If access to electronic devices at home is not available, alternative access (such as via a kiosk in clinic) should be provided

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Byczkowski et al. [93]	Mixed methods study (telephone survey with semi-structured interviews) Post Web-based portal (Integrated PHR; system used not specified)	Parents *n*=126 completed telephone survey; *n*=15 completed interview (5 from each of the disease-specific groups)	Survey - parent opinions on portal: • Information utility, timeliness, and accuracy • Ease of use • Confidentiality/viewing upsetting information • Portal's effect on perceptions of outcomes • Messaging function satisfaction • Usage frequency • Portal quality • Additional concerns • Suggestions for improvement. Interviews - reasons for not using the portal.	• 53% of parents used portal once a month • 58% used portal instead of calling their HCP • 56% always/usually felt comforted not having to rely on others for their child's medical information • Most common reason for not using portal was loss of or not receiving password; other=no time to use portal, parents perceived their child was not sick enough to warranting use or that they received information by another means • A majority thought health information on the portal was accurate//useful/timely; most thought it was easy to learn • >50% never had difficulties using the portal • 39% of respondents emailed HCPs via the portal - 81% reported this function very useful, 74% = always received the information required, 71% = always received a timely response • Overall, parents rated the portal as: excellent (15%), very good (53%), good (24%), or fair or poor (8%)	• Parents largely agreed that the information on the portal was accurate, timely, and useful • Parents were not overly concerned about confidentiality or what they would read on the portal • Parents understanding of their child's illness, and how to manage it was increased • Parents of children with chronic diseases may find patient portals useful in managing their child's health

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Kelly et al. [75]	Cross-sectional analytic study (tablet metadata, survey) Post Tethered portal (MyChart Bedside) linked to Epic EPR	Parents *n*=296 used portal, sending *n*=176 requests/ *n*=36 messages *n*=90 completed survey	Tablet metadata: Parental access to portal functions, number of messages, notes and requests (and their content) sent to the HCT Survey: Parental perception of their portal use, its impact on parents' information needs/identification of medication errors/likes/dislikes/other portal features/useful tablet applications	• The most visited and popular functions included vitals and medication list; HCT information and schedules • 90% of parent respondents demonstrated portal satisfied, 98% reported ease of use, 94% stated it improved care; aiding understanding required to monitor/make decisions/care for their child • 60% ↑HCT communication as a result of portal use • 89% perceived portal ↓errors in care - 8% of respondents found medication list errors on their child's portal	• Participants demonstrated satisfaction with MyChart bedside • Patient portals play a role in engaging parents in hospital care, facilitating identification of medication errors by parents, and improving their perceptions of quality and safety.
Kelly et al. [98]	Qualitative descriptive study (interviews) Post Tethered portal (MyChart Bedside) linked to Epic EPR	Parents *n*=14	To understand why parents used MyChart bedside during their child's hospital stay To gain participant perspectives on potential improvements to the portal	• The reasons why parents used the portal are presented in 5 themes: following progress; being less reliant on staff – feeling empowered; helping them remember important information; to encourage communication and/or decision-making during rounds; ensuring information accuracy; • Parents advocated continued portal use within the hospital • Expansion to allow admission question completion, doctors' daily notes access and feedback suggested	• Real-time access to clinical information for parents via MyChart bedside can improve engagement in care-giving processes, which is crucial to promoting the quality and safety of inpatient care

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Selvadurai et al. [87]	Cross sectional analytic study (survey) Post My Health Memory (MHM) portal	Parents *n*=25	Parents/families of children with asthma's use/experiences of using MHM app	• Most parent users of MHM accessed app at least one time/month (62.5%%, *n*=5); MHM helpful to 63.6% (*n*=7) of respondents, or very helpful, (36.4% (*n*=4); MHM's most helpful features = appointment reminders (75% respondents); communication with care team asthma clinic (50% respondents) • Parents who had not accessed the app reported they did not have frequent appointments or were not aware of it • All respondents reported they would like to use MHM app, and saw its value in improving care management	• Parents valued MHM app as an effective and efficient way to manage their child's care, including communicating with their care team and managing appointments
Data only					
Lee et al. [78]	Non-randomised controlled trial (access logs, portal usage data) Not directly related to implementation Tethered m-PHR (My Chart in My Hand - MCMH), in-house hospital information system	Access logs and usage patterns of m-PHR users selected for analysis during 18-month study period	To identify health portal user characteristics and what influences its use	• Total m-PHR logins = *n*=105,603, median number of logins = *n*=15; frequently accessed menus = ''My Chart'' menu; ''Outpatient Department Service Support'' and ''Health Management'' • Users with patient ID more frequently those with chronic disease, experience of hospital visits including ED/OPD, be 0–19 years (*n*=2,186) ($p < 0.001$), accessed sub-menus: online appointment, laboratory result and medication lists more frequently • A similar trend was seen in the heavy user group (*n*=1,123)	• Ways for HCPs/technology developers to design useful patient portals are recommended • Usage characteristics demonstrated patients with chronic disease are active users of PHRs

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Shenson et al. [83]	Cross sectional analytic study (secure message data analysis) Not directly related to implementation My Health at Vanderbilt (MHAV) patient portal	Secure message threads (*n*=83,912) to surgical providers from *n*=20,484 unique MHAV patient portal users (96 % patients/3 % surrogates/1 % delegates)	To establish how many surgical OPD visits occurred, and patient-initiated patient portal message threads were sent to surgical providers over study period	• Care was delivered in *n*=648,200 clinic visits by surgical providers, *n*=83,912 messages were received equating to a growth of >200 % in monthly message volume • Highest proportion of messages received by orthopedics/podiatry (25.1 %), otolaryngology (20.1 %), urology (10.8 %), and general surgery (9.6 %) • Fewest messages were received by vascular (0.8 %) and paediatric general (0.2%) surgical specialities	• Significant increases in OPD interaction were demonstrated after the rapid adoption of secure messaging via the portal across surgical specialties • Specialities requiring long-term follow-up, demonstrated greater numbers of secure messaging encounters than in-person • Promotion of service for paediatric patients needed due to portal only available to paediatrics and their parents for 1 year before study period
Zhou et al. [90]	Retrospective observational cohort study: (PHR use data) Not directly related to implementation ‘KP HealthConnect’ integrated PHR	Data from *n*=2286 paediatric members aged 6 months to 2.5 years	To assess relationships between parental PHR use and paediatric patient use of clinical services of 2 Kaiser Permanente regions: OPD/ED visits and telephone encounters	• Children registered on the PHR compared with nonregistered children, had more OPD visits (21%; P<.0001) and more telephone encounters (26%; P<.0001) • Differences seen in utilisation greater in nonprimary care providers than primary care providers • Quartile with highest PHR use = OPD visits/telephone encounters; no differences noted in 3 lowest-use quartiles	• Parental PHR use was associated with statistically significant ↑OPD visits among paediatric patients with ↑telephone encounters

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Studies relating to another EPR-related intervention *n*=7					
Healthcare professionals/hospital staff only as participants					
Aylor et al. [92]	Mixed methods quality improvement study Pre/post EpicCare	Paediatric/family medicine residents *n*=9 participated in survey *n*=8 participated in focus group	Perceptions of documentation via EPR; length and time taken to complete progress notes pre/post-implementation of note templates	• Pre: *n*=454 progress notes identified; post template introduction *n*=610 notes identified • New template note length ↓263 characters (*p*= .004)/mean end time 73 minutes later (*p*< .0001); Sub-analysis of *n*=100 notes revealed assessment/plan ↓46 words when using new template (P< .01) • Survey: 89% respondents favored newly implemented templates; 78% reported completion of notes facilitated by new template • Focus group: participants were ambivalent toward EPR-based notes	• Newly implemented templates facilitated shorter notes • Participants appreciative of EPR-based templates but were uncertain if EPR supports note writing overall
Cillessen et al. [86]	Retrospective cross sectional analytic study (survey/log files) Post Hospital homegrown EPR	Physicians: *n*=1,793 used the application (app) to write progress notes for *n*=219,755 patients; *n*=700 physicians selected; *n*=285 completed survey	EPR usage/usability for physicians in medical specialties (users and patients) over 4 years	• App used by *n*=1,793 physicians to record *n*=219,755 patients progress notes • 3.2 = Overall satisfaction score (1 = highly dissatisfied; 5 = highly satisfied • Statistically significant difference in satisfaction occurred by medical specialty • No statistically significant differences in satisfaction seen by sex/age/professional experience/ training hours • Physician satisfaction unrelated to level of app	• All medical specialities used clinical notes application within 2 years of transition to EPR; neutral user satisfaction demonstrated (3.2 on a 1–5 scale) • Significant factors affecting successful implementation echoed other studies: Collaboration with end-users; a consistent approach with transparent app design; on-going monitoring; an incremental rollout

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Palma et al. [80]	Cross sectional analytic study (survey) Pre/post EPR-integrated neonatal handoff tool	All NICU care faculty/hospitalists/ fellows/nurse practitioners Pre: *n*=52; post: *n*=46	Provider reported accuracy of sign-out information and their satisfaction with: sign-out information process; sign-out printed document; time spent updating sign-out information (impact on workflow, plus time taken transcribing EPR information for sign-out purposes); use of either standalone or EPR-integrated neonatal handoff tool	• Participants perceived sign-out information to be somewhat/very accurate with standalone handoff tool (78%); 91% with EPR-integrated tool (*p* <0.01) • Pre: 35% satisfaction with sign-out process; 71% satisfaction with sign-out printed document • Post: 92% satisfaction with sign-out process (*p* <0.01); 98% satisfaction with printed sign-out document (*p* <0.01) • NICU staff reported a median of 11 to 15 min/day taken completing standalone sign-out document; 16 to 20 min/day completing EPR-integrated sign-out document (*p*.0.026) • Statistically significant reduction in time transcribing information from EPR was seen: pre = 25 to 49%; post = <25% (*p* <0.01)	• Following implementation of a NICU-specific EPR-integrated hand-off tool, participants perceived ↑sign-out accuracy, ↑satisfaction in at least one aspect of workflow
Raval et al. [81]	Cross sectional analytic study (handoff/rounding list review and survey) Pre/post Epic	Interns/residents/fellows/nurse practitioners MAD list: *n*=21 EPR-based list: *n*=29	To establish the amount of time spent by professionals using both versions of the list. Perceived utility/quality/safety of each mode of list. Comparison made during two study periods of reported serious safety events	• EPR-integrated list ↑efficiency by auto-populating data such as vital signs etc., and clerical errors were eliminated • Survey: Per week 43 min saved for each team member = annual saving of 372 work hours for single service • Perceived ↑efficiency/safety/accuracy and ↑satisfaction reported by users of EPR-integrated list • Serious safety events reported as unchanged	• Creation of EPR-integrated handoff/rounding list demonstrated ↑efficiency, ↑accuracy, and enabled the provision of safe care.

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Healthcare professionals/hospital staff and parents as participants					
Byrd et al. [94]	Mixed methods quality improvement study Pre/post Hewlett-Packard EliteBook Revolve devices (Linked EPR - system not mentioned)	Paediatric physicians/physician assistants: *n*=7 Residents: *n*=33 Parents/guardians: *n*=76	To show during FCR mobile device integration ↑access to patient information and educational resources at the point-of-care; does ↑ use of/access to such technology during FCR ↑efficiency/affect perceptions of clinical teaching	• Pre: Mobile computing cart average use 3.3 times per FCR round for resident education • Following 3rd cycle: Clinical teaching via devices ↑~79% to 5.9 times per FCR round • Residents' perceptions saw statistically significant ↑preparedness for FCR rounds, receiving clinical teaching, and feeling able to provide parental bedside teaching • ↓average time per patient on FCR rounds	• Mobile device implementation into the medicine teaching service in the paediatric setting can facilitate patient care/↑perception of resident teaching by improving knowledge resource access, whereby extending EPR's utility in care decisions
Singh et al. [84]	Cross sectional analytic study (survey) Pre/post Novel EPR-based tool with names, photos, and definitions of TTM	Physicians: Phase 1 only: *n*=63 Parents/legal guardians/primary caregivers: Phase 1: *n*=61 Phase 2: *n*=59	Parent surveys: evaluated parental identification of TTMs and their satisfaction, plus trust in TTMs and computer use TTMs surveys: level of training (e.g., resident/attending), evaluated perceptions on parental ability to identify TTMs, impact on family satisfaction and trust in TTMs	• Post: ↑subjects correctly identifying names of attending physicians (71% vs. 28%, *p*<.001); correctly defined terms intern/resident/attending (*p*≤.03) • 79% participants and 87% TTMs 87% stated being able to identify TTMs moderately or strongly impacted satisfaction/trust • Most participants reported electronic TTM identification was beneficial in each phase	• Significantly greater TTM identification by parents for those who used tool • Although few could identify TTMs prior to using the tool, identification of TTMs was reported to impact aspects of TTM relationship • This study's finding suggest families will engage in computer-based activity related to their child's care

Study (*n*=36)	**Design, pre/post-implementation, EPR system**	**Participants**	**Focus of measures**	**Range of outcomes**	**Conclusions**
Wieck et al. [85]	Cross sectional analytic study (survey) Post Epic	Nurses: *n*=36 Surgeons: *n*=25 Parents: *n*=50	To assess the use and satisfaction of pager system	• Patient satisfaction ↑30% ($p<0.05$) • >90% families reported pager ease of use/enabled receipt of information perioperatively • >90% nurses reported system ease of use and perceptions of ↑experience for families • All surgeons indicated ↑communication intraoperatively and facilitated easy finding of families postoperatively	• Efficiency and staff satisfaction was increased through utilisation of EPR-based perioperative family communication

Abbreviations: AHP – Allied Health Professional; CPOE – Computerised Physician Order Entry; ED – Emergency department; EPR – Electronic patient record; FCR – Family Centered Rounds; HCPs – Healthcare professionals; HCT – Healthcare team; IT – Information technology; MAD – Microsoft Access Database; m-PHR – Mobile personal health record; NICU – Neonatal intensive care unit; OPD – Outpatient department; PHR – Personal health records; PICU – Paediatric intensive care unit; RR – Response rate; SD – Standard deviation; TTM – Treatment team members

3.5.3 Findings

3.5.3.1 Benefits of using an EPR system/portal

Seven studies reported staff benefits related to using an EPR system [68, 72, 73, 79, 81, 88, 99] with perceived efficiency as the factor most frequently associated with EPR-related satisfaction [68, 72, 79, 88, 99], resulting in a perceived positive influence on patient care [68, 88]. A wide range of benefits were described including ease of use/documenting/access [68, 99], clearer and more legible documentation [68, 99], readability and fluidity of records [79] that are editable/modifiable and trackable [68], improved retrievability [68] and increased accuracy and completeness of the record [68, 73, 99]. Time-saving benefits included faster charting [68, 72, 79, 99] and effective workflow, with an improved working environment [68].

Benefits to patient safety were documented in five studies [68, 74, 75, 79, 99]; a reduction in errors, both in terms of medication errors [79, 99] and charting and information errors [68], and feedback on mistakes or missing information from parents who accessed their child’s EPR/portal [74, 75] were reported.

Benefits of EPR and patient portal use identified by parents included improved communication with the healthcare team (HCT) [70, 76, 82, 87, 93, 97]; useful, accurate and timely access to information [93]; and systems were easy to use and learn [67, 75, 93]. Parental access to EPR and patient portals also helped facilitate recognition of HCT members [76], and this was also reflected by HCT members also perceived that parents felt more in control and more involved in their child’s care [76]. Parents felt they had a better understanding of their child’s illness [70, 93]; medical tests/results [82]; and medical terminology [91, 97]. Parents were empowered to advocate for their child [70]; manage their child’s condition [93]; and felt less reliant on staff [75]. Parents reported greater satisfaction with care processes when they were able to access an EPR/portal [67] with perceptions of improved care quality and safety [75, 82].

3.5.3.2 Challenges of using an EPR system/portal

Despite documented benefits, a wide range of challenges were described for all users, predominantly under the following themes: time and increased workload, practical/technical IT issues; cognitive challenges; documentation issues; and concerns about understanding terminology, results, and jargon.

The impact of EPR and portal use on time and increased workload for HCPs were recurring themes [68, 70, 73, 74, 76, 79], with time-consuming data entry processes [68] and time spent on computers [79] both affecting workflow [76], with a resultant impact on patient care provision [68, 74, 76], and reduced patient interaction in the clinical setting [73, 76, 79].

Cognitive challenges, including increased cognitive workload [71, 100] and information overload [100], for staff were identified. These were especially evident in the early phases post EPR/portal implementation [71] and abated at differing rates post-implementation [71]. Being able to make data interconnections and understand the EPR flowsheet chronologically proved to be cognitively complex, without adjustment of workday schedules to accommodate this additional cognitive workload [100].

Doctors were hesitant to document sensitive information in the EPR due to concerns regarding parents’ ability to understand information and were apprehensive about allowing unsupervised EPR access despite parents wanting to view their child’s medical record [70]. It was suggested that access to an epicrisis (a critical or analytical summary) would be preferable to the whole record [74]. In one study HCPs denied patients access to information because they were worried it might cause them harm or affect their professional relationship [74]. Conversely, in another study it was reported that the patient might become suspicious and mistrustful if access was denied, thereby harming the patient-therapist relationship [92].

Healthcare professionals worried that parental portal access would create too many questions for them to answer, with additional worries about parents knowing test results ahead of the clinical team or misinterpreting clinical data [76]. Although rare, parent reported portal challenges included information or portal not demonstrating utility [75]; staff not responding to messages promptly; technical difficulties; being too busy to use it [75]; or concerns about health information privacy [67].

3.5.3.3 Information and support needs

Eight studies incorporated EPR user information and support needs [68, 71, 77, 79, 88, 89, 99, 100], and three additional studies applied this to portal users [91, 93, 98]. Technical problems were noted, especially immediately post-implementation, including poor internet connections/loss of Wi-Fi [68, 79]; log-on issues [79]; and system crashes or freezes, which could all increase downtime [79, 99]. Inaccessibility of patient data during downtime could compromise patient safety, especially in emergencies when prompt action was required. Moving to a paper-based record or back-up system was a temporary remedy to downtime, enabling continued patient care provision until EPR was back online, emphasising the importance of contingency planning [99].

Support was required to understand new EPR-related terminology [68], navigate system complexity [68, 89] and learn EPR functionality [74]. A lack of IT support could create barriers to system use and usability [89], further detracting from patient care [68]. A lack of computers or workstations [68, 79], and ergonomic concerns such as computer space monopolisation [79], created additional stressors.

A “One-size-fits-all” strategy of staff support may not be applicable to all EPR users, and variability in the ability of staff to adapt to using a new system should be anticipated [71]. Consequently, extended periods of technical support may be required for some staff members [71]. Overall, staff satisfaction ratings improved over time post-implementation [77]. During major upgrades, targeted training for ‘at-risk’ groups (staff groups who may need additional support to become competent with newly implemented system updates or changes), and continued monitoring to improve efficiency were shown to increase satisfaction, enabling the continuation of high-quality care provision [88].

In one study, HCPs reported a lack of knowledge about the evolving state of the patient because of the disjointed and unchronological way EPR emphasised patient data values, as opposed to paper records which promoted chronology and interconnectedness [100]. The EPR was found to deconstruct data interconnections, thereby affecting HCP’s clinical reasoning [100]. This study emphasised the importance of preparing HCP who are EPR users, educating them about information connectivity, ensuring chronologically framed data interconnections were understood, bridging the gap between paper and EPR [100].

Parental portal use was primarily to access their child’s information and check its accuracy, monitor progress, aid care plan recollection and communicate with their care team during ward rounds [75, 87, 98]. However, parents desired faster access to and release of information. This included quicker email responses and updates from clinic visits [93], quicker access to medical reports, and an increase in the amount of information released [93, 98]. A disease-specific app, with access to personalised treatment plans, provided greater information need fulfillment and user satisfaction than a pan-disease portal for all other users [91]. These portal services provided accurate disease-specific patient health information, helping patients and parents make decisions more efficiently, with an increase in participant knowledge after portal use [91].

3.5.3.4 Strategies for successful implementation

Authors of six studies made suggestions for successful EPR implementation [77, 79, 86, 88, 89, 99] and in two studies recommendations for successful portal implementation were made [67, 96]. It was reported that, the specific clinical requirements of EPR users and what challenges they encountered to using EPR effectively was important to understand during the system procurement, design and implementation phases to ensure system utility [89]. Targeting technology resources to ensure efficiency and satisfaction during clinical use [88], and to facilitate implementation success [77, 79, 86] was also deemed important. During the design phase, such collaboration was reported to lessen concerns about technical issues, inappropriate communication channel use and potential data entry errors [99]. Continuous monitoring was important [77, 86], with utilisation of super-user support [79]. Other suggestions for implementation success included robust, accessible channels of communication throughout implementation [77], valuing user feedback [79], transparent design of the application [86] and an incremental rollout [86].

To facilitate successful portal implementation, authors suggested that clinics should consider hands-on demonstrations of portals to raise awareness, encourage understanding and use, and provide alternative access venues (e.g. kiosk) if home computers were not available [67]. Authors in another study advocated that design efforts must consider the different communication preferences of adolescents and parents [96].

3.5.3.5 Strategies for system design improvements

A number of strategies for design improvements were identified, including interoperability with other institutions [25], focused order sets and disease-specific templates for documentation [25], efficient research data capture and report generation [25], and EPRs and portals with a focused design for specialties and sub-specialties [25, 73, 91]. Conversely, one study suggested combining portals across diseases [93]. In one study the authors demonstrated that EPR system customisation to meet unique clinical demands was possible [80], and that opportunities existed to automate clinical information retrieval from EPR, including more laboratory, pharmacy and radiology information, and use of the EPR as a clinical decision support tool [80]. Evaluating future enhancements to EPRs and portals on provider workflow, accuracy, adverse events, clinical outcomes and decision support functions, and patient harm was emphasised [80]. To facilitate improvements in functionality, networking among groups and providers who utilise common EPR platforms was promoted [25].

3.5.3.6 Desirable portal functionality

Parents reported a wide range of views on desirable functionality for portals including combining parental account access for multiple children [67], a symptom checker [67], and the provision of age-appropriate mechanisms for reviewing health data [96]. In one study parent reported desirable functionality included easier website access, log-in, navigation and use, clearer explanation of laboratory results and terminology, results notifications, the ability to add or edit data, more links to resources and education, and personalised medication specific information [93]. Suggestions concentrated on enhancing rather than changing portal functionalities [98]. The authors of one study advocated that usage characteristics could facilitate the development of patient-centric patient portals by healthcare providers and technology companies [78].

3.5.3.7 Future portal use and reasons for not using portal

Only one study reported parents' intended future portal use, with 69% of parents saying they would continue to use it, but 28% were unsure about future use [67]. With limited numbers of patients having daily computer access to use the portal, alternative access venues (such as the kiosk in clinic) were deemed necessary [67].

Three studies described parents' reasons for not using the portal [67, 87, 93]. Reasons included never receiving or losing the password [93]; information being received through different channels [93]; lacking time to use the portal [93]; limitations in their own technological knowledge and skills [67], being previously unaware of a portal [67, 87]; feeling that their child was not sick enough to require portal use [93]; and clinic visits being too infrequent to warrant use [87].

3.5.3.8 Transitioning young people to adult services

Only one study reported parents' and CYP's perceptions of patient portal use when transitioning from pediatric into adult services [96]. Value was seen in the portal's archived medical information, retrievable at a later date, as importance was placed on referring to such health data during the transition process, when communicating with other medical staff, and for other aspects of life e.g., applying for college. Furthermore, being able to keep in touch with the pediatric clinicians via the portal once transitioning out of pediatric care was also important to parents and CYP [96].

3.5.3.9 Ethical and legal considerations

Four studies raised ethical issues related to EPRs/portals: inequity in access [67]; confidentiality [93]; viewing worrisome health-related information via patient portals [93, 96]; and parents' rights to view their child's EPR [70]. Three studies raised documentation-related issues, with potential professional or legal implications [68, 74, 92].

In one in-patient study, 94% of parents wanted to view their child's EPR, with almost all (98%) feeling the information was important for them. This compared to only 78% of doctors agreeing that parents have the right to view their child's EPR [70]. In a further study, inequity of access was highlighted, with limited computer access preventing parents/patients being able to use the portal regularly. As a result, important health-related information may have been missed [67].

Children and young people indicated that they were not worried about what their parents would see on the portal [96]. However, some parents had concerns about misinterpretation of medical tests or results that might lead to their child being anxious or upset [96]. Parents in another study were not overly worried about confidentiality or seeing potentially concerning health-related information about their child, ascribing this to having cared for their child with a chronic illness long-term, being knowledgeable about their child’s condition, and experienced in receiving such information and how to process it [93].

Evaluation of EPR documentation revealed incomplete records [68, 74] with some doctors hesitant to document transparently for fear of litigation [92], raising both professional [102], and potential legal consequences for the institution should freedom of information mandates need to be fulfilled [103].

3.6 Discussion

Maintaining high quality patient records and effective communication within care teams, and with the patient and their family has never been more important in supporting safe, effective, and appropriate patient care [104-107]. Digital health innovation promises to enable enhanced collaboration with other health agencies involved in the care of the patient [6, 105], with potential to improve population health surveillance and management through health information exchange [6, 108]. However, with these promises comes unanticipated consequences. The focus is often on the technological factors, at the expense of the human/social influences that affect the performance of technical systems: implementing structure is essential [109].

According to Berg et al. (1998) the system should yield immediate benefits for primary users, supporting rather than creating additional work [109]. However, it is evident that transitioning to a new electronic health system can disrupt workflow and normal ways of working, creating additional burdens on HCPs, detracting from patient care, particularly in the early phases post-implementation. Therefore, recommendations for design and implementation include the following: user preparation and support; targeted system design based on user needs to facilitate and promote prolonged user engagement, utility, user satisfaction, digital literacy, and implementation success [77, 79, 86, 97, 98, 110]. Moreover, an implementing strategy based on detailed, empirical knowledge of the practice involved is crucial with a focus on sociotechnical design, rather than technical aspects alone [109]. ‘Sociotechnical design’ refers to a philosophical approach that “describes a process and a humanistic set of principles” that in the context of implementing computerised systems “is associated with technology and change” (p.317) [111]. This philosophical approach is innately human-centred, essential for successful system implementation, as the whole is considered during design and implementation efforts [112]. This is echoed in the Wachter report, which advocates embracing user-centred design [6], and the Topol Review (2019), which recommends keeping the end-user in the developing process, with special attention paid to marginalised/vulnerable groups to promote equity and inclusion [9].

Whilst there is evidence of some institutions allowing patients/parents access to medical records, in others this is denied, with one example of doctors restricting EPR access by other HCPs [113]. In practice, a culture change is required to shift attitudes from traditional, paternalistic practices to a more collaborative, transparent approach. This culture change is also required if the NHS is to fulfil the strategic objectives outlined in Chapter 1, with pan-NHS digitalisation and the provision of electronic access to health records for patients, supporting them to manage their own care and control their personal information. To promote engagement, and understanding of health-related information, it is advocated that documentation styles require adaptation to one that will be understood by CYP and their family [74, 114]. Omitting details of the medical record must be avoided if an accurate record is to be maintained, thus avoiding any related professional or legal ramifications [103, 105, 115, 116]. In addition to minimising inequities in access to medical notes, the provision of equitable access to patient portals is important to support equitable health outcomes [117]. Thus will require initiatives across policy, practice, research and implementation [118]. This review identifies the need to understand more about the ethical issues and the relationship between CYP, parents and HCPs, given that some important ethical and legal issues were raised but these only focused on in a small number of studies.

This study adds to our knowledge on this topic in a number of areas. Firstly, there is a consensus that where stakeholders have been engaged with the process prior to and throughout implementation, transition to an EPR system is more successful. Secondly, inequity in access exists to both medical records and patient portals, leaving some families with less opportunity to benefit from the advantages access to health information and digital health systems provide. Thirdly, some professional groups are under-represented or absent from the research and CYP's views are not considered. Furthermore, this systematic review confirms the absence in the literature of large-scale studies involving all relevant stakeholders spanning the period from pre to post EPR implementation in the paediatric tertiary hospital setting, as highlighted in Chapter 1, despite the implementation of EPR in some of the world's other leading children's centres. This further highlights the importance of the Going Digital study.

3.7 Strengths and limitations

3.7.1 Strengths

Strengths of this review included its extensive and comprehensive search strategy, the use of established PRISMA guidelines, utilisation of databases from the fields of health, social science and psychology, and the inclusion of all types of study designs and multiple stakeholder groups from around the world. The inclusion of research from 2010 enabled inclusion of research literature during EPR's exponential global growth and the current incarnation of EPRs.

3.7.2 Limitations

A limitation of the review is that most studies were conducted in specialist pediatric hospitals/areas; therefore, results may have limited applicability to other paediatric care settings. Nevertheless, these findings contribute to the limited body of literature in specialist paediatric areas, with considerations for young people and parents in the wider digital health context. A further limitation is that the full paper for eight studies could not be obtained. Finally, as studies with positive results are represented more frequently in the literature, creating publication bias [119], under-representation of negative experiences around the implementation of EPR and portals must be considered.

3.8 Implications for practice

The results of this systematic review indicate that collaboration and engagement with all relevant stakeholders are essential prior to, during and after implementation of an EPR system or patient portal. Findings also indicate that ongoing consultation with users, valuing their feedback and incorporating their views into system improvements will increase user satisfaction, utility, and engagement. Special consideration ought to be given to the views of CYP, their specific needs and preferences [96], to empower them to be involved in and ownership of their health [120, 121].

3.9 Implications for future research

Although other professional groups such as pharmacists and laboratory staff were included in the search terms, no studies were identified in which the impact of EPR implementation on these groups was investigated, emphasising the need for further research with other professional groups.

No studies solely focused on the views, experiences, and perceptions of CYP when accessing their digital health records. This highlights the need for research directly with CYP, especially related to their views about accessing their health data and how digital health innovations can empower them to take ownership of their health and help them during transition into adult services. This systematic review demonstrates overwhelmingly that CYP’s views are not considered, despite care, treatment and digital health data being about them.

3.10 Implications for the Going Digital study

These findings have shaped the Going Digital study, with decisions made to:

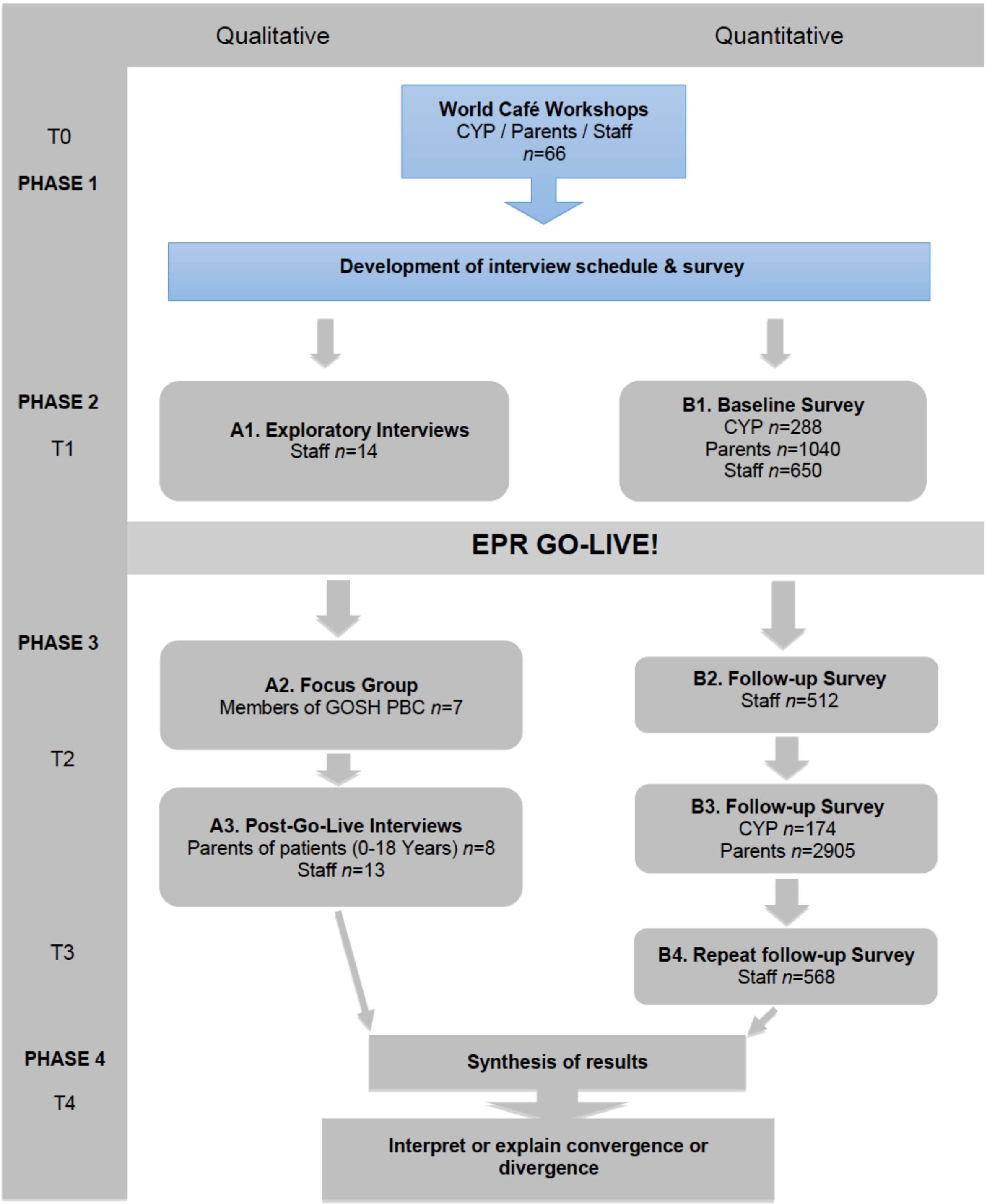
- Focus on CYP views and experiences
- Include all staff groups in the research
- Collect pre and post data
- Consider the ethical/legal issues

3.11 Conclusion

Experiences of all who use EPRs and patient portals in the paediatric hospital setting are heterogenous. There are many described benefits; however, challenges exist, particularly in the early post-implementation phases. Although tailoring information and support to the individual needs of users can be complex, this is essential in order to facilitate prolonged utility, user engagement and satisfaction which, in turn, will promote safe, effective care provision. This process should begin pre-implementation for all relevant stakeholders, and system design and implementation should incorporate sociotechnical design, and be based on detailed, empirical knowledge of the practice area involved. Disease-specific portals may increase utility and prolonged user engagement and taking into consideration children’s and young people’s views and needs is essential. Institutions need to acknowledge digital poverty as potentially leading to inequity when CYP and their parents cannot access health records remotely. The provision of alternative portal access points and alternative forms of communication is essential to maintain engagement for the benefit of the patient. Culture change is required to enable further collaboration with patients and parents, with transparent documentation and improved access to medical notes.

In the next chapter, the phase one World Café Workshop methodology and findings will be presented. The aim of the workshops was to develop the surveys for each stakeholder group for Trust-wide distribution pre and post EPR implementation.

Chapter 4 World Café Workshops



4

4 World Café workshops (phase one)

4.1 Introduction

This chapter sets out the principal research objectives of phase one, and how these were met. The creative qualitative methodology of ‘World Café’ was utilised for this phase and will be described, as will the Framework method of thematic analysis that was applied [122-125]. The workshop findings will be presented, and the formulation of the surveys and interview schedules for each stakeholder group will be described.

4.2 Aim

To inform:

- The content of a survey for all stakeholder groups to be distributed Trust-wide during phases two and three of the research pre and post Go-Live of EPR/MyGOSH
- The format of the surveys (paper/electronic)
- The timing of the surveys
- Potential barriers to completing the surveys
- The content of the interview schedules

4.3 Methodology

World Café methodology was utilised to facilitate the generation of ideas for the survey and stimulate innovative thinking through workshops with each stakeholder group [126-128]. This methodology is based on seven core principles, which are presented in Table 4-1, alongside the application of the methodological process. This methodology was chosen because it enables groups of people to create, “dynamic networks of conversation and knowledge sharing” around critical topics or questions of importance to the individual and the organisation, which was well suited to the purpose of the Going Digital study (Brown and Isaacs, 2005, p4)[129]. World Café involves multiple rounds of discussion at different ‘topic’ tables, enabling data collection from a large number of participants simultaneously, with discussion evolving throughout the workshop. This methodology was preferred over focus groups because, the use of a moderator at each table ensured each round of discussion built upon the last, identifying inter-linking themes, patterns or insights, and enabling deeper questions to be explored [129]. Furthermore, the workshops enabled the bringing together of larger numbers of participants than is possible in a focus group [129]. World Café methodology enabled inclusivity because all stakeholders wanting to be a part of the study were able to participate.

Table 4-1: World Café methodology core principles and application

Principle	Method	Application
1	Setting the context	- Information sheets given to all participants - Welcome and 'ground rules' at start of workshop
2	Creating a hospitable environment	- Café style tables with tablecloths - Decoration, food/drink - Regular comfort breaks - Non-clinical setting
3	Exploring questions that matter	- Topic guide informed by literature - Scenarios to aid discussion
4	Encourage everyone's contribution	- Experienced researcher moderating each table - Participation from everyone encouraged - Additional needs of participants accommodated* - Post-it notes available on tables for participants to write on
5	Cross-pollinate and connect diverse perspectives	- Moderators facilitated building of discussion, drawing out/exploring diverse views - Participants moved to a different topic table after each discussion*
6	Listen together for patterns, insights, and deeper questions	- Moderators built on dialogue in each subsequent discussion - Identified inter-linking themes
7	Harvest and share collective discoveries	- Analysis of recordings - Formulation of surveys - All participants invited to pilot survey - Feedback incorporated into final version

Brown and Isaacs (2005)[129].

*This approach was modified due to some of the participants of the World Café workshop for young people having significant physical disabilities, requiring the use of a wheelchair. Moderators rotated to each table at the end of each topic discussion, taking into consideration the needs of the participants and promoting inclusion.

4.4 Methods

4.4.1 Participant inclusion and exclusion criteria

4.4.1.1 Inclusion

- All members of the Young People’s Forum
- Parents from an existing hospital wide EPR special interest group
- All hospital staff members

4.4.1.2 Exclusion

- None

4.4.2 Sampling strategy

The study sample included three key stakeholder groups to inform the relevant survey – Members of the Young People’s Forum (YPF), parents from an existing hospital wide special EPR interest group, and hospital staff. Targeted sampling was utilised for the members of the YPF and parents. It was intended that staff would be purposively sampled, utilising a sampling matrix to ensure staff from different professions, levels of seniority and different specialities within the Trust were represented. However, the study team decided that inclusion of all those who expressed an interest to participate were included in the workshops.

4.4.3 Participant recruitment and consent

4.4.3.1 Children and Young People

Through liaison with Great Ormond Street Hospital’s Patient Experience and Involvement Officer, young people who were members of the YPF were invited to participate in the World Café workshop as they had been involved in the EPR process since its inception (Appendices 10 and 11). This was held during one of their quarterly meetings, and the topic was fully introduced to them at the PPIE event to enable their questions to be answered. Prior to participation, the YPF members were given a pack containing age-appropriate participant information sheets for them (Appendices 12 and 13), and their parents/carers as (Appendix 14) appropriate, along with assent/consent forms (Appendices 15-17), and contact details of the research team. Participants (and their parents, as appropriate) were asked to provide written informed assent/consent prior to their participation.

4.4.3.2 Parents

A member of the EPR team invited parents who had expressed an interest, or had already been engaged, in the EPR process at GOSH via an e-mail that included information about the study, with an invitation for them to contact the research team if they were willing to take part in the World Café workshops (Appendices 18 and 19). Participants were asked to provide written informed consent prior to their participation (Appendix 20).

4.4.3.3 Staff

Staff were recruited via a number of different routes: individual e-mails from the EPR team to ‘Subject Matter Experts’ or ‘SMEs’ (those who have been involved in the EPR process); posters containing study information and researcher contact details in staff areas across the Trust; the Trust screensaver; the Trust newsletter; the EPR newsletter; and on GOSHweb (a sample of staff recruitment information is found in Appendix 21). Interested staff members were sent participant information sheets via Trust email (Appendix 22), and were asked to provide written informed consent prior to their participation (Appendix 23).

The Patient Experience and Involvement team also assisted with recruitment to stakeholders to the workshops. Consent was re-confirmed with all participants on the day of each of the respective workshops.

4.4.4 Sample size

Initially it was anticipated that the sample size would be *n*=24 for each of the four proposed workshops, with a total of *n*=96. As described already, the study team agreed to be as inclusive as possible including all those who volunteered to participate.

4.4.5 Data collection

Data collection was carried out in separate workshops for each stakeholder group. The staff workshops were arranged to accommodate different working patterns with one at lunchtime and one after regular working hours. Expectations were set for the workshop including welcoming participants and setting ground rules. Participants worked in small groups and spent approximately 20 minutes at each of the four topic tables. Each table had a moderator to facilitate, to build on each discussion (as per Principle 4 in Table 4.1).

Dialogue was built around a topic guide (Appendix 24) and included scenarios to stimulate discussion (Appendix 25).

Topic areas covered were:

- Expectations;
- Benefits and challenges;
- Information and support needs of the different participant groups;
- Ethical or legal dilemmas;
- The format, length, type of questions in the survey (discussed at each topic table at the end of each round).

Discussions were audio recorded for transcription purposes. Moderators and an additional researcher also took notes as they felt necessary. The workshop was complete when all topics had been discussed (taking approximately an hour and three-quarters).

4.4.6 Data analysis

The Framework method of thematic analysis was used. This involved five highly interconnected yet distinct stages: familiarisation; identifying a thematic framework; indexing (or coding); charting; mapping and interpretation [122-125, 130]. This method was chosen to assist in exploring the views of young people, parents and staff whilst still acknowledging each individual participant's views and their stories. According to Gale et al. (2013), "while in-depth analyses of key themes can take place across the whole data set, the views of each research participant remain connected to other aspects of their account … so that the context of the individual's views is not lost" (p.118) [125]. Furthermore, in addition to the Framework approach enabling the researcher to classify and organise data into themes [131], the methodology lends itself to a variety of documents including interview transcripts, field notes and other materials [125]. Notes from each round of the workshop discussions, taken by an additional researcher, were cross referenced during data analysis to ensure completeness.

Familiarisation of the data involved repeatedly listening to the audio recordings and reading the written material. Each strand of data was indexed, labelled, and classified from the transcripts. The framework was developed and reviewed by the research team over several iterations identifying any duplicate or superfluous codes. Data were charted into a framework matrix comprising rows (cases), columns (codes), "cells" of summarised data and illustrative quotes (see Table 4-2) [125].

As the focus of this research was primarily on the experiences of CYP, the framework was built incrementally, starting with the findings from the young people's workshop, then mapping the parent and staff data onto that. Any convergent or divergent themes were identified. The findings from the workshop with young people are presented in depth followed by a table to represent how the parent and staff data were added to the framework.

Table 4-2: Practical application of Framework analysis

Framework method	Practical application
Familiarisation	• Recordings listened to repeated times • Recordings transcribed • Direct quotes transcribed verbatim
Identifying a thematic framework	• Text was categorized, developing a framework of ideas exemplifying the same theoretical or descriptive idea [132]
Indexing (or coding)	• Text was indexed (coded), labelling and classifying passages from the transcripts
Charting	• Indexed (coded) text was then charted in a word document prior to organising data into themes
Mapping and interpretation	• Recurrent themes were mapped in a table (within word). From these the main themes were classified, demonstrating the same phenomena or idea [132] • Themes were interpreted, questions were formulated from the themes that needed to be asked in the survey • Data and process was confirmed with Primary supervisor, themes and survey looked at together during different phases of its development

4.5 Results

4.5.1 Participants

A total of *n*=66 participants took part in the workshops, comprising 26 young people; two parents; and 38 members of hospital staff (Table 4-3). There was an approximate total 1050 mins recording across the workshops.

Table 4-3: Workshop participants

Participant group	Participants	*n=*
YPF Members (age 12-15)	Patients	24
	Siblings of patients	2
Parents	Parents	2
Staff	Nursing/Medical	20
	Management/Clerical/Other Non-Patient Facing Professional	8
	Allied Healthcare Professionals	7
	Other	3
	Overall total	**66**

A further breakdown of the staff member group reveals the range of specialities represented at the workshops (Table 4-4).

Table 4-4: Specialities represented at the staff workshops (x2)

Specialities/departments		
Bereavement Services	International and Private Patients	Quality and Safety
Cardiac Intensive Care	Legal	Renal/Nephrology
Cardiac Services	Metabolic	Research Nurse
Complex Surgery	Medical	Research Physio
Endocrine	Neurology	Sleep
ENT/Voice/Speech and Language	Neuro-disabilities	Spinal Surgery
EPR	Oncology/Chemotherapy	Theatres/Anaesthetics
Gastroenterology	Ophthalmology	Transition
General Paediatrics	Orthopaedics	Urology
Haemophilia Centre	Orthotics	MRI
Infection Control		

4.5.2 Findings from young people's workshop

Eight themes were identified from the young people's workshop (Figure 4-1): potential benefits; the need to set expectations; privacy and security of their health data; ownership of their health data; access considerations; worries, anxieties and the need for support; ethical and legal considerations; and desirable functionality. These themes will be presented in turn, with verbatim quotes to illustrate meaning.

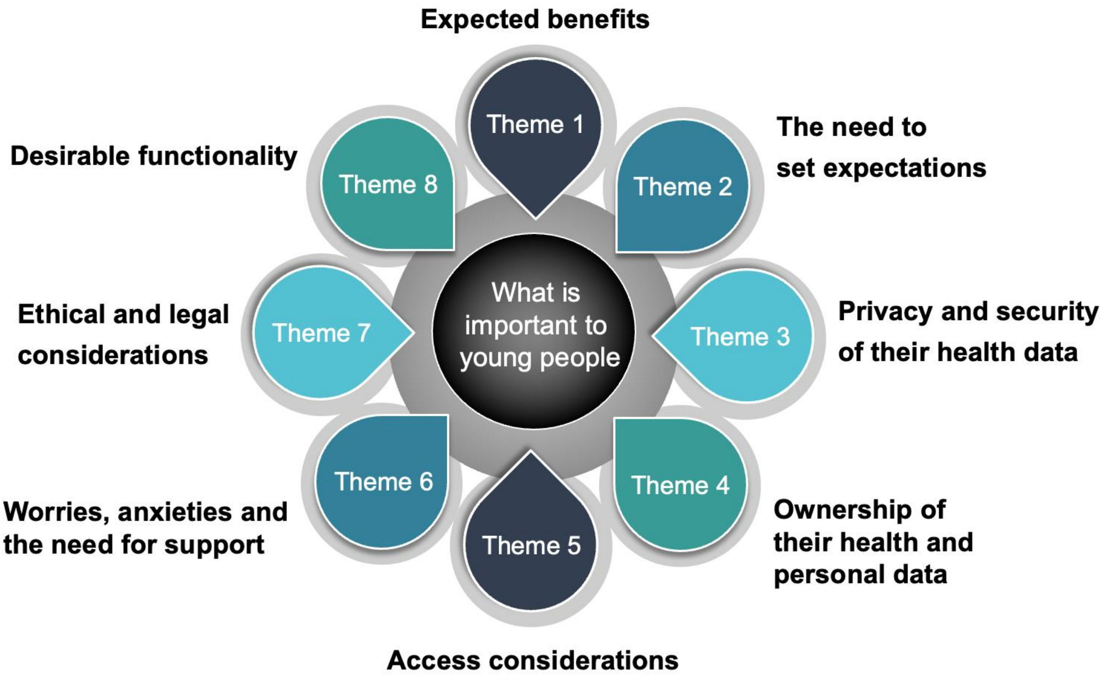


Figure 4-1: Themes from the YPF World Café workshop

4.5.2.1 Expected benefits from implementing EPR and MyGOSH

Young people described numerous expected benefits of the hospital transitioning to an EPR system and the implementation of MyGOSH. As shown in Table 4-5, these benefits were described in relation to patients, parents and hospital staff.

Young people felt there would be an advantage to patient information being in one place, with staff having easy access to health data and appointments via MyGOSH, as well as anticipated time-savings for patient, parents, and staff. One participant explained, "*My mum is always calling and trying to find things* (like appointments) *... so if it is all on the same thing* (MyGOSH) *she only has to look on that and doesn't have to look everywhere* (at home)" (YP1).

Table 4-5: Young People's views on expected benefits of EPR/MyGOSH

Expected benefits	Who the benefit will affect (patients, parents, or staff)
All information in one place	All
Easy access to health data and information via MyGOSH	Patients/parents
Less repetition when describing condition (all notes in one place)	All but primarily patients/parents
Won't need to carry paper notes around the hospital	Patients/parents
Letters and paper notes won't get lost	All
Better for the environment	All
Online information leaflets and hyperlinks. Helps with: - understanding of condition, terminology - preparation for procedures - preparing for transition	Primarily patients/parents but also staff
Better communication - Use MyGOSH to communicate with care team - Use MyGOSH to ask questions - Keeping care team up to date - More personalised care - Less time wasted in clinic as care team will already be up to date with patient's information - Potential for video clinic appointments	All
Young people will feel more involved in their care - ↑confidence - Feel more responsible - Feel more independent	Patients
Young people will feel more in control of condition and care	Patients
Be able to see who will be looking after them (name, photograph)	Patients/parents
The ability to access appointments on MyGOSH	All
The ability to change/co-ordinate appointments on MyGOSH with parents	All
The ability to see results on MyGOSH	Patients/parents
Time will be saved - Healthcare professionals (HCPs) will have more time to talk to and care for their patients - Parents will save time – easy access to appointments, less journeys to hospital	All
HCPs will have a better understanding of patient's condition and situation	All
Better coordination/efficiencies around the hospital	All
Digitalisation seen as positive	All
Reduction in repeated clinical tests	Primarily patients, but also parents and staff

A recurring ‘worry’ (described more in a later theme) expressed by young people was not wanting to be reminded of their condition all of the time, and having to recount their diagnosis numerous times. One patient described how, *“You have to tell your story every single time”* but through EPR it was felt that less repetition will be of benefit because, *“If you put it all in one place then they* (staff) *can see it before they come into your appointment so then you don’t have to tell the same story”* (YP2)*.* This participant went on to say, *“It will help them* (staff) *as well, as they will* <u>*know*</u> *your story”* (YP2)*.* Linked to this point was the hope that EPR would lead to better communication between staff, who would have “*A lot more understanding”* (YP3) of patients’ individual conditions throughout the hospital:

> *“When you see the different departments, sometimes they should know, but sometimes you have to explain what’s been happening the last month ... but that (EPR and MyGOSH) might make that easier” (YP3).*

Additional expected benefits described by the young people were related to operational efficiencies. For example, when talking about timesaving benefits a participant said, *“I think EPR would ensure that more time is spent talking about things that are important rather than searching around for different things”* (YP4)*.* For many young people, spending more time with their clinician was considered a good outcome. The importance of young people being able to communicate more easily with their care team was evident. One participant suggested that she may, *“Use it* (MyGOSH) *to … keep my consultant updated”* because*, “sometimes … I need to be admitted into my local hospital if something happens and sometimes they don’t always know about that”* (YP7)*.*

The idea of results being shared on the portal was appealing to the young people because this meant they could access them quickly and more easily. However, emphasis was placed on the need for the results to indicate, “*if they* *are in the normal range or not. Many things might be not in the normal range but normal for me*" (YP16).

Young people expressed a desire to know in advance who will be looking after them. The ability of MyGOSH to enable them to see photographs of members of their care team was seen as helping relationships and rapport to be developed online via the messaging service in advance. This was seen as important because, "*Going to GOSH itself is a big thing because GOSH isn't like your local hospital that you just go for a check-up … putting faces to names, it gives you more a friendlier environment*" (YP8). One participant described how, "*It will be nice to work out who they are and what they are doing*" and that having this knowledge would make her feel, "*happier and more comfortable*" (YP5), whilst another said, "*That's what is missing in the hospital at the moment – the basis of knowing your carers* (hospital staff) *properly"* (YP22). Building rapport with the clinician was seen by young people as extending beyond creating a nice environment, to including the development of a trusting relationship with their clinician, with one participant explaining that:

> *"Even getting to know them on the computer would, kind of, help you to recognise them and make you feel more comfortable telling them things that you wouldn't necessarily tell your parents" (YP9).*

It was hoped that MyGOSH may ameliorate clinical tests being repeated with patients because results cannot be accessed or found. One of the older participants explained:

> *"Sometimes I have been asked to do a test 3 times in 4 months as they cannot access the results so it needs repeating, so EPR will help prevent this" (YP19).*

Young people felt positive about the potential for repeated tests to be reduced once EPR was in place. The discussion provided a powerful illustration of what young people hoped MyGOSH would do for them and other patients, and the vision that expected benefits would contribute to more personalised care and better patient experience. Digital transformation, "*Will help a lot of people and it will make their hospital experience overall a lot smoother*" (YP7).

4.5.2.2 The need to set expectations

The need to set expectations was not discussed in as much detail as other topics, but nevertheless appeared to be of significance to young people. They were vocal about the need to set expectations early on about what MyGOSH is and what it can do. There was an awareness that, "*Go-live is just the start of things, it has a lot of potential for the future*" (YP10). Linked to setting expectations, young people also felt that the hospital should be careful about what information is available on MyGOSH insofar as potentially raising hopes falsely if a proposed treatment does not work. It was felt that the timing of information released onto the portal was also important so that it did not create unnecessary anxiety for the patient. There was the expectation that waits may be longer immediately after 'Go-Live', "*If you have an appointment after go-live you may have to wait longer than normal*" (YP6).

When thinking about the messaging function on MyGOSH and how quickly young people would want to hear back after messaging a staff member, it was clear that they had high expectations. As one participant highlighted, they would expect the response to be, "*Very quick. Coz you want to know the answer as soon as possible*" (YP11).

4.5.2.3 Privacy and security of young people's health data

Young people placed great importance on the privacy and security of their health data. They expressed wanting assurances about the security of their information and that confidentiality would be maintained. Young people compared MyGOSH portal to online banking, insofar as needing it to log off automatically after a period of time, to protect data and the importance of staff setting up their own password to promote security. Hacking was raised as a major concern by many, with questions being raised such as, "*Could it get hacked easily?"* (YP13). One participant in particular described his concerns:

> *"What I'm worried about is if the files are deleted, what are we going to do? So that's patient files and everything that everyone's worked really hard to get this far – what will we do?" (YP10)*

This young person goes on to say that they, "*need protection from suicide hackers that would take over the whole system and take it down. If the system goes down the whole hospital comes to a standstill!*" (YP10), reiterating the need for reassurances that necessary cyber security procedures are in place. In light of previous episodes when NHS Trusts have been hacked he said, "*I want to see the cyber defences they are putting in place"* (YP10).

It was apparent from listening to participants that the current technologically minded generation of young people are acutely aware of the possibility of threats to data safety and integrity. These vulnerabilities were highlighted by one participant who described how she felt about the security and privacy of her health data:

> *"There's such important things on there – like that's our lives … so it is quite scary thinking that some unauthorised party could get hold of that" (YP26).*

The reference to ‘our lives’ in this quote is expressed most strongly within theme 4, described next.

4.5.2.4 Ownership of young people’s health and personal data

It was apparent from listening to the young people that they held strong feelings about the ownership of their health and personal data, regardless of how old they were, and that they wanted to be involved in decisions about their treatment and care, and be more responsible for their own healthcare. This was raised numerous times by different participants. One of the older participants explained how, through the use of MyGOSH, she can, *“be more involved than before … more in control … less childlike*” (YP15). Another of the older participants described that they would feel:

> *“A lot more in control (when using MyGOSH), especially when you are asked to go over your medical history at an appointment somewhere else and you think, ‘what tests have I had done?’ I don’t really remember, and if you can see the ones you’ve had done at GOSH then (this will be easier)” (YP24).*

As this quote highlights, having ownership of their data was not just about gaining control but also related to the challenges young people might experience with remembering aspects of their condition and treatment – clearly important to being involved in discussions and decision-making.

Young people also described wanting ownership of aspects of their health data that may be considered sensitive as well as wanting responsibility for knowing when they needed to see their clinician, sometimes on their own. One of the older participants, who described suffering from anxiety, described how he felt:

> *“Mental health, it’s a very sensitive topic … I would prefer it if I went to see a psychologist without my parents knowing at times because then at times your parents might think OK, this isn’t good for you, going to a psychologist … then sometimes you might just end up having long discussions about going to a psychologist when really there shouldn’t really be any discussion” (YP19).*

This example highlights particularly clearly the tensions that can exists between young people and their parents about what is best for the young person when it comes to management of their healthcare.

When talking about the possibility of being able to schedule more than one appointment per outpatient visit to reduce the number of separate hospital visits, one participant described how being able to manage her appointments through MyGOSH would be useful:

> *“I have two appointments in the same place but on two different dates and it could be the day after each other so it’s not practical … it would be really good to manage appointments. Being in hospital kind of throws off life … not being in hospital when you’ve got so many appointments is, it’s almost abnormal ... it would be like getting that normality back” (YP17).*

It was evident that ownership of their health and personal data was important to young people and, they hoped, would result in a greater understanding of their condition. This was seen as positive by the young people because such understanding would make life a bit easier. The use of hyperlinks within online information via MyGOSH was described by participants as, “*So cool!*” (YP3) and one participant felt that greater understanding would, “*Help you feel a bit more* *positive about what you are going through ... It would sort of make you happier you are understanding your condition*” (YP20).

When talking about promoting independence through ownership of their health and personal data it was felt by young people that familiarising themselves with scientific terms would help not just with their understanding but also with transitioning into adult services. When discussing transition, young people did not want people sharing their notes, did not want people they did not know accessing their notes, they wanted control over who does have access, and one of the older participants was explicit in stating that he, “*Did not want people no longer in their care team to be able to access their notes*” (YP10). In addition, young people’s desire for ownership of their health and personal data meant that if they saw something documented incorrectly they thought it would be easier to get it corrected when digitalised.

4.5.2.5 Access considerations

This theme focuses on who has access to young people’s healthcare records and how that is managed in practice, with concerns expressed about equity of access for those with additional needs.

There was much debate amongst the young people about who was accessing their health data and why. They expressed concerns about clinicians or staff members not known to them accessing their information, and people accessing it that should not be able to, for example, hospital staff not directly involved in their care, or other unauthorised parties. This interlinks with young people’s ownership of their health and personal data. In addition, the considerations around parents giving their consent for their child aged 12-15 years of age to access MyGOSH were discussed, as was the topic of those who are 16 years and above having sole access. There was a strong feeling that it was their right to have access to their health data but that it should remain a decision for each individual and their family:

> *"I think I'd have a right to it because it is my healthcare. I'd still want my parents involved so that option has to be there ... so it's kinda up to the individual and how they get along with their family" (YP12).*

Young people felt strongly that if their parents did not grant them MyGOSH access, "*My rights have been taken away*" (YP14). One of the younger participants said, "*As a patient you need it* (access) *because I don't think your parents should have everything in their control because it's actually you that's getting the care*" (YP18). The young people felt that not being given access may mean information is being hidden from them, "*I would probably first have the conversation with them* (parents) *'Why are you trying to hide something?'* " (YP21). When thinking about being excluded from MyGOSH, another participant described how she would feel:

> *"…a bit annoyed … because that's my health condition, that's my life so why shouldn't I be able to have access to it if it's affecting me on a daily (basis) … I should be able to see it" (YP20).*

Although young people recognised that parents may be trying to protect their child from potentially worrying information or if the diagnosis is not confirmed, one participant indicated that not being given access was worse than knowing the truth, "*When you don't know what's going on with you, your worries aren't alleviated. You just panic!"* (YP20). It was also felt that because some parents will not entirely know what MyGOSH is, it was important that MyGOSH's uses and benefits were made really clear to them by the hospital, so that they may be more open to allowing their children access to it.

Some group members had significant physical or sensory impairments, or intellectual disability. This made them think of others with similar conditions and their potential difficulty in accessing MyGOSH, including if they did not feel well enough to operate the portal. For example, one of the older participants felt that, “*Some patients may not be physically able to use it if you cannot move your hands”* (YP23). Suggestions were provided of ways to help those who may find access difficult including, “*voice activated parts of the portal”* and, *“larger font size for those with poor sight*” (YP23). The young people felt that not everyone will a) have internet to be able to access MyGOSH, b) have access to computers, smartphones or tablets, and c) may find it difficult to use the technology. As one participant said:

> *“I think not everyone in our parents’ generation are a tech wiz, so it’s bound to be hard for them as well to come to terms with relying on technology” (YP10).*

Furthermore, the issue was raised of how an English-only roll-out of EPR and MyGOSH will affect young people and their parents for whom English was not their first language. As one of the older participants said:

> *“Some parents like mine can’t read English so that would worry me because they don’t understand, they don’t know what’s going on with my care – then I would have to explain things to them which is difficult” (YP23).*

This young person felt uncomfortable translating for her parents. It was suggested by several young people that to promote equitable access there should be a translation function on the portal amid concerns that inaccurate translation of their health data represented a safety issue from information not being properly understood. However, this raised additional concerns as to whether the information would be translated correctly.

4.5.2.6 Worries, anxieties, and the need for support

One of the main worries young people had around using an EPR system was the potential for loss of face-to-face contact. It was seen as important from different perspectives. Firstly, it was suggested that immediately after ‘Go-Live’ clinicians may be, “*more interested in the computer than the patient and that might mean less discussion*” (YP10). Young people felt that, “*Staff could be very stressed and if this was the case the patient may get nervous. And might not know what to do*” (YP23). Secondly, young people’s anxieties related to the practical changeover from paper to digital was raised as an issue, with the risk of loss of health and personal information. There was a, “*worry that something could be overlooked which could change the whole of your healthcare in a worse way*” (YP25). Young people also expressed concern about the potential difficulties of receiving support or reassurance via InBasket messaging, the messaging system within MyGOSH, and the potential for misunderstanding when not receiving information in person. During face-to-face contact, “*you get the gist of how the medical professional feels” and “how reassured they are about the future of the condition*” (YP10), which young people worried could be lost or misunderstood during other means of communication.

A recurrent theme was young people’s worries of being constantly reminded of their diagnosis. One participant explained that, “*Sometimes it gets you down if you see your condition all the time, are reminded all the time*” (YP25). Similarly, another participant said, “*I don’t want a constant reminder of what I’ve got going on*” (YP21). They felt that reading something they did not want to read would be upsetting, with one participant suggesting the value of, “*having all your conditions and diagnoses hidden away so that you are not reminded all the time*” (YP25).

Conversely, another participant felt that she, “*would worry if parts of MyGOSH were ‘locked’ so I couldn’t see parts of it – like I am going to die or something*” (YP18). These contrasting examples highlight the need for transparent, communication between young people, their parents, and clinicians to determine the individuals' needs are met.

Support when accessing MyGOSH was raised in two different contexts: from the perspective of needing technical help from parents or professionals to access the portal in the context of a "*24/7 support network*" (YP16), and in terms of support from an emotional perspective about clinical aspects relating to their health. When describing the need to access MyGOSH in partnership with her mum for support, one of the younger participants said:

> *"At my age I don't understand everything that I have. I understand the main bits … but … in the deeper ways of things of how surgery gets done … I don't really understand. So, I feel like if my mum can access it (with me), it will be so much better because then she could actually tell me in a better way where I would understand. It would be easier for me, and I would feel less stressed in a way, because I tend to have anxiety and stress on what's happening" (YP20).*

The issue of posting results on social media was raised. One participant suggested that there should be advice on MyGOSH about the risks of sharing health information on social media including cyberbullying, harassment, or peer pressure to share information. This young person added, "*Don't share results because it is a) not necessary and b) you don't want the pressure of people doing that* (peer pressure)" (YP20). Furthermore, it was felt that sharing health information, *"could lead to stress for people, like stress breakdowns for people, who ...* (suffer with) *… stress and anxiety so they can sort of be pushed in that direction to share, even when they don't want to"* (YP20).

4.5.2.7 Ethical and legal considerations

Both ethical and legal issues were identified by the young people. Some aspects have been highlighted already, for example young people do not want to be constantly reminded of their condition due to the anxiety that this causes, and wanted to maintain a sense of normality, wherever possible. They feel that their rights will be taken away if they are not given access to MyGOSH, and by not giving them access, they would feel that information was being hidden from them. Non-disclosure of health information such as the diagnosis or prognosis was seen as particularly problematic. Although it was recognised by the young people that their parents may be trying to protect them, the notion of secrecy was viewed negatively. It was felt that, "*It should be the young person's choice if things are hidden*" (YP10) to avoid anxiety of wondering what they will find when accessing MyGOSH, highlighting the young people's need to be in control of their health and personal data.

Discussions revealed that the notion of seriousness was an important issue in terms of young people's condition(s), diagnoses, and prognoses. This related to what should be visible on MyGOSH and whether important things such as diagnoses, or test results should be delivered face-to-face rather than online. One of the older participants said, "*Diagnosis should be face-to-face … anything serious should be face-to-face, not online and not finding things out on your own*" (YP10). Another older participant expressed how they may not want to tell their parents their diagnosis and when thinking about posting results on MyGOSH, suggested the inclusion of a, "*Comment box when results have been posted if serious – from the doctor that says, 'you can call me on Monday morning if you want to talk'* " (YP19), especially if results are released on Friday evening.

During one discussion an interesting perspective was raised about how, whilst the Mental Capacity Act allows young people to consent for treatment at 16 years of age, one of the older participants believed this age should be 18. She described some of the complexities of medical care for young people of her age:

> *"It is such a grey area … you can physically discharge yourself from medical hospital, you can request your own notes. I can get fully admitted to hospital for days and my mum doesn't know anything about it … I think in EPR it needs to be clear what the rules are, and I think really it should be 18 (rather than 16) … Realistically, I know I won't give my mum an account … and if I'm starting to get tests and diagnoses and message my doctor, and significant stuff is coming up … I really think they should know … It's such a danger" (YP17).*

The insights this participant has into their own health behaviour highlights just how important it is that young people are included in matters that concern them. She is able to reflect on the negative implications of having the freedom to make independent decisions about care and treatment before such a time that she is perhaps ready. Rather, she felt that if the law dictated that young people could not consent to treatment and make such decisions on their own until they are 18, then it would take away the dilemma about giving her parents access to MyGOSH or not before that time. Another young person suggested the need for a, "*discussion at the appointment to see whether you are responsible enough to not have your parents involved"* (YP17).

4.5.2.8 Desirable functionality

The group were innovative in their ideas for desirable functionality on MyGOSH. They wanted clarity insofar as, "*Clear guidelines on what can be accessed*" (YP2) and that it, "*needs a simple format*" (YP6). "*It needs to be made clear what's on that page, how much you can access*" (YP2) with "*clear information about MyGOSH and how to use it*" (YP16). The group wanted *"FAQs"* (YP16;

frequently asked questions), and when thinking about the use of technical language suggested a, “*facility to hover over a term and it comes up with it in layman’s language*” (YP10). In addition, knowing who accessed their health data, an issue discussed previously, was seen as a desirable function within MyGOSH.

Some of the participants talked about how they use health apps or devices to help them with their condition(s). It was felt that “*EPR needs to join up with other companies for example accucheck”* (YP17) to sync results with MyGOSH, and for apps such as ‘MyMedicalNotes’ to integrate that information from/to EPR. It was suggested by one of the older participants that they would like to use MyGOSH like a diary so that the clinicians “*Can see what is going on*” (YP19), and that push notifications were essential to act as a reminder as, “*We all have hectic lives*” (YP19). This particular participant felt that this would take the pressure off them trying to remember everything if it was charted on MyGOSH with clinicians being able to access that information.

They would also like a, “*Fun fact*” (YP10) about members of their care team, to further personalise the experience and suggested, “*Live chat*” and “*Video chat*” (YP18) functions that they would find useful in the future.

4.5.3 Parent and staff findings

As the focus of this study was primarily on the experience and perceptions of CYP, the views of young people were presented in-depth within this chapter. The parent and staff findings were then mapped onto the findings from the workshop with members of the YPF, identifying any convergences or divergences by comparing findings across the three datasets from related topics (Table 4-6).

Table 4-6: Mapping of parent/staff data onto YPF data

Young people	Parent	Staff	Convergent/Divergent
Expected benefits			
• Easy access to health data, all in one place • Information leaflets accessible • Better communication • YP will feel more involved in care, more in control of condition/care, more informed • Ability to change/access/co-ordinate appointments via MyGOSH • Ability to see results via MyGOSH • Time-saving benefits • HCPs will have better understanding of patient's condition • ↑coordination/efficiencies around hospital • ↓need for repeated clinical tests • Positivity about digital transformation	• Many benefits foreseen including rapid access for everyone, all information in one place, and EPR will help parents make decisions about their child • Improved communication – everyone up-to-date and 'in the know' • Aids partnership in care • In-basket messaging – should eliminate communication frustrations but added burden on professionals • Parent seemed sceptical about whether managing appointments will be easier	• Many benefits foreseen including wider accessibility, shared documentation, all information in one place, remote access, chronological order of notes, less duplication of note writing • Consistent information to families • Everyone knows child's plan of care = ↑transparency • Improved communication, ↑use of family friendly language = less jargon • ↓errors = ↑patient safety • Time-saving benefits for staff in long run (but may ↑burden initially) • ↑patent/family experience • Practical benefits • Cost saving benefits for hospital • Showcases hospital as more professional	**Convergent** • Expected benefits anticipated by all stakeholder groups **Divergent** • Patients and parents more focused on expected long-term benefits, whereas staff looked more broadly at benefits to patients, parents, staff, the hospital, and perceived status of the hospital.
The need to set expectations			
• YP wanted their expectations set early on what they can expect from MyGOSH/the new system • How quickly to expect response via InBasket messaging • Thoughtful release of information via MyGOSH (e.g., not on a Friday afternoon without explanation)	• Parents had high expectations, but hospital needs to set realistic expectations prior to Go-Live • Can the Trust meet those expectations and deliver on all that has been promised?	• Staff concerned about preparation of families about big change in ways of working, potential for clinical delays • Need to set expectations about responses via InBasket messaging in an era of immediacy – how will clinicians manage this?	**Convergent** • All stakeholders identify need to set expectations **Divergent** • Staff identify potential burden of managing additional workload when managing messages from families via MyGOSH

Young people	Parent	Staff	Convergent/Divergent
Privacy and security of young people's health data			
• YP were acutely aware of possible threats to data safety and integrity, and placed great emphasis on privacy and security of their health data • YP wanted assurances about the privacy/security/confidentiality of their health data**,** can the system be hacked?	• Parents less concerned with security than other considerations listed	• Appropriate and effective use of patient data • Appropriate access by staff members – audit trail • Concerns about hacking • Confidentiality issues of access data remotely (e.g., during on-call) • Privacy/security of sensitive notes	**Convergent** • YP and staff concerned about hacking **Divergent** • Parents not overly concerned about security of data • Staff identified considerations around confidentiality of data during remote access and privacy/security of sensitive notes
Ownership of young people's health and personal data			
• YP wanted ownership of their personal and health data, and control over who accesses their data • YP want to be involved in decisions about their care • MyGOSH will help with transition into adult services	• More in control, more autonomous, more informed = parental empowerment • Parental ownership of child's care and health data • Emphasis on ensuring health information is correct • May help parent prepare the child for increasing independence, including preparation for transition into adult services • But added responsibility – onus on parent e.g. ensure child's health data is correct, supporting child's access to avoid anxiety	• Clinician/patient paradigm changing = ↑autonomy and empowerment of patient/family • YP/family taking ownership of health/data can help prepare them for transition into adult services • Staff identified complexities around ownership of data e.g. who actually owns the data? Documenting parent details in child's records. Staff wanted assurances these issues will be resolved before Go-Live	**Convergent** • MyGOSH may help YP prepare for transition into adult services • ↑Empowerment of patient/parent **Divergent** • YP and parents both want ownership over the data – parent feels responsible. Staff identify complexities in ownership of data.

Young people	Parent	Staff	Convergent/Divergent
Access considerations			
• YP felt it as their right to have access • Will my parents give me access? • If access is not granted what information is being hidden? • Who will be accessing my data? • Potential inequities in access • Considerations around sole access at 16 years of age	• More concerned with accessibility than security • Some parents may not give their child access to MyGOSH (12-15 years old) • Should access be at 11 years old – secondary school age? • Young person aged 16 years old or above not giving their parent access – risk of YP blocking parent, risk of conflict • Practical accessibility issues may be an issue e.g. accessing MyGOSH if password lost/forgotten	• Will all staff have the skills to access and use EPR effectively? • Inequities in access for families – low literacy levels, English not first language, generational implications, those with sensory/physical impairment • What if access fails when accessing system remotely?	**Convergent** • YP and parents thinking about age of accessing MyGOSH and for sole access • All stakeholder groups identified areas of possible inequity in access **Divergent** • Staff were thinking about potential remote access issues

Young people	Parent	Staff	Convergent/Divergent
Worries, anxieties, and the need for support			
• Potential for/issues due to loss of face-to-face contact – when staff were learning the new system; worries about misinterpreting information via MyGOSH when not face-to-face • YP raised the notion of seriousness, and the importance of delivering test results with serious implications face-to-face rather than online • Being constantly reminded of their diagnosis/condition(s) - YP wanted to maintain a sense of normality, wherever possible • Potential conflict if not being given access by parents/non-disclosure of diagnosis/prognosis information the YP considers important • YP had anxieties about information being concealed from them • Balance between being constantly reminded of condition, yet wanted access and YP not wanting health information to be hidden from them	• Child may read something parent does not want them to read • Will too much information lead to ↑anxiety for child? • Changing appointments online – will it be easy? • Worries around less time with clinician in clinic due to the use of EPR, leading to less face-to-face contact • Results on MyGOSH - child may see before parent has discussed with them • How easy will it be to get hold of a clinician via InBasket messaging? • Will technical support be available? • Worries around going from GOSH to hospitals without EPR – how will the information be managed? • Parents were unhappy about the potential for child to post health results on social media platforms	• Extremely high anxiety levels about Go-Live • Worries around patient safety over Go-Live period, afraid of being asking something by families/other staff and not knowing the answer, too much change in one go? • Staff worried about the loss of face-to-face contact with families – how to maintain clinician/patient relationship, will patients/families be more inclined to self-diagnose? • Staff worries about families posting about them, the hospital, or the care team on social media, ?↑ability to share health information on social media due to MyGOSH access • Worries about managing families' anxieties (additional burdens on staff)	**Convergent** • Loss of face-to-face contact • Concerns about the sharing of information or people posting on social media • The need for support **Divergent** • Staff were particularly worried about the Go-Live period – not knowing what to do, how to use system, patient safety, managing burden of work/managing family anxieties • Parents worried about going to other hospitals without EPR and how information will be managed between GOSH and local without EPR • Parents worried about their child either reading information they didn't want them to read or didn't understand

Young people	Parent	Staff	Convergent/Divergent
Ethical/legal considerations			
• Debate about age at which YP should have sole access • Need for support – technical and emotional Posting health information and results on social media – would this lead to cyberbullying or harassment, peer-pressure to share? • Support when accessing results was important to YP, as was timing of results release e.g., not late on a Friday with no explanation	• Who will assess child's competence/capacity to gain MyGOSH access? • Who will assess parents' capacity to access MyGOSH? • Parents may not engage if shielding child from diagnosis/prognosis	• Concerns about assessing capacity – training needed • Potential for conflict over non-disclosure of diagnosis when parents do not want their child to know diagnosis/prognosis • Child or YP not wanting their parents to know medical details	**Convergent** • Capacity assessment • Potential for conflict over non-disclosure of diagnosis **Divergent** • Staff identified training needs and areas of potential conflict
Desirable functionality			
• "How to" guides • Facility to hover over a medical term and explanation is provided • Ability to sync with other health-related apps or devices • Push notifications • Fun fact about staff members • Live chat or video chat functions	• Not described by parents	• Not described by staff	**Convergent** • None **Divergent** • Desirable functionality only considered by YP

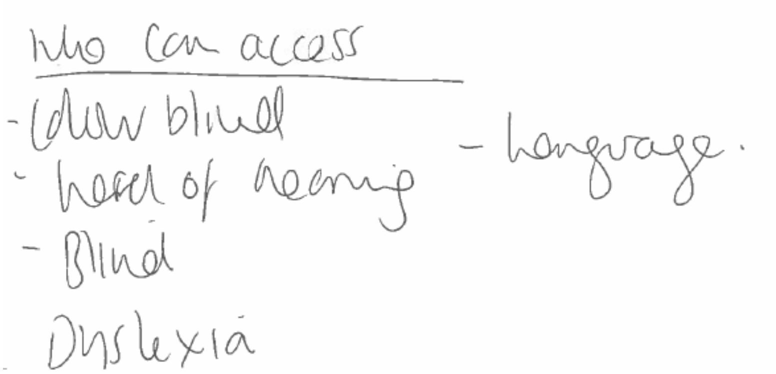
4.6 Survey development from the themes

Development of the identified themes were performed using the process outlined in Table 4.2. Framework method enabled recurrent themes to be mapped in table format so that important issues were highlighted. Survey questions were developed from the recurrent themes from working with two PhD supervisors through verification of important issues, revising and refining questions over a series of meetings before finalising survey content to be piloted by workshop participants. An example of the transition of one aspect of a theme from the thematic framework to survey question development is presented in Table 4-7:

Table 4-7: Excerpt from thematic framework – Barriers to accessing MyGOSH

Participant	Recording identifier	A: Description	B: Relevant quotes
YP17	C1	Blind, hard of hearing, colour blind, non-English speakers	*"May need larger font sizes for those with poor sight"*
YP23	C2	Physical disability inhibiting use of portal	*"If you are not feeling well enough to operate it some patients may not be physically able to use it – can't move hands – cannot touch screen"* *"Need voice activated parts of the portal"*
YP10	C4	Parents not tech minded; parents' understanding of technology	*"I think not everyone in our parents' generation are a tech wiz, so it's bound to be hard for them as well to come to terms with relying on technology"*
YP23	EL 1	Worries about translating health information for parents who don't understand English	*"Some parents like mine can't read English so that would worry me because they don't understand, they don't know what's going on with my care – then I would have to explain things to them which is difficult"*
YP23	EL1	Language barriers – home and hospital	*"Some parents can't speak English"*

These data were cross-referenced with notes taken during the workshops (Figure 4-2) and formulated into a survey question (Figure 4-3).



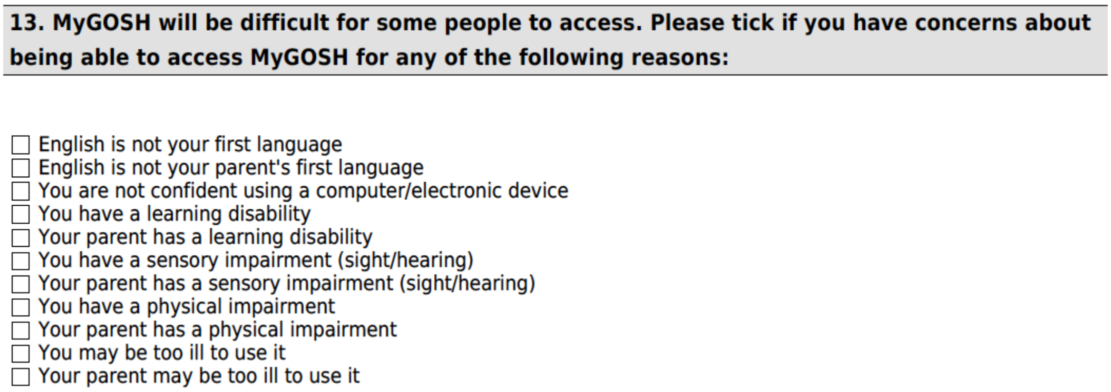
Who can access

- Colour blind
- hard of hearing
- Blind

Dyslexia

- language.

Figure-4-2: Example from workshop notes



13. MyGOSH will be difficult for some people to access. Please tick if you have concerns about being able to access MyGOSH for any of the following reasons:

☐ English is not your first language
☐ English is not your parent's first language
☐ You are not confident using a computer/electronic device
☐ You have a learning disability
☐ Your parent has a learning disability
☐ You have a sensory impairment (sight/hearing)
☐ Your parent has a sensory impairment (sight/hearing)
☐ You have a physical impairment
☐ Your parent has a physical impairment
☐ You may be too ill to use it
☐ Your parent may be too ill to use it

Figure-4-3: Formulation of the survey question

The same process was applied to the parent and staff datasets. All baseline and follow-up surveys are included as Appendices (26-31).

4.6.1 Piloting the surveys

Each stakeholder groups' respective survey was sent to all workshop participants for piloting via hospital email. One young person, one parent, and seven members of staff responded with feedback. Received feedback is provided in Table 4-8.

Table 4-8: Examples of feedback from survey pilot

Participant group	Comments
YPF Member *n*=1	I'd say that the length of the survey is on spot, it's not too long and not too short, it made me feel satisfied, it's not boring and it didn't tire me out or anything. I think the wording is simple, understandable, and easy to read. I think the wording is simple, understandable and easy to read. Will there be a tutorial on MYGOSH?
Parent *n*=1	Could the questions be in bold? Section 7- will the parents have been fully informed of how EPR will work before we move over? I know the team expect parents to all be totally up to speed on how it will work but I still haven't been given a clear indication of how it will have been explained to them. I am worried this might pose a problem for their responses to this section of questions. I find all the questions appropriate, and you have covered such a huge variety of scenarios I think this will undoubtedly be invaluable to the future success of EPR!
Staff *n*=7	Looks fairly comprehensive to me. I have nothing to add. It covers most of what we discussed In the introduction you mention 'patients' having access to MyGOSH and their health data. In Q12 and Q13 you talk about 'giving children access'. In my head this is quite emotive and has the potential to introduce bias-no one under 12 will have access. It would feel very different if you said 'giving young people access' or stuck with 'giving patients access'. Similarly, Q12 talks about having 'concerns about children accessing their health data'. Young children won't be able to. If you call them young people or patients not children it makes a difference. Same for Q13. Who is the survey going to? Will role, or whether the person answering the survey is clinical or non-clinical be captured? Will there be a 'not sure' or 'not applicable' answer option? e.g., I imagine that EPR will improve clinical staff's ability to provide joined up care but this wouldn't impact me personally therefore I wouldn't be sure how to answer the question, or should I answer disagree as it won't make a difference to my ability? Equally, I couldn't answer question 14 and 15. Will the same survey be sent post go-live? I think a free text option in one or two areas might be helpful for capturing anything else/quotes of how EPR go-live has personally impacted individuals. The survey looks really good. I had a look at the draft survey and think it looks really good. I don't have any suggestions to add. I think you've done a great job at capturing all the anxieties and comments from the Café night! I did notice you've only a single question about ethical implications, but that was a big discussion table for us… so don't know if you wanted to expand/include a smidge more of a prompt on those? Nothing else jumped out at me, either for being included or excluded.

The results of the survey pilot were discussed with the PhD supervisory team, reaching agreement on what was to be included in the final versions. Feedback was incorporated, where possible, before Trust-wide distribution during the quantitative aspects of phases two and three of the study. Free text boxes and the option for ‘not applicable’ were added to questions that were thought to not be applicable to all roles, or that staff members were unable to provide an option about. The debate around whether to use ‘children and young people’ or ‘young people’ was resolved by using ‘patient’, to also prevent confusion when talking about the parent’s child. It was emphasised in the opening information that this survey was for those aged 12 years old or above, matching the age for MyGOSH access. Despite there being one specific question in the staff survey on the ethical implications of EPR and MyGOSH, questions on the different topics raised were present across all three surveys. Those who completed the pilot only saw the survey for their participant group, for example, young people piloted the CYP survey, parents piloted the parent survey and so on. The recurrent raising of ethical dilemmas also helped to inform the addition of the focus group with the members of the Paediatric Bioethics Centre to the study design, as presented in Chapter 9.

Overall, the main differences between the participant group findings were the young people’s focus on being in control of their own health and having ownership of their health data, wanting to be involved and included in all aspects of their care, but also needing support to be able to do this. In contrast, parents had an overall feeling of responsibility for their child, their health and their data, and wanted to be empowered by having access to MyGOSH. This is an area of contention to be explored in later data collection. Parents had hopes of benefits and wanted the hospital to deliver on promises. Staff very much focused on the Go-Live period with worries about the practicalities related to this, which is reflected in the staff surveys (Appendices 30/31).

4.7 Informing the interview schedule

The workshop findings informed the development of the interview schedules, as shown below with some examples from the parent data.

Parents revealed concerns about whether technical support was going to be available when using MyGOSH, and they had worries around having less time with clinicians when in clinic with their child due to the use of EPR, leading to reduced face-to-face contact. In response to this, the following questions were added to the parent interview schedule (Appendix 32):

- Are there any aspects of MyGOSH you or your child have needed support with?
  Prompts: For example, technical help, accessing test results, health information, contacting the care team, booking appointments

- How has EPR changed your experience?
  Prompts: For example, interactions with staff during clinic, coordination of care, communication with your care team

Furthermore, considerations around parents giving or not giving their children MyGOSH access was raised by both the parents and the young people, resulting in the following question being added to the interview schedule.

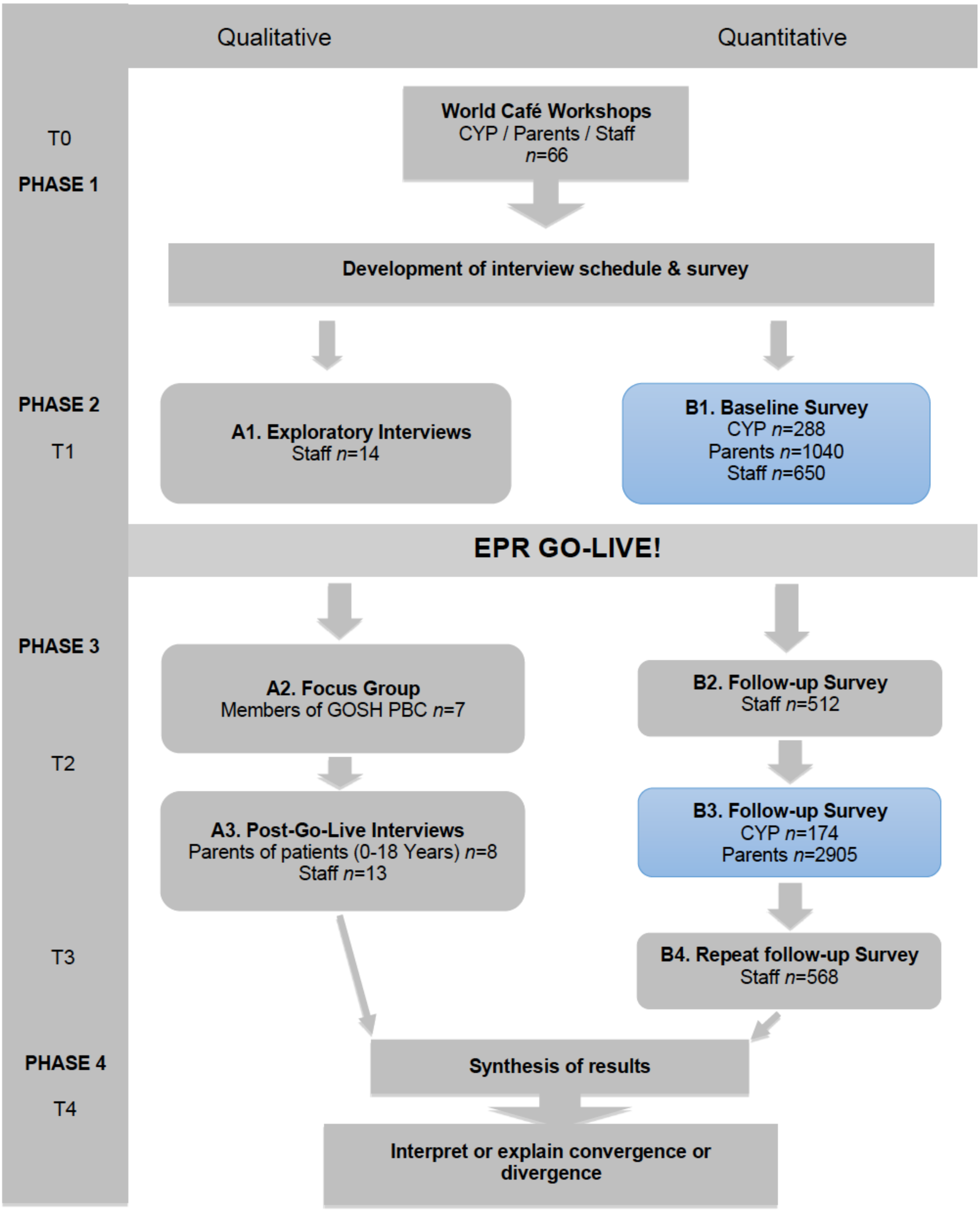
- How do you feel about the age limit for children accessing MyGOSH (12 years of age)?

4.8 Summary

This chapter has presented the young people's World Café workshop findings, with the parent and staff data mapped onto the key themes highlighting areas of convergence and divergence. Young people were able to clearly articulate how they felt about the introduction of EPR and the MyGOSH patient portal, and what the benefits and challenges that might bring to other patients, parents and hospital staff. Their insightful and thought-provoking views on data security, ownership of health data, equity of access and the potential ethical issues associated with shared and sole access to health information, highlights just how important it is that the views of young people are taken into account on matters that concern them. Data from the workshops enabled successful formulation of the surveys, as well as the interview schedules.

The next chapter presents the findings from the children’s and young people’s survey from phases two and three of the study.

Chapter 5 Children's and Young People's Survey



5

5 Children's and young people's survey (phases two and three)

5.1 Introduction

The findings from the CYP surveys that were conducted during the quantitative aspect of phases two and three of the study are presented in this chapter. The methods are described, followed by statistical analysis and significance of the results comparing the baseline and follow-up surveys. Results will be presented by stating the hypotheses the survey aimed to address, with the corresponding findings from the survey questions. This is followed by a discussion of the findings, with critical analysis of the related research literature, then lastly, a chapter summary.

5.2 Aim

The aim of this research activity was to understand children's and young people's perceptions and experiences of the hospital transitioning to an Electronic patient record (EPR) system and the use of the MyGOSH patient portal for managing aspects of their care.

5.3 Methods

The detailed survey methodology will be presented in this chapter, but this also applies to the subsequent quantitative chapters on the parent and staff survey findings. Only differences in methodology will be presented in those chapters to reduce repetition.

5.3.1 Study setting and design

Great Ormond Street Hospital (GOSH) implemented EPR and MyGOSH patient portal (hereafter MyGOSH) in April 2019, in a one-step Trust-wide implementation (Epic Systems, Verona, WI, USA). A cross sectional survey was used to study CYP experiences and perceptions from the time of implementation of an EPR system (baseline = T_1), and at 16-18 months post-implementation (follow-up = T_2).

5.3.2 Survey development

The survey was developed and piloted following the World Café workshop held with the members of GOSH's Young People's Forum (YPF), as described in the previous chapter (Chapter 4). Questions primarily took the form of rating scales. Satisfaction questions were based on a 10-point scale ('Not satisfied at all' to 'Extremely satisfied'), which was selected for its ease of understanding for participants. Whilst this scale also shows the individuals own assessment of value, when results are collected at scale, trends can be determined from the comparative dataset [133]. Other questions were based on a 4-point Likert scale ('Strongly disagree to 'Strongly agree'), a 4-point behavioural frequency scale ('Never' to 'Frequently'), or multiple answer option. A mid-point (neither disagree nor agree) was not used to minimise response style behaviour which may cause non-random response errors [134]. Although subjective continuum scales for ordinal data are just as they are named – subjective, there is an assumption that in order to make meaningful analyses, responses are sufficiently different to have meaning, for example, 'Strongly agree' is sufficiently different to 'Agree'. Therefore, despite there being a certain degree of unreliability in measurement due to respondents' individual interpretation of the rating scale, responses can still correlate with the underlying meaning or feeling that is being measuring [135]. 'N/A' was included for questions that may not have been applicable to all. This was omitted for questions where it was felt participants would be able to share their views. Participants were also asked their age, and how many teams they were being cared for by at GOSH. Additional demographic questions were added to the follow-up survey to aid our understanding of whether the study sample was representative of the GOSH patient population. These included: ethnicity; which languages were spoken at home; who they lived with; and their sex. No personally identifiable information was collected, meaning that the surveys were anonymous, and no-one could be identified from their responses.

5.3.3 Participant inclusion and exclusion criteria

5.3.3.1 Inclusion

5.3.3.1.1 Baseline (T1)

- Children and young people aged 12 – <25 years old attending an appointment at any of the outpatient departments within the hospital.

An upper age limit was set to ensure all young people's views were captured, given that adult patients of varying ages are cared for at GOSH by some specialist services.

5.3.3.1.2 Follow-up (T2)

- All CYP aged 12 – <25 years old who had signed up to MyGOSH.

5.3.3.2 Exclusion

5.3.3.2.1 Baseline (T_1) and follow-up (T_2)

- Children and young people <12 years of age
- Children and young people who were private patients

Permissions were not granted by the hospital to include this patient population due to the limitations with an English-only system – system functionality only facilitates translation of after-visit summaries into Arabic).

5.3.4 Survey distribution

5.3.4.1 Baseline (T_1)

A pre-identified group of clinical staff distributed paper copies of the surveys, within their outpatient clinical areas for the period of four months immediately following EPR Go-Live. The aim of this approach was to identify families visiting the hospital for the first time since EPR implementation, and to recruit them into the study prior to or as they were being offered MyGOSH sign-up. Children and young people were invited to complete the survey (with parental consent if under 16 years of age). Assent was also sought from the child or young person. Young people aged 16 years or over with the capacity to complete the survey provided their own consent to participate, in accordance with the Mental Capacity Act 2005 [31]. Completed surveys were returned to sealed post boxes in each clinical area. Members of the YPF were also emailed the surveys by the Young People's Participation Officer.

5.3.4.2 Follow-up (T_2)

5.3.4.2.1 Children and young people aged 12 – 15 years of age

Children and young people aged 12 – 15 years of age were sent an invitation to complete the survey via their parent's email (given by the parent at time of signing up to MyGOSH), ensuring parental consent to participate was sought prior to the CYP completing the survey. This was sent from the hospital email system containing the REDCap (Research Electronic Data Capture) survey link. As parents were also invited to complete a survey, the parent survey automatically redirected to the CYP's survey once completed. Parents were also sent separate survey links so that they could forward the CYP survey directly to their child.

5.3.4.2.2 Young people aged ≥16 years and <25 years of age

Young people aged 16 years of age or over (but less than 25) were sent the REDCap link via MyGOSH. This was performed by creating a report within Epic EPR capturing the patients within this age group. A bulk email message containing the REDCap survey link was sent to all patients in this group inviting them to participate. The parent survey link was also sent to the young person's MyGOSH account, because parents who still had access to their son's/daughter's portal (granted by the young person) would have been able to access the parent survey via MyGOSH.

5.3.5 Data collection

Study data were collected using REDCap electronic data capture tools hosted at UCL [136]. REDCap is a secure, web-based application designed to support data capture for research studies, providing: 1) an intuitive interface for validated data entry; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for importing data from external sources [136]. Completion of the survey was taken as consent to participate.

5.3.6 Sample size

The required representative sample (GOSH patient population) comprised 288 responses for each time point. This was calculated prior to the start of the Going Digital study based on the total number of patients predicted to be attending the hospital during the expected data collection period. Sample size was based on an expected number of *n*=2000 CYP aged 12-25 years attending in a 2 week period, assuming 20% (*n*=400) ineligible, 60% of the eligible *n*=1600 will be approached (*n*=960), with a predicted response rate of 30%, resulting in *n*=288 minimum number of anticipated responses [137].

5.3.7 Statistical analysis

Survey data were exported from REDCap into SPSS (IBM SPSS Statistics for Macintosh, Version 27.0). SPSS was used for all analyses and a *p*-value of <0.05 was used to indicate statistical significance. Findings where a statistically significant different was seen will be marked in bold text. Findings from the survey are summarised with medians and inter-quartile ranges for continuous data, and frequencies and percentages for categorical data. Comparisons between baseline and follow-up (which were cross-sectional comparisons because they were different groups of CYP) were undertaken using the chi-square test for trend for nominal data, and the Mann–Whitney U test for ordinal data.

5.3.8 Duplicate data

At T_1, eight respondents did not answer any questions after completing their age: one additional respondent did not answer any questions and a comment was left, “Does not want to fill in”, presumably by the parent. The respondents' ages were included in the report in order to accurately represent those who returned a questionnaire. However, as no further questions were answered, these respondents are not included in any other analyses.

One blank response was submitted with a comment saying, “Sadly, my daughter cannot read this, it needs to be N36, Sorry”. This was from the ophthalmology clinic and relates to the size of the font required to enable readability for that child.

5.3.9 Missing data

The returned survey completeness rate was high (>86%) for all questions. See Appendix 33 for the number of missing responses for each question.

5.4 Results

5.4.1 Demographic characteristics

Respondent demographics for both time-points are presented below in Table 5-1. Most demographic questions were not asked at T_1, but were added as an amendment to the follow-up survey at T_2, to aid with representativeness analysis (Appendix 34).

Table 5-1: Respondent demographics

	T_1	T_2
CYP Age	***n*=288 (%)**	***n*=174 (%)**
12	32 (11.1)	10 (5.7)
13	44 (15.3)	18 (10.3)
14	50 (17.3)	14 (8.1)
15	52 (18.1)	29 (16.7)
16+	102 (35.4)	87 (50.0)
Not known	8 (2.8)	16 (9.2)
CYP Ethnicity		***n*=174 (%)**
White (White/White Irish/other)	N/A	116 (66.7)
Asian (Indian/Pakistani/Bangladeshi/other)	N/A	27 (15.5)
Black (Black/Black British – Caribbean/ African/other)	N/A	2 (1.1)
Mixed	N/A	9 (5.2)
Any other background	N/A	4 (2.3)
Prefer not to say	N/A	Not asked
Not known	N/A	16 (9.2)
CYP Sex		***n*=174 (%)**
Male	N/A	71 (40.8)
Female	N/A	85 (48.9)
Prefer not to say	N/A	1 (0.6)
Not known	N/A	17 (9.7)
Who lives with you at home?		***n*=174 (%)**
Single parent household	N/A	34 (19.5)
Both parents	N/A	119 (68.4)
Legal guardian/guardian/another person with PR*	N/A	6 (3.4)
Sibling(s)	N/A	127 (72.9)
Other family	N/A	9 (5.2)
Other	N/A	5 (2.9)
Number of teams CYP were under	***n*=288 (%)**	***n*=174 (%)**
1	106 (36.8)	70 (40.3)
2	69 (24.0)	47 (27.0)
3	42 (14.6)	20 (11.5)
4	17 (5.9)	7 (4.0)
5+	16 (5.5)	11 (6.3)
Not known	38 (13.2)	19 (10.9)

*PR = parental responsibility

The majority of the respondents were White, lived with both parents and had siblings. There was representation from children of all age groups and under varying numbers of speciality teams.

In addition to the information in Table 5-1, respondents (*n*=174) were asked at T_2 what languages they spoke at home: 88 spoke English only; 28 spoke

English and another language; three participants spoke English and used British sign language; and five respondents spoke one of four other languages as their primary language at home. Fifty respondents did not complete this question.

5.4.1.1 Comparison with the GOSH patient population

To understand whether the study sample was representative of the GOSH patient population, comparisons were drawn with information obtained from the hospital’s Health Information Services Department (Table 5-2). Information pertained to patients visiting the hospital over an 18-month period between April 2019 and September 2020 (time-points span from the timing of the baseline to the follow-up survey). GOSH population: *n*=68,743.

No statistical difference was seen between the proportion of males and females completing the surveys and the GOSH population. There was a significant difference in the distribution of number of teams the children were under. The highest proportion of GOSH patients were under a single speciality. However, the patients who responded to the survey were more complex, with a higher proportion being under two or more teams. The average age of patients at GOSH was eight years old. A comparison between the ages of the GOSH and study populations could not be completed as the study participants were limited to those aged 12 to 25 years of age.

Table 5-2: Sample compared with GOSH population

	T_1	T_2	GOSH population	*P* value
Sex	***n*= (%)**	***n*=174 (%)**	***n*=68,743 (%)**	
Male	N/A	71 (40.8)	36,436 (53.0)	*p*=0.06
Female	N/A	85 (48.9)	32,104 (46.7)	
Prefer not to say/not known	N/A	18 (10.3)	203 (0.3)	
Number of teams CYP cared for by	***n*=288 (%)**	***n*=174 (%)**	***n*=68,743 (%)**	
1	106 (36.8)	70 (40.2)	43,010 (62.6)	***p*<0.001**
2	69 (23.9)	47 (27.0)	13,973 (20.3)	
3	42 (14.6)	20 (11.5)	5741 (8.4)	
4	17 (5.9)	7 (4.0)	2750 (4.0)	
5+	16 (5.6)	11 (6.3)	3252 (4.7)	
Not known	38 (13.2)	19 (11.0)	17 (0.0)*	
Ethnicity	***n*= (%)**	***n*=174 (%)**	***n*=68,743 (%)**	
White (White/White Irish/other)	N/A	116 (66.7)	33,441 (48.6)	***p*<0.001**
Asian (Indian/Pakistani/ Bangladeshi/other)	N/A	27 (15.5)	8613 (12.6)	
Black (Black/Black British – Caribbean/African/other)	N/A	2 (1.1)	4588 (6.7)	
Mixed	N/A	9 (5.2)	2772 (4.0)	
Any other background	N/A	4 (2.3)	4420 (6.4)	
Prefer not to say	N/A	Not asked	1775 (2.6)	
Not known	N/A	16 (9.2)	13,134 (19.1)	

*17 members of the GOSH population = 0.02% (rounded to 0)

5.4.2 Response rate

5.4.2.1 Baseline

Baseline survey collection data are presented in Table 5-3:

Table 5-3: Baseline survey distribution and response rate

	Packs Made	**Remaining**	**Distributed**	**Responses *n*=**	**Response rate %**
Parents/CYP aged 12 –15 years of age*	800	335	465*	188	40.4%*
YP ≥16 years of age but <25 years	249	97	152*	96	63.1%*
YPF Members (all ≥16 years of age but <25 years)	N/A	N/A	28	6	21.4%

*Due to needing parental consent for this age group, CYP surveys were contained in packs with parent information

**Three clinical areas disposed of or cleared away surveys/collection boxes during the study period, hindering accurate response rate calculation. Difficulties are described further in 'Limitations of this research' in Chapter 10.

5.4.2.2 Follow-up

Follow-up survey collection data are presented in Table 5-4:

Table 5-4: Follow-up survey distribution and response rate

	Number of eligible patients ***n=***	**No email registered** ***n=***	**Undeliverable** ***n=***	**Final number sent** ***n=***	**Number of Responses** ***n=***	**Response rate %**
Parents of CYP 12 – 15 years of age*	4482	562 (12.5%)	119	3801**	71	1.9%
YP ≥16 years of age but <25	909	N/A***	N/A***	909	87	9.7%
Number of surveys with participant age not completed	-	-	-	-	16	-

*Due to needing parental consent for this age group, CYP surveys were contained in packs with parent information

**Invitation email sent to all parents with children within this age group who were registered to access MyGOSH. Unable to determine whether the child had the physical or mental capability to either access MyGOSH or complete the survey.

***Unable to determine whether there was an email registered or messages not delivered if sent via MyGOSH without manually checking all patients (which was not deemed practicable).

5.4.3 Survey findings

5.4.3.1 Children’s and young people’s satisfaction

Hypothesis 1: Children’s and young people’s overall satisfaction with current aspects of their care will increase from baseline (T_1) to follow-up (T_2) following experience of EPR and use of MyGOSH patient portal.

Children and young people were asked a series of questions about their satisfaction with different aspects of their care, ranking their answer on a scale of 1-10, with 1 being the lowest (not at all satisfied) and 10 being the highest (extremely satisfied). Responses are presented in Table 5-5:

Table 5-5: Satisfaction with aspects of care

	T_1		T_2		
Survey statement	***n*=**	**Median (IQR*)**	***n*=**	**Median (IQR*)**	***P* value****
Coordination of appointments	*n*=267	8 (6-10)	*n*=152	9 (7-10)	**$p=0.01$**
Convenience of appointments	*n*=271	8 (6-9)	*n*=154	8 (7-10)	**$p<0.001$**
Ease of speaking to care team member	*n*=261	8 (6-10)	*n*=152	8 (7-10)	$p=0.28$
Overall communication from care team	*n*=262	8 (7-10)	*n*=154	9 (7-10)	$p=0.25$
Ease of getting questions answered	*n*=256	8 (7-10)	*n*=151	9 (7-10)	**$p=0.05$**
Time to receiving test results	*n*=247	8 (6-9)	*n*=150	8 (6-10)	**$p<0.01$**
Mode of receiving test results	*n*=243	8 (6-9)	*n*=150	8 (7-10)	**$p=0.07$**
Involvement in decisions about care	*n*=261	8 (7-10)	*n*=153	8 (7-10)	$p=0.12$
Informed about care	*n*=259	9 (7-10)	*n*=155	9 (7-10)	$p=0.17$

*IQR = Interquartile range

**Significance testing was performed using two-tailed Mann-Whitney U non-parametric test

Baseline patient satisfaction with different aspects of care prior to EPR and MyGOSH implementation was high, with median scores of eight for all but one question, and a median score of nine for the remaining question. T_2 data demonstrated a statistically significant difference from T_1 data relation to five out of nine aspects of care: the coordination and convenience of appointments, ease of getting questions answered, and the time to and mode of receiving test results via MyGOSH, indicating improvements in these areas following MyGOSH implementation. The results did not indicate improved satisfaction in relation to with the care team or being informed about, or involved in decisions about, their care. Therefore, the hypothesis was partially supported. These findings are represented in box plot form in Figure 5-1 below

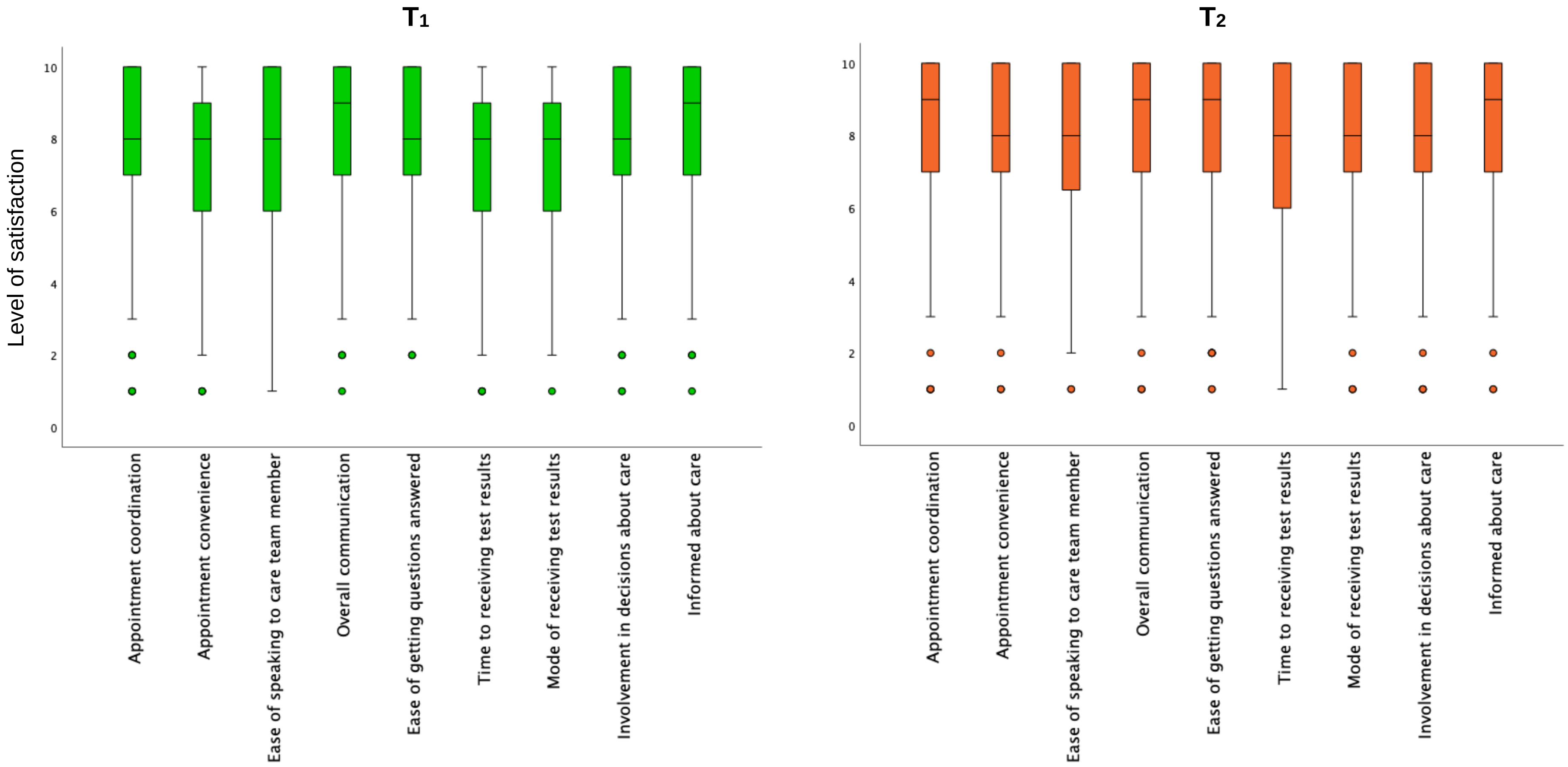


Figure 5-1: Satisfaction with care at T_1 and T_2 [vi]

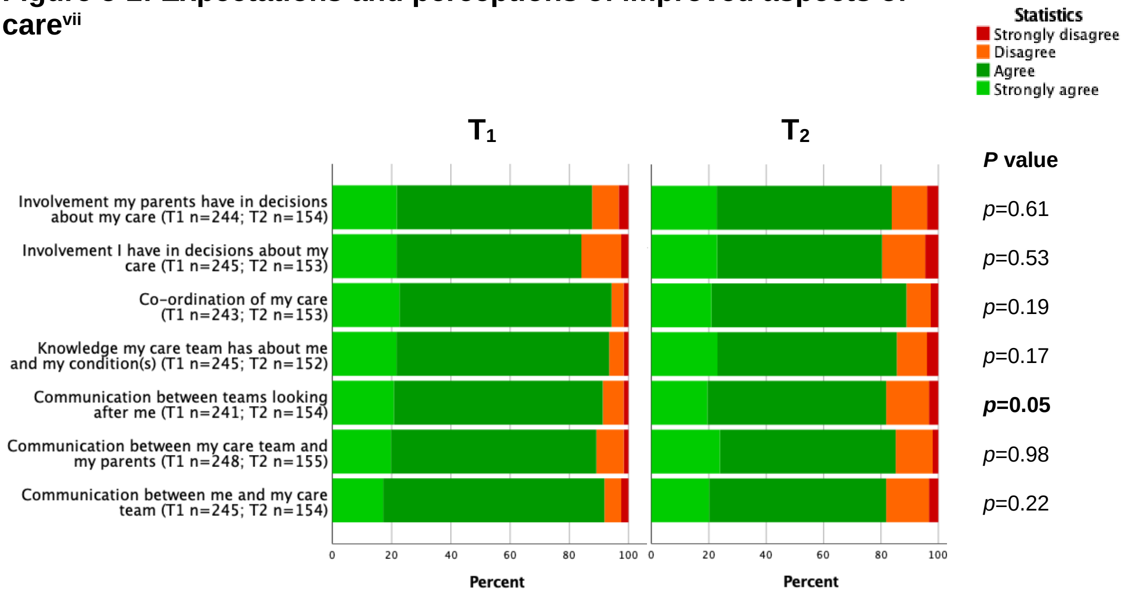
[vi] Box plot representation of these data show the upper and lower quartiles (the rectangle), with the median demonstrated as the horizontal line. Variability outside these quartiles is represented by the vertical lines (whiskers) either side of the rectangle, with outliers plotted as individual points.

5.4.3.2 Children's and young people's expectations prior to MyGOSH implementation and perceptions post-implementation

Hypothesis 2: At T_2, CYP will perceive that MyGOSH has facilitated improved aspects of care.

Expectations were sought from CYP about improved aspects of care prior to MyGOSH implementation (T_1) and their perceptions post-implementation (T_2; Figure 5-2):

Figure 5-2: Expectations and perceptions of improved aspects of care[vii]



At T_2, there was a significant trend for a lower proportion of CYP to perceive that MyGOSH enabled improved aspects of care related to communication between teams looking after them, compared with those who responded at T_1.

[vii] Please note that the colour coding used in the stacked bar charts reflects what is considered a positive or negative response for the question e.g. green represents a positive response; red represents a negative response. At times, this may mean that disagreement is a positive thing, and would be reflected in green, or that agreement is a negative, and reflected in red. It is acknowledged that people who are colour blind may find the chosen colours difficult to interpret but the aim is to present the results in a manner which conveys the voice of young people and their experience of transition to EPR and MyGOSH.

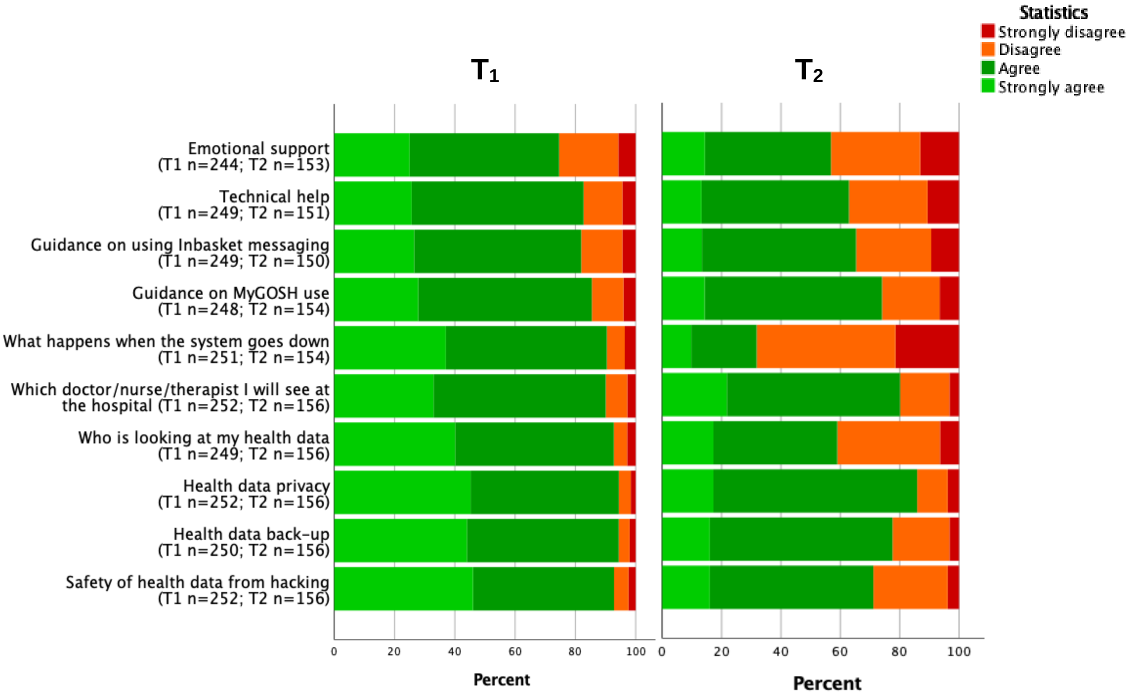
Overall responses at baseline in each domain were positive, indicating high levels of expectation of MyGOSH improving aspects of care. However, no improvements were seen at T_2. This hypothesis was not supported.

5.4.3.3 Children's and young people's information and support needs

Hypothesis 3: Children's and young people's information and support needs will be met by the hospital after EPR/MyGOSH implementation.

Pre-implementation, we were interested in what children and young people wanted to know about what would be available to them in terms of information and support post implementation. At T_2 we then asked children and young people whether they had received the information and support they needed (Figure 5-3).

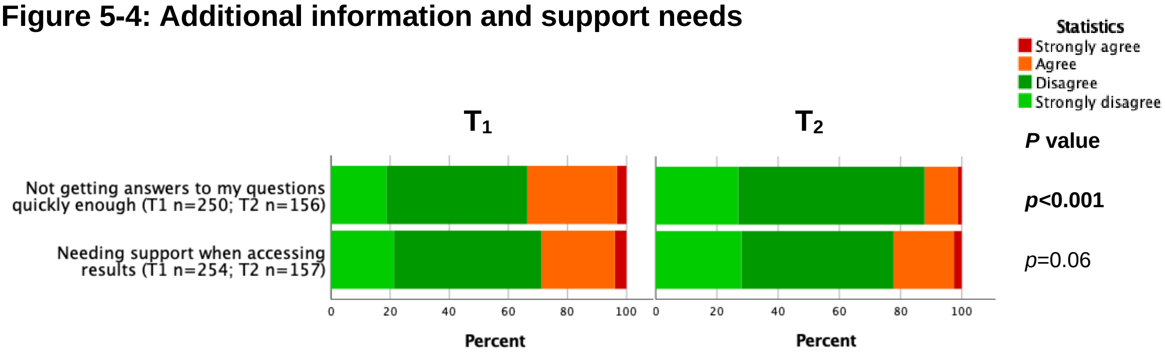
Figure 5-3: Information and support needs



At T_1, CYP reported a high level of agreement that they wanted to know that they would get the information/support that they would need, particularly related to data security and privacy. At T_2 between 32-86% agreed that they got the information/support they needed, with lower rates reported in relation to knowing what happens when the system goes down (31.8%), emotional support (56.9%), who is looking at their health data (59%), and guidance and information pertaining to data safety. These finding indicate CYP had a level of unmet need, and the hypothesis was not supported.

Respondents were also asked whether they worried about getting answers to their questions quickly enough and whether they would need support when accessing their results (T_1) and whether this happened after implementation (T_2; Figure 5-4).

Figure 5-4: Additional information and support needs



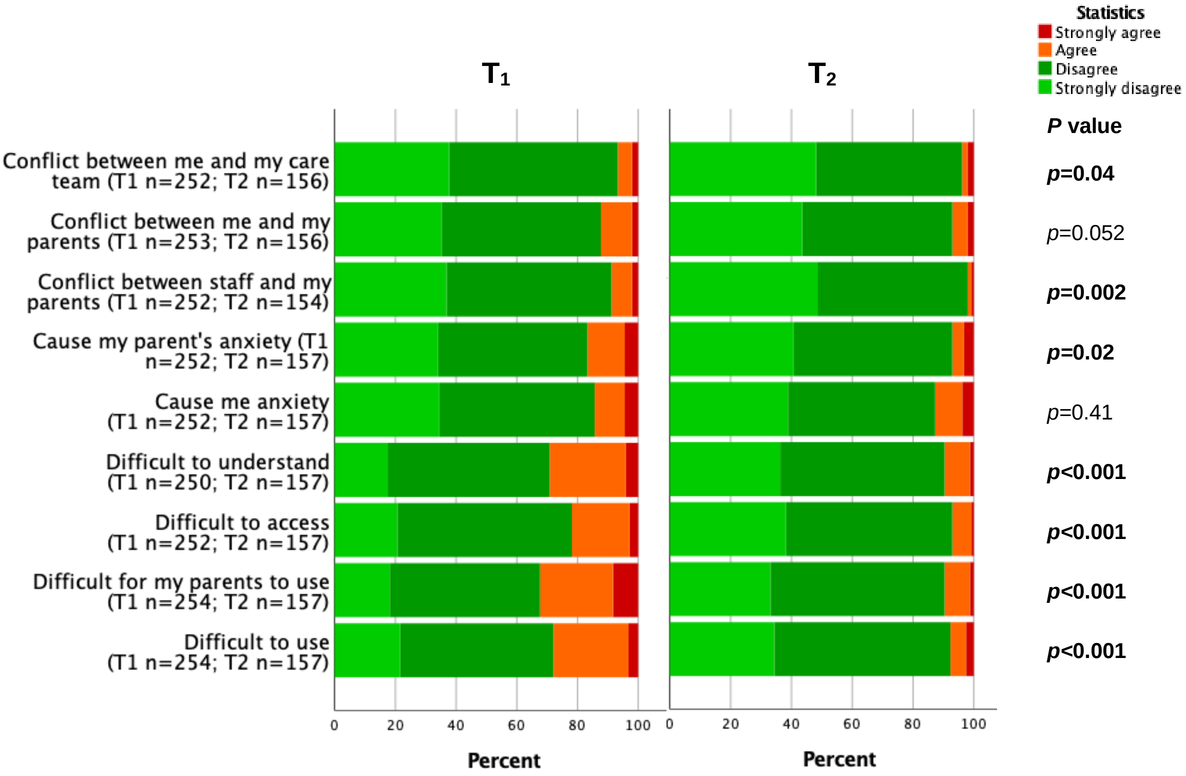
At T_2, there was a significant trend for a lower proportion of respondents to report that they did not get answers quickly enough, compared with those who responded at T_1, for example, at T_1 33% of respondents thought they would not get answers quickly enough but at T_2, only 12% agreed/strongly agreed that they had not had answers quickly enough. Over a fifth of respondents at T_2 reported needing support when accessing results via MyGOSH.

5.4.3.4 Children and young people will have worries about using an electronic health system/patient portal

Hypothesis 4: Children and young people will have fewer worries at T_2 compared with T_1 in relation to: difficulty in using, accessing, and understanding MyGOSH; constantly being reminded of their condition; reading something they did not understand or did not want to read.

Children and young people were asked if they worried MyGOSH would be difficult for them or their parents to use, difficult to access or understand, or cause any conflict (T_1), and whether any of these were experienced with MyGOSH use (T_2; Figure 5-5):

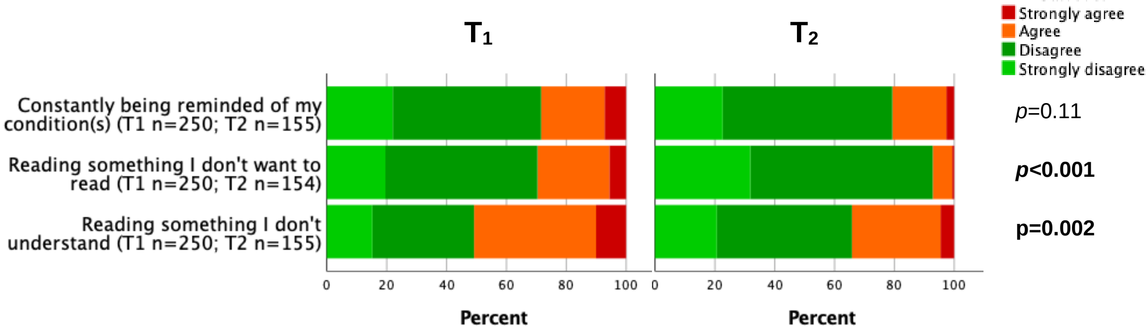
Figure 5-5: Worries about using MyGOSH



At T_2, there was a significant trend for a lower proportion of respondents to report worries in relation to MyGOSH causing a) conflict between them their care team, b) conflict between staff and their parents, and c) parental anxiety and for MyGOSH to be a) difficult to use, b) access and c) understand, compared with those who completed the survey at T_1. This means that concerns pre-implementation were worse than the reality of using MyGOSH. There was no significant trend from T_1 to T_2 in relation to CYP's own anxiety levels. The hypothesis is partially supported.

Questions addressing additional worries raised in the workshops in relation to being constantly reminded of their condition, and reading something they don't want to or don't understand, were included in the survey (Figure 5-6).

Figure 5-6: Additional worries



T_2 data demonstrated a significant trend for a lower proportion of respondents to experience worries about both reading something they do not want to read and reading something they do not understand compared with those who responded at T_1. Despite this, it should be noted that just over a third of CYP reported reading something they did not understand at T_2. Furthermore, although no trend was seen, between one fifth and one quarter of CYP worried about being constantly reminded of their condition(s) at both time-points.

5.4.3.5 Children's and young people's views on age limits for accessing MyGOSH, and whether they feel well informed about MyGOSH

Hypothesis 5: The majority of CYP will:

- Think that the lower age limit of 12 years old for accessing MyGOSH (with their parents' consent) is acceptable
- Give their parents permission to access MyGOSH when they turn 16 years of age
- Feel more informed about MyGOSH at T_2

Children and young people were asked their views on the age limit for accessing MyGOSH, whether they would grant their parents access when they turned 16, and how informed they felt (Table 5-6):

Table 5-6: CYP's views – age limits/feeling informed about MyGOSH

		T_1	T_2	***P* value**
Survey statement		***n*=248 (%)**	***n*=153 (%)**	
Do you think the lower age limit of 12 years old for being able to access MyGOSH (with your parent's consent) is acceptable?	**Yes**	185 (74.6)	130 (85.0)	***p*=0.01**
	No	63 (25.4)	23 (15.0)	
Survey statement		***n*=247 (%)**	***n*=158 (%)**	
When you turn 16 will you give permission for your parents to access MyGOSH?	**Yes**	197 (79.8)	135 (85.4)	*p*=0.054
	No	8 (3.2)	9 (5.7)	
	Not sure	42 (14.9)	14 (8.9)	
Survey statement		***n*=246 (%)**	***n*=157 (%)**	
I feel well informed about MyGOSH	**Very**	80 (32.5)	74 (47.1)	***p*=0.001**
	Somewhat	136 (55.3)	74 (47.1)	
	Not at all	30 (12.2)	9 (5.7)	

At T_2, there was a significant trend for a higher proportion of CYP to report that 12 years of age was acceptable for being able to access MyGOSH with parental consent, compared with those who responded at T_1. Although no trend was seen, a large and similar proportion of CYP at both T_1 and T_2 reported they would give their parents permission to access MyGOSH when they turned 16 years of age.

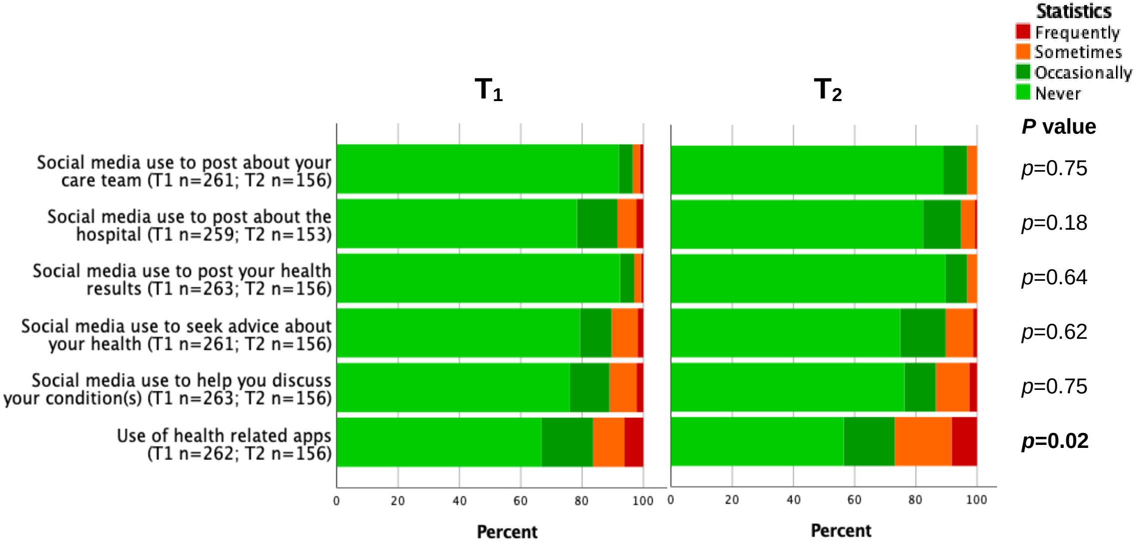
T_2 demonstrated a significant trend for a higher proportion of respondents to feel well informed about the EPR system compared with respondents at T_1. These findings support the hypothesis.

5.4.3.6 Children's and young people's perceptions of their app and social media use

Hypothesis 6: The proportion of CYP using social media to discuss or seek advice from others about their condition, and to utilise health related apps, will increase with the use of MyGOSH.

Respondents were asked about their social media and health related app use (Figure 5-7):

Figure 5-7: Social media/health app use



Health-related social media use was low at both T_1 and T_2, with the largest proportion of responses to each question being 'never'. There was a significant trend for a higher proportion of respondents at T_2 to report the use of health-related apps compared with those who completed the survey at T_1. This hypothesis was only partially supported.

5.4.3.7 Potential barriers to CYP accessing MyGOSH

We were also interested in understanding potential perceived barriers to CYP accessing MyGOSH.

Children and young people were asked whether a range of issues posed a barrier for them being able to access MyGOSH (Table 5-7):

Table 5-7: Barriers to accessing MyGOSH

Survey Statement	**T_1** ***n*= (%)**	**T_2** ***n*= (%)**
English is not your first language	13 (4.6)	5 (2.9)
English is not your parent's first language	17 (6.0)	10 (5.7)
You are not confident using a computer/electronic device	16 (5.7)	6 (3.4)
You have a learning disability	14 (5.0)	24 (13.8)
Your parent has a learning disability	0 (0)	4 (2.3)
You have a sensory impairment (sight/hearing)	18 (6.4)	6 (3.4)
Your parent has a sensory impairment (sight/hearing)	1 (0.4)	0 (0)
You have a physical impairment	8 (2.8)	8 (4.6)
Your parent has a physical impairment	0 (0)	2 (1.1)
You may be too ill to use MyGOSH	8 (2.8)	9 (5.2)
Your parent may be too ill to use MyGOSH	1 (0.4)	4 (2.3)

The number of participants completing this question was relatively small as participants were only required to complete this if it applied to them. Fewer respondents at T_2 were those for whom English was not their first language or were not confident in using a computer/electronic device. It is also noted that there were also more CYP with a learning disability completing the survey at T_2. The data were examined to determine if the same individuals were experiencing numerous potential barriers. Responses were distributed throughout the participants, except from one participant at T_1 who checked seven out of the 11 possible responses, highlighting the extent of complexity of the sample.

5.5 Discussion

Children's and young people's views and perceptions from before (*n*=288) and after (*n*=174) EPR and MyGOSH implementation were sought and analysed. The survey respondents were representative of the GOSH patient population in terms of gender, but statistically significant differences were seen in the distribution of number of teams the children were under and ethnicity. Whilst the highest proportion of GOSH patients were under a single speciality, a higher proportion of survey respondents were under two or more teams, indicating that the survey captured the views of patients with more complex conditions. Furthermore, the GOSH population contained a lower proportion of patients who described themselves as 'White', however, 19% of the GOSH population were recorded as 'Not known', making a full comparison impossible.

5.5.1 How the key findings relate to the hypotheses and literature

Each of the hypotheses, the key findings and whether each hypothesis was supported are summarised below in Table 5-8, followed by a discussion with reference to pertinent research literature.

Change within healthcare is a frequent occurrence, therefore meaningful evaluation of patient-reported satisfaction is important to determine implementation success, and to identify any related gaps in care provision [138]. We wanted to assess overall levels of satisfaction with aspects of care comparing how services were provided before and after EPR/MyGOSH implementation, hypothesising that satisfaction would be higher post-implementation. Although baseline satisfaction was high, statistically significant increases were seen at T_2 related to coordination and convenience of appointments, and the amount of time patients waited before receiving results. The benefits of managing appointments via a patient portal have been previously described [87]. Our findings concur with evidence that patient portals facilitate quicker access to test results [139].

Table 5-8: Hypotheses, key findings and whether each hypothesis was supported

<table>
<tr><td colspan="2">Hypothesis 1: CYP’s overall satisfaction with current aspects of care will increase from baseline (T_1) to follow-up (T_2) following experience of EPR/use of MyGOSH patient portal</td></tr>
<tr><td>• Baseline satisfaction was high
• Statistically significant improvements seen at T_2 only related to coordination/convenience of appointments, ease of speaking to a team member, and the time to/mode of receiving test results via MyGOSH</td><td>Hypothesis partially supported</td></tr>
<tr><td colspan="2">Hypothesis 2: At T_2, CYP will perceive that MyGOSH has facilitated improved aspects of care</td></tr>
<tr><td>• Baseline responses were positive
• No differences seen at T_2, except for deterioration in responses in relation to communication between teams looking after the CYP.</td><td>Hypothesis not supported</td></tr>
<tr><td colspan="2">Hypothesis 3: CYP’s information and support needs will be met by the hospital after EPR/MyGOSH implementation</td></tr>
<tr><td>• CYP had a level of unmet information/support needs following EPR and MyGOSH implementation
• At T_2, just over 1/3 CYP read something they did not understand on MyGOSH</td><td>Hypothesis not supported</td></tr>
<tr><td colspan="2">Hypothesis 4: CYP will have fewer worries at T_2 compared with T_1 in relation to: difficulty in using, accessing/understanding MyGOSH; constantly being reminded of their condition; reading something they did not understand/did not want to read</td></tr>
<tr><td>• CYP worried more about MyGOSH prior to using it, with anticipation worse than reality
• No difference seen relating to worries about MyGOSH causing conflict between them and their parents and MyGOSH causing them anxiety</td><td>Hypothesis partially supported</td></tr>
<tr><td colspan="2">Hypothesis 5: The majority of CYP will:
• Think that access to MyGOSH at 12 years old is acceptable
• Give their parents permission to access MyGOSH when they turn 16 years of age
• Feel more informed about MyGOSH at T_2</td></tr>
<tr><td>• CYP agreement high at both time-points
• Overall acceptability of age for accessing MyGOSH and allowing parents access to MyGOSH when they turned 16, and how well informed they felt about MyGOSH.</td><td>Hypothesis supported</td></tr>
<tr><td colspan="2">Hypothesis 6: The proportion of CYP using social media to discuss or seek advice from others about their condition, and to utilise health related apps, will increase with the use of MyGOSH.</td></tr>
<tr><td>• CYP reported low social media use related to seeking advice/support/ posting health related information online at T_1/T_2
• CYP reported increased health related app use at T_2</td><td>Hypothesis partially supported</td></tr>
</table>

Electronic patient records and patient portals have promised improved aspects of care, including improved and effective communication [82, 83, 87, 93, 97], which is pivotal to the success of care provision via virtual methods [70, 97]. In view of this we asked CYP about their expectations of the improvements to aspects of care MyGOSH would bring and whether these were realised. We hypothesised that CYP will expect that MyGOSH will improve involvement of them and their parents in decisions about their care; care coordination; knowledge the care team has about them; and communication between all those involved in their care. However, despite baseline responses being positive, statistically significant changes were seen at T_2 demonstrated a deterioration in the responses related to communication between teams looking after CYP. This suggests that expectations were not met and that there is work to do in improving communication via the portal. Evidence suggests that clinician engagement may have been impacted during the transition phase by trying to understand new EPR-related terminology [68], navigating the complex system [68, 89] and learning EPR functionality [74], which are all factors that can detract from patient care [68]. Furthermore, system design must incorporate the communication preferences of CYP and their parents for it to be successful [96], assessment of which is outside the remit of this study.

Leading on from the points above, it has been identified in the literature that ongoing support is required for all stakeholders whilst adapting to transitioning to EPR with a patient portal, and the resultant changes in practice [71, 79, 86]. In a study by Hong et al. [96], CYP expressed more confidence in managing their health when using MyCHART,[viii] using it to seek information such as laboratory results, messaging, and appointments. However, there is evidence that CYP's information and support needs were not fully met in relation to using MyGOSH. At T_2, just over a third of CYP read something they did not understand, indicating we need to do more to help CYP comprehend the information released onto MyGOSH, and supporting them to throughout this process. However, findings also show that CYP worried more about the impact of MyGOSH before they had used it than when they had actually been using it.

[viii] MyGOSH is MyChart, renamed for GOSH.

This indicates that CYP are not adequately prepared for MyGOSH use. Setting the expectations and ensuring CYP are prepared for and supported during MyGOSH use is crucial to long-term engagement and portal utilisation, albeit having financial and time implications for the hospital [97]. It is important to remain mindful of the minority who would not allow parents access, or who are unsure about that. Support is required to help them to make that decision or communicate that with their parents, who may find the prospect of being denied access difficult [34].

The General Medical Council advocates that CYP should be given access to their health records, as long as access to such information does not cause them serious harm [140]. Furthermore, from the age of 16 years, young people with capacity, assumed under the Mental Capacity Act 2005 [31], have the *legal right* to access their own health records, and can also grant or deny access by others, including their parents [140]. Great Ormond Street Hospital has embraced this by allowing CYP from 12 years of age to access MyGOSH patient portal, with their parents' consent. Our findings report overall acceptability of the age for accessing MyGOSH by CYP, and that a large proportion of respondents at both time-points reported they would give their parents permission to access MyGOSH when they turned 16 years of age. The intention of most respondents' (but not all) to continue to allow their parents to access MyGOSH, even after the age that they could have sole access, may reflect the complex needs of our patient population and the important role of parents in helping young people manage their health conditions. MyGOSH access can play an important role in empowering CYP to assume responsibility for their healthcare in a safe and supported way, and be an important mechanism for helping CYP during transition from children's health services into adult services, as they approach adulthood [96]. Transition is defined as the "purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents/young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems" (p. 570) [141]. The literature on transition suggests that this process should commence within the second decade of life [142], with the maximum age to transfer into adult services identified as 25 years [143].

There is debate in the literature about how best to promote confidentiality and privacy for the young person, especially related to communication between them and the care team [34, 144, 145]. This includes in consultations and via patient portals. Wilcox et al. (2018) describe teenagers as being characterised by both ‘increases in autonomy—developmentally, socially and legally—and potentially sensitive health needs’ (p1084) [144]. Evidence suggests that CYP are reluctant to seek medical advice or treatment on sensitive topics such as sexual health, contraception, alcohol and drugs or other issues if their parents are privy to such information, and are more likely to engage in risky or unsafe behaviour as a result [144-147].

It is reported in the literature that increasingly, young people are using social media for health-related information [148]. Furthermore, it is well documented that young people with long-term medical conditions seek advice or support about their condition(s) via social media or use social media to share their experiences with others who have the same condition(s) [149-151]. Concerns were raised during the World Café Workshops that increased ease of access to health information via the portal would lead to an increase in CYP sharing their health data via social media. However, despite patients being likely to have long-terms conditions (due to the nature of needing to be treated at GOSH), survey participants reported low social media use related to seeking advice, support or posting health related information online at both T_1 and T_2. Although it can only be reported that CYP did not *say* they used social media for the above reasons, the baseline and follow-up data were from two independent groups with results showing similar trends. Our findings concur with the results of a study by Van der Velden and El Emam (2013) who found that most teenagers do not disclose their health information on social media [152]. Despite teenagers being pervasive users of social media sites such as Facebook, this was seen as a place to be a ‘regular’ teenager, to keep up-to-date with their social life, rather than someone who is ill [152]. Related to health app usage, thousands of health apps for smartphones are currently commercially available, designed to support health management [153]. Our findings reported increased health app usage at T_2, which could be explained by MyGOSH use post-implementation. However, we do not know which health apps CYP were using.

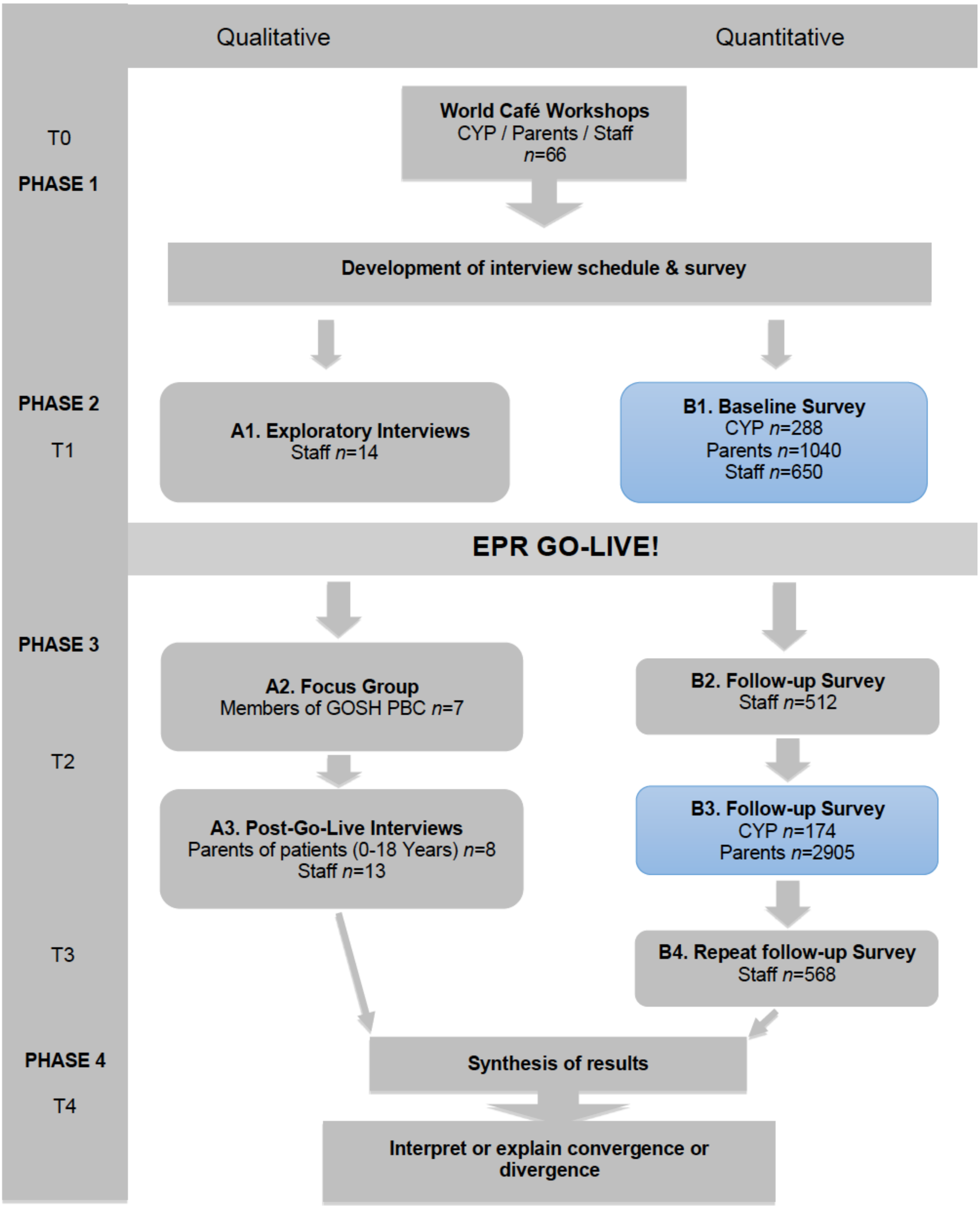
The digital health divide related to patient access to health portals is well documented, [154-159] which has been widened further during the pandemic [160-162]. Digital health platforms have not been adjusted to facilitate access for those who do not have English as a first language, or those with a physical, intellectual, or sensory disability. This is demonstrated in the study findings, supporting the notion that some CYP will experience barriers to accessing and using MyGOSH, with implications relating to equity of access to care. Despite a quarter of the T_2 respondents being from ethnic minority groups this study's findings demonstrate that a greater proportion of English-speaking families are accessing MyGOSH than non-English speakers.

5.6 Summary

Children and young people were positive about accessing and using MyGOSH from 12 years of age, and also about the continued inclusion of their parents from the age of 16 years. However, CYP require ongoing support and information when transitioning to an EPR system with a patient portal. More worries were evident prior to using the portal than after they had been using it for almost 18 months. Our findings suggest that CYP at GOSH do not share their health information on social media. There are concerns about inclusion of CYP in research and enabling CYP to have their say. Further work is required on strategies to promote inclusion in research, and to improve communication via the portal. There is work to do to promote equal access to digital health services and the inclusion of those who may have difficulty accessing patient portals and, thus, reducing the digital divide. Ongoing support of staff members during transition to EPR and patient portal use is required to enable them to support families in accessing and benefitting from using MyGOSH, with the need for research to be embedded into practice [163].

The next chapter will present the findings from the parent surveys. The aim of this is to understand parent perceptions and experiences of the hospital transitioning to an EPR system and the use of MyGOSH patient portal for managing aspects of their child’s care.

Chapter 6 Parent Survey



6

6 Parent survey (phases two and three)

6.1 Introduction

The findings from the parent surveys conducted during the quantitative aspect of phases two and three of the study will be presented in this chapter. In the same manner as the preceding chapter, the methods, data collection, analysis, and hypotheses linked to the results are described. The discussion and critical analysis of the related research literature will follow, then lastly, a chapter summary.

6.2 Aim

This research activity sought to understand parent perceptions and experiences of the hospital transitioning to an EPR system and the use of MyGOSH patient portal for managing aspects of their child's care.

6.3 Methods

6.3.1 Study setting and design

A cross sectional survey was utilised to study parent experiences and perceptions from the time of EPR implementation (baseline = T_1), and at 16-18 months post-transition (follow-up = T_2) in the same study setting as described in the preceding chapter.

6.3.2 Survey development

The parent survey was also developed and piloted following a workshop held with parents who had expressed an interest in EPR development since its inception, as described in Chapter 4. Questions covered the same themes as presented in the preceding chapter, but the focus was on the parents' perspective and their views on their child's needs related to using the new system. Response categories were the same as those used in the children's and young people's (CYP's) survey, with a combination of satisfaction scales and Likert scales. Parents were also asked the age of their child (if they had more than one child who were patients at GOSH, they were asked to answer for the oldest child), and how many teams cared for their child at GOSH. Additional demographic elements were also added to the follow-up survey to aid our understanding of whether the study sample was representative of the GOSH patient population. No personally identifiable information was collected, meaning that the surveys were anonymous, and no-one could be identified from their responses, unless they volunteered their email address if they were interested in participating in other aspects of the study.

6.3.3 Participant inclusion and exclusion criteria

6.3.3.1 Inclusion

6.3.3.1.1 Baseline (T_1)

- Parents accompanying their children, who were patients at GOSH, attending an appointment at any of the outpatient departments within the hospital.

6.3.3.1.2 Follow-up (T_2)

- All parents of children who were patients at GOSH and who had signed up to MyGOSH.

6.3.3.2 Exclusion

6.3.3.2.1 Baseline (T_1) and follow-up (T_2)

- Parents of children who were private patients.

6.3.4 Survey distribution

6.3.4.1 Baseline (T_1)

Upon the families' arrival to the outpatient area, parents were invited to complete a paper copy of the survey by clinical staff within the hospital's outpatient clinical areas. This was done whilst they were offered MyGOSH sign-up. Completed surveys were returned to sealed post boxes in each clinical area and collected by the researcher. Parents of members of the YPF were also emailed the surveys by the Young People's Participation Officer.

6.3.4.2 Follow-up (T_2)

6.3.4.2.1 Parents of CYP aged 12 – 15 years old

Parents were sent an invitation to complete the survey to the email address that was given at the time of signing up to MyGOSH. This was sent from the hospital email system containing the REDCap survey link.

6.3.4.2.2 Parents of CYP aged <12 years, or ≥16 years but <25 years of age

Parents of CYP <12 years of age were sent the REDCap link via MyGOSH. This was performed by creating a report within Epic EPR capturing the patients within this age group, and a bulk email invitation containing the survey link was sent to all patients' MyGOSH account in this group. If parents of young people aged 16 years or above but under 25 years of age had access to their son's/daughter's MyGOSH account, they would have been able to access the parent survey via their son's/daughter's account.

6.3.5 Data collection

Parent survey data were collected using REDCap electronic data capture tools hosted at UCL [136]. Completion of the survey was taken as consent to participate.

6.3.6 Sample size

The required representative sample (parents of GOSH patient population) comprised 1008 parent respondents. This was calculated in the same manner as the CYP's survey based on the total number of parents predicted to be attending the hospital with their children during the expected data collection period. Sample size was based on a predicted number of *n*=7000 parents of CYP 0-18 years attending in a two week period (in- and out-patient), assuming 20% (*n*=1400) would be ineligible, 60% of the eligible (*n*=5600) would be approached (*n*=3360), with a predicted response rate of 30%, resulting in *n*=1008 minimum number of anticipated responses [137].

6.3.7 Statistical analysis

The same process of data analysis described in the previous chapter for CYP survey data was utilised for the parent data, with survey data exported from REDCap into SPSS (IBM SPSS Statistics for Macintosh, Version 27.0), and findings summarised with medians and inter-quartile ranges for continuous data, and frequencies and percentages for categorical data. Pre/post differences in parents' perceptions were compared using the chi-square test for trend for nominal data and the Mann–Whitney U test for ordinal data to assess for differences between the two groups of respondents. A *p*-value of <0.05 was used to indicate statistical significance.

6.3.8 Duplicate data

At T_2, 11 responses were removed as they were noted to be identical duplicates from the same parents (initially *n*=2916 responses, leaving *n*=2905 valid responses).

6.3.9 Missing data and not applicable responses

The returned survey completeness rate was high (>88%) for the majority of questions, except for those related to parents’ views about their child accessing MyGOSH at 12 years of age, feeling well informed about MyGOSH, and how happy they were with their children accessing/using MyGOSH or social media. For these questions, completeness rate was (>77%). The number of missing responses for each question, and the number of questions which were answered N/A (due to all parents being invited to participate, even if their child was <12 years of age) can be found in Appendix 35.

6.4 Results

6.4.1 Demographic characteristics

Respondent demographics for both time-points are presented below (Table 6-1).

Table 6-1: Respondent demographics

	T_1	T_2
No of children the parent has who are GOSH patients	***n*=1040 (%)**	***n*=2905 (%)**
1	919 (88.4)	2633 (90.6)
2	83 (8.0)	214 (7.4)
3	13 (1.2)	26 (0.9)
4+	5 (0.5)	6 (0.2)
Not known	20 (1.9)	26 (0.9)
Age of child (if more than one – age of the eldest)	***n*=1040 (%)**	***n*=2905 (%)**
<12	732 (70.4)	2301 (79.2)
12	65 (6.2)	129 (4.4)
13	58 (5.6)	127 (4.4)
14	72 (6.9)	116 (4.0)
15	61 (5.9)	115 (4.0)
16+	41 (3.9)	100 (3.4)
Not known	11 (1.1)	17 (0.6)
Parent ethnicity		***n*=2905 (%)**
White (White/White Irish/other)	N/A	2242 (77.2)
Asian (Indian/Pakistani/Bangladeshi/other)	N/A	296 (10.2)
Black (Black/Black British – Caribbean/ African/other)	N/A	124 (4.3)
Mixed	N/A	78 (2.7)
Any other background	N/A	86 (2.9)
Prefer not to say	N/A	N/A
Not known	N/A	79 (2.7)
Who completed the survey?		***n*=2905 (%)**
Mother	N/A	2471 (85.1)
Father	N/A	336 (11.6)
Legal guardian/guardian/another person with PR*	N/A	30 (1.0)
Other	N/A	6 (0.2)
Not known	N/A	62 (2.1)
Age of person completing survey		***n*=2905 (%)**
<20	N/A	9 (0.3)
20-29	N/A	183 (6.3)
30-39	N/A	1076 (37.0)
40-49	N/A	1276 (43.9)
50	N/A	296 (10.2)
Not known	N/A	65 (2.2)
Who lives with the child at home		***n*=2905 (%)**
Both parents	N/A	2223 (76.5)
Single parent household	N/A	541 (18.6)
Legal guardian/guardian/another person with PR*	N/A	72 (2.5)
Sibling(s)	N/A	2087 (71.8)
Other family	N/A	164 (5.6)
Other	N/A	49 (1.7)
Number of teams child was under	***n*=1040 (%)**	***n*=2905 (%)**
1	461 (44.3)	1355 (46.6)
2	267 (25.7)	802 (27.6)
3	128 (12.3)	350 (12.0)
4	53 (5.1)	154 (5.3)
5+	87 (8.4)	213 (7.4)
Not known	44 (4.2)	31 (1.1)

*PR = parental responsibility

The majority of respondents (T_1=88.4% and T_2=90.6%) had one child who received care from GOSH, and the majority of respondents (T_1=70.4% and T_2=79.2%) had a child less than 12 years of age receiving care from GOSH. Over three-quarters of respondents at T_2 described themselves as white (77.2%), and 26.6% described themselves as non-white, giving representation from multiple mixed and ethnic minority backgrounds. Mothers comprised 85% of those completing the survey at T_2, fathers comprised 11.6% and 1% of the surveys were completed by the legal guardian. Follow-up data shows responses from all age groups of parents, with the highest proportions of respondents being in the 30-39 and 40-49 age groups. The majority of children lived with both parents and had siblings. There was representation from parents of children under all listed numbers of teams.

Additional to the information in Table 6-1, respondents (*n*=2905) were asked at T_2 what languages they spoke at home: 1002 spoke English only; 370 spoke English and at least one other language; 10 participants spoke English and used British sign language; 8 spoke English and used Makaton; and 109 respondents spoke one of 36 other languages as their primary language at home. The question was not completed by 1406 respondents.

6.4.1.1 Comparison with the GOSH patient population

To understand whether the study sample was representative of the GOSH patient population a comparison was made with information obtained from the hospital’s Health Information Services Department on patient attendees to GOSH (Table 6-2). Information pertained to patients visiting the hospital over an 18-month period between April 2019 and September 2020 (time-points span from the timing of the baseline to the follow-up survey). GOSH population: *n*=68,743.

Table 6-2: Sample compared with GOSH population

	T_1	T_2	GOSH population	*P* value
Number of teams CYP are cared for by	***n*=1040 (%)**	***n*=2905 (%)**	***n*=68,743 (%)**	
1	461 (44.3)	1355 (46.6)	43,010 (62.6)	***p*<0.001**
2	267 (25.7)	802 (27.6)	13,973 (20.3)	
3	128 (12.3)	350 (12.0)	5741 (8.4)	
4	53 (5.1)	154 (5.3)	2750 (4.0)	
5+	87 (8.4)	213 (7.4)	3252 (4.7)	
Not known	44 (4.2)	31 (1.1)	17 (0.0)*	
Ethnicity**	***n*= (%)**	***n*=2905 (%)**	***n*=68,743 (%)**	
White (White/White Irish/other)	N/A	2242 (77.2)	33,441 (48.6)	***p*<0.001**
Asian (Indian/Pakistani/Bangladeshi/other)	N/A	296 (10.2)	8613 (12.6)	
Black (Black/Black British – Caribbean/African/other)	N/A	124 (4.3)	4588 (6.7)	
Mixed	N/A	78 (2.7)	2772 (4.0)	
Any other background	N/A	86 (2.9)	4420 (6.4)	
Prefer not to say	N/A	Not asked	1775 (2.6)	
Not known	N/A	79 (2.7)	13,134 (19.1)	

*17 members of the GOSH population = 0.02% (rounded to 0)

**Data on participant ethnicity was only collected in the follow-up survey

Both T_1 and T_2 captured the responses of parents of children with more complex illnesses than the GOSH population. A higher proportion of survey respondents were seen by two or more specialities (teams), whereas the highest proportion of the wider GOSH population were under a single speciality.

6.4.2 *Response rate*

6.4.2.1 Baseline

Baseline survey distribution and response rate data are presented in Tables 6-3. The parent survey location and number of collected surveys can be found in Appendix 36.

Table 6-3: Baseline survey distribution and response rate

	Packs Made	Remaining	Distributed	Responses	Response rate %
Parents of CYP ages <12 years of age and ≥16 years	1500	92	1008*	770	76.4%*
Parents/CYP aged 12 – 15 years of age	800	335	465*	256	55.0%*
Parents of YPF Members (responses were all from those with children ≥16 years of age but <25 years)	N/A	N/A	28	3 parent responses	10.7%
Number of surveys with participant age not completed	-	-	-	11	-

*Three clinical areas disposed of or cleared away surveys and collection boxes during the study period, hindering accurate response rate calculation.

6.4.2.2 Follow-up

Follow-up survey collection data are presented in Table 6-4:

Table 6-4: Follow-up survey distribution and response rate

	Number of eligible patients *n*=	**No email registered *n*=**	**Undeliverable *n*=**	**Final number sent *n*=**	**Number of responses *n*=**	**Response rate %**
Parents of CYP ages <12 years of age and ≥16 years	12,928	N/A**	N/A**	12,928	2401	18.6%
Parents of CYP aged 12 – 15 years of age	4482	562 (12.5%)	119	3801*	487	12.8%
Number of surveys with participant age not completed	-	-	-	-	17	-

*Invitation email sent to all parents with children within this age group who were registered to access MyGOSH.

**Unable to determine whether there was an email registered or messages not delivered if sent via MyGOSH without manually checking all patients (which was not deemed practicable).

6.4.3 Survey findings

6.4.3.1 Parents' sign up/intention to sign up for MyGOSH (T_1 only)

Parents were asked whether they had signed up to MyGOSH and, if not, whether they intended to if they had not done so (*n*=1012; Figure 6-1).

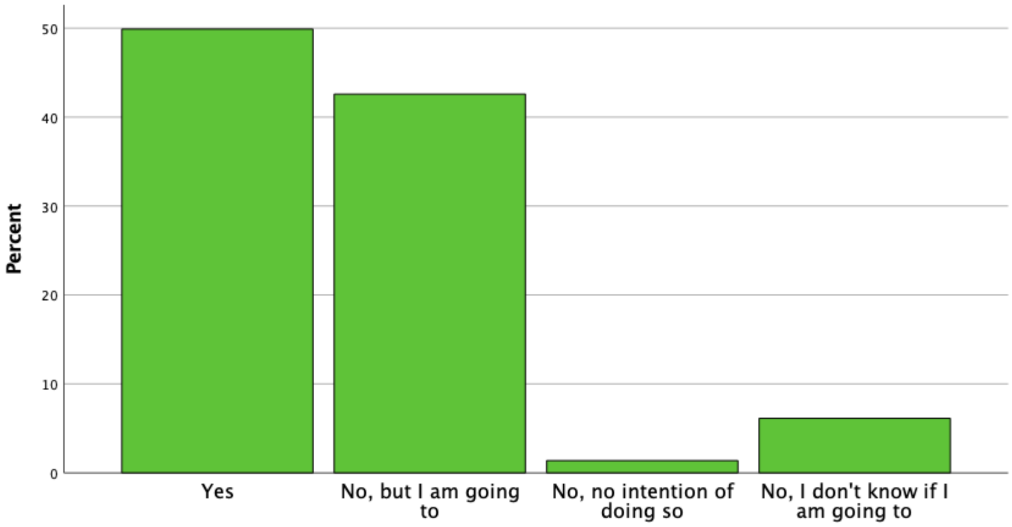


Figure 6-1: Parent sign up/intention to sign up for MyGOSH

The responses indicated that over 90% of parents surveyed had either signed up or intended to sign up to MyGOSH. At T_2, parents were also asked who signed them up to MyGOSH. These data can be found in Appendix 37.

6.4.3.2 Parents' satisfaction

Hypothesis 1: Parents' overall satisfaction with current aspects of their child's care will increase from baseline (T_1) to follow-up (T_2) following experience of EPR and use of the MyGOSH patient portal.

Parents were asked a series of questions about their satisfaction with different aspects of their child's care, ranking their answer on a scale of 1-10, with 1 being not at all satisfied and 10 being extremely satisfied. Responses are presented in Table 6-5:

Table 6-5: Satisfaction with aspects of care

	T_1		T_2		
Survey statement	***n*=**	**Median (IQR*)**	***n*=**	**Median (IQR*)**	***P* value****
How appointments are booked	1013	9 (7-10)	2877	9 (7-10)	***p*=0.004**
How appointments are changed	988	8 (6-10)	2825	8 (7-10)	***p*=0.001**
Coordination of appointments	953	8 (6-10)	2785	9 (6-10)	***p*=0.02**
Convenience of appointments	1002	8 (6-10)	2863	8 (6-10)	***p*=0.03**
Time to receiving clinic letter	995	8 (6-10)	2848	8 (6-10)	***p*=0.01**
Ease of speaking to member of care team	980	8 (5-10)	2845	8 (6-10)	***p*<0.001**
Overall communication from care team	992	8 (6-10)	2863	9 (7-10)	***p*=0.006**
Ease of getting questions answered	987	8 (7-10)	2846	8 (6-10)	*p*=0.7
Time to receiving test results	937	8 (6-10)	2769	8 (6-10)	*p*=0.37
Mode of receiving test results	938	8 (6-10)	2767	8 (6-10)	*p*=0.14
Involvement in decisions about your child’s care	987	9 (8-10)	2848	9 (8-10)	*p*=0.38
Informed about your child’s care	984	9 (8-10)	2854	9 (8-10)	*p*=0.54

*IQR = Interquartile range; **Significance testing was performed using two-tailed Mann-Whitney U non-parametric test

Baseline parent satisfaction with different aspects of their child's care prior to EPR and MyGOSH implementation was high, with median scores of eight for most questions, and with a score of nine for three questions. T_2 data indicated statistically significantly higher levels of satisfaction compared with T_1 on questions related to how appointments were booked and changed, the coordination of appointments, the convenience of appointments, the time it takes to receive a clinic letter, ease of speaking to a member of the care team, and overall communication from the care team. However, no statistical difference was seen at T_2 related to ease of getting questions answered, time to receiving test results, mode of receiving test results (via MyGOSH), how involved they felt in decisions about their child's care and how informed they felt. Therefore, the hypothesis was partially supported. Figure 6-2 provides box plot representations of the above findings.[ix]

[ix] Box plot representation of these data show the upper and lower quartiles (the rectangle), with the median demonstrated as the horizontal line. Variability outside these quartiles is represented by the vertical lines (whiskers) either side of the rectangle, with outliers plotted as individual points.

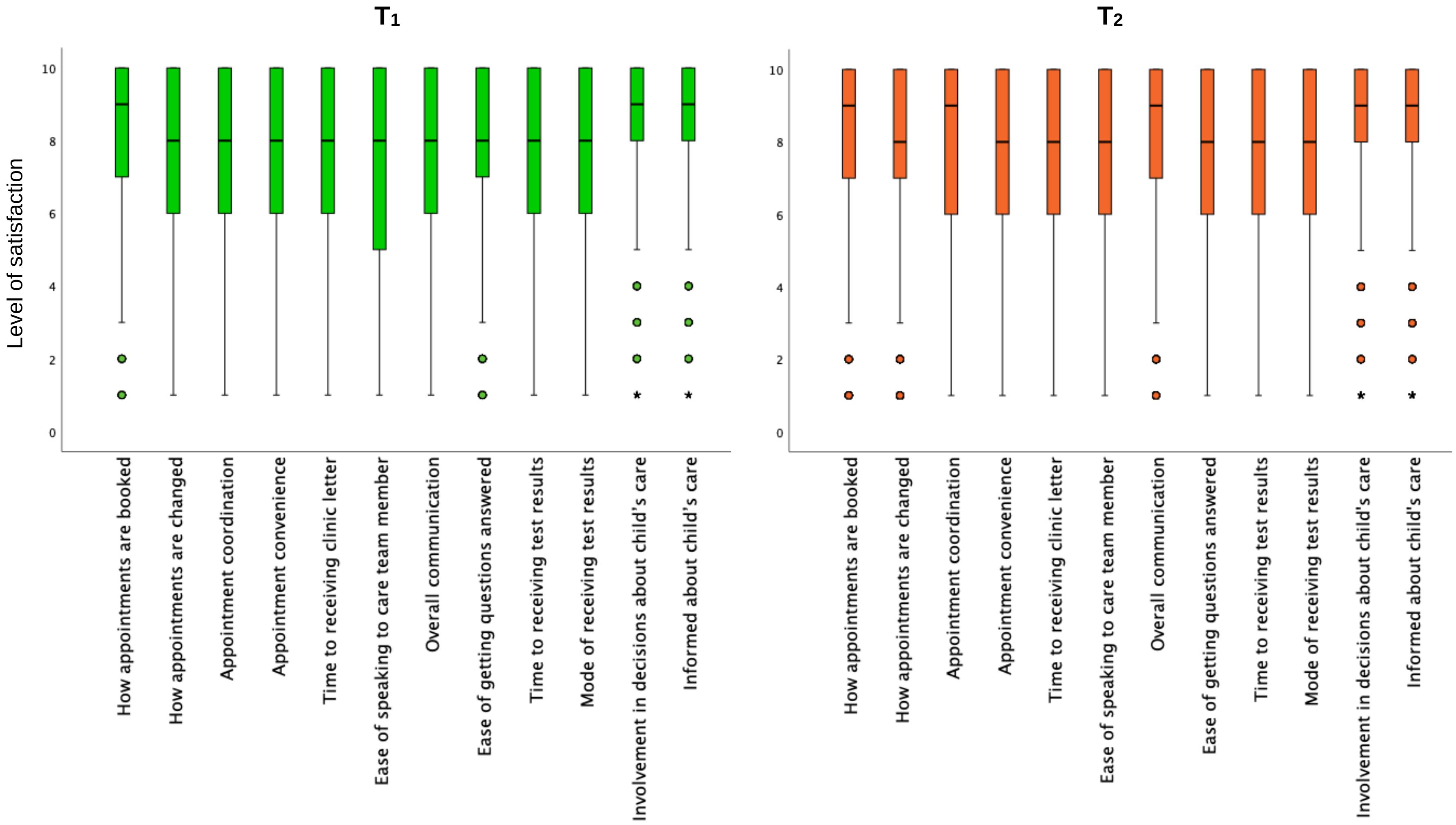


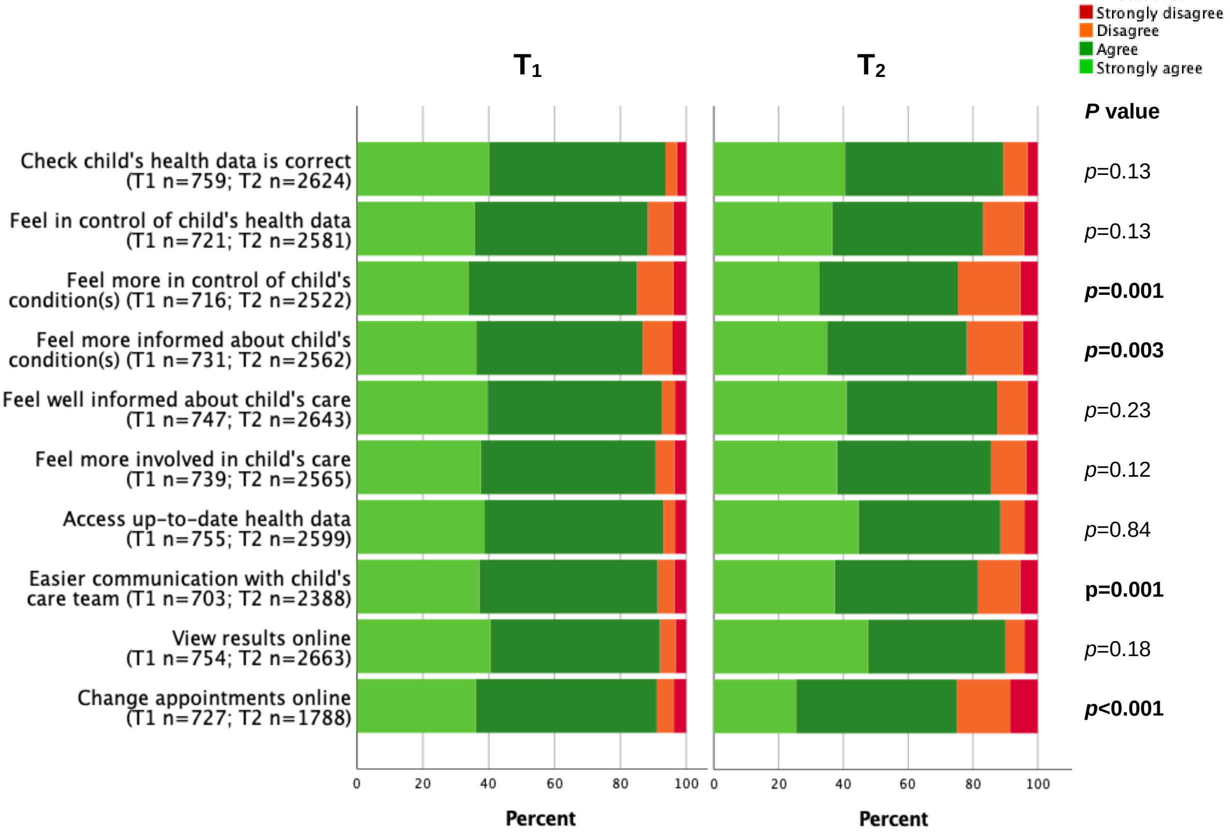
Figure 6-2: Satisfaction with care at T_1 and T_2

6.4.3.3 Parents' expectations prior to MyGOSH implementation and perceptions post-implementation

Hypothesis 2: At T_2, parents will perceive that MyGOSH has facilitated benefits and improved aspects of care.

Parents were asked about their expectations of the benefits of MyGOSH prior to implementation (T_1) and their perceptions post-implementation (T_2; Figure 6-3).

Figure 6-3: Expectations and perceptions of the benefits of MyGOSH[x]



---

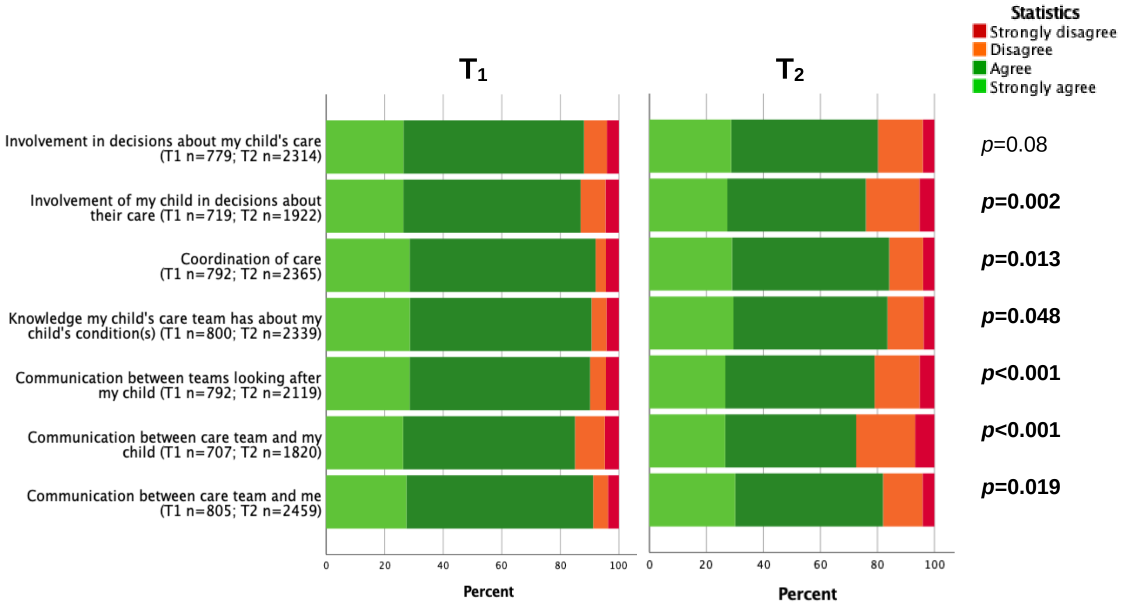
[x] This is to remind the reader that the colour coding used in the stacked bar charts reflects what is considered a positive or negative response for the question e.g. green represents a positive response; red represents a negative response. At times, this may mean that disagreement is a positive thing, and would be reflected in green, or that agreement is a negative, and reflected in red. It is acknowledged that people who are colour blind may find the chosen colours difficult to interpret but the aim is to present the results in a manner which conveys the voice of young people and their experience of transition to EPR and MyGOSH.

In the parents surveyed post-implementation, there was a significant trend for a higher proportion to report that MyGOSH made parents feel less in control of their child's condition, less informed about their child's care, communication was not as easy with the care team, and changing appointments online to a convenient day/time seemed more difficult, compared with the proportion of parents who expected this to happen pre MyGOSH implementation. No domains showed improvement.

Varying numbers of respondents answered 'Don't know' to the questions, with proportions ranging between 22.9% and 28.6% at T_1, and 9.0% and 16.5% at T_2, except for two questions at T_2: 'change appointments' where 37.5% of respondents said they didn't know; and 'easier communication with child's care team' where 16.5% said they didn't know.

Parents were also asked about their expectations about improved aspects of care prior to MyGOSH implementation and their perceptions post-implementation (Figure 6-4).

Figure 6-4: Expectations and perceptions of improved aspects of care



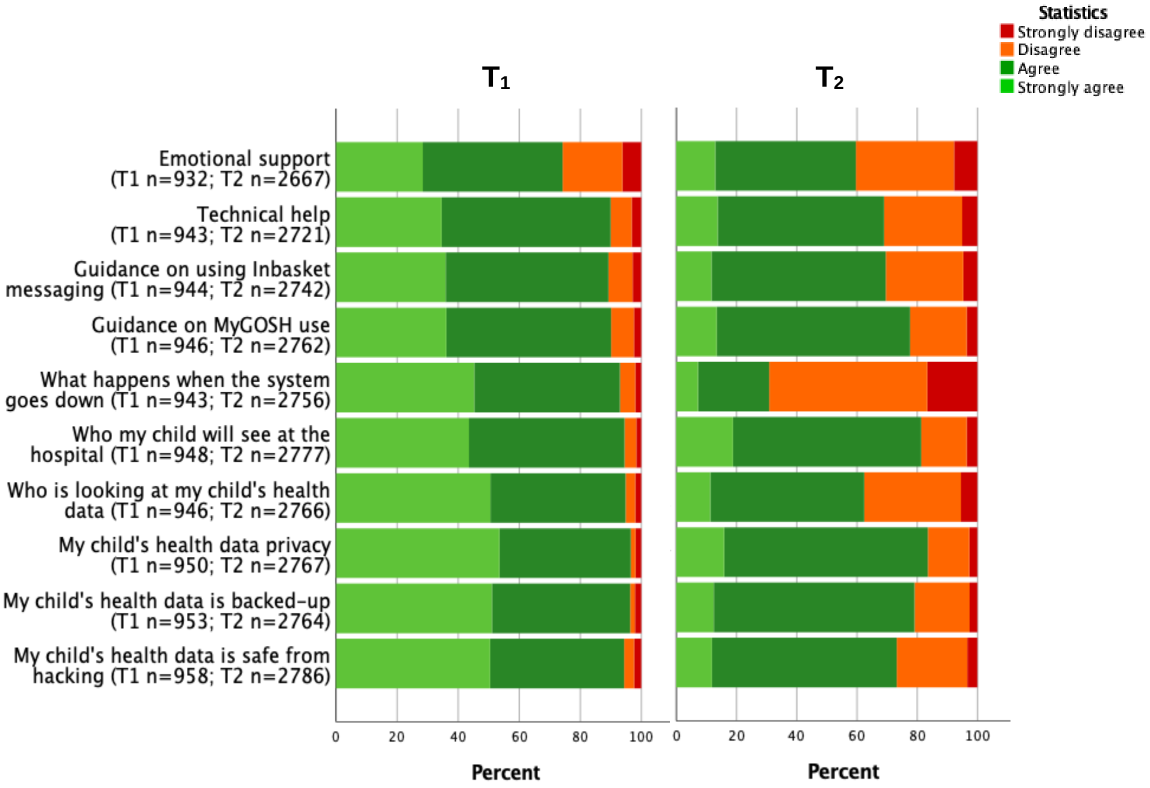
At T_2, there was a significant trend for a lower proportion of respondents to perceive that MyGOSH enabled improved aspects of care related to the care team's knowledge of their child's condition, involvement of their child in decision making, care coordination and communication, compared with the number of respondents who expected this to happen at T_1. Overall, the hypothesis was not supported.

6.4.3.4 Parents' information and support needs

Hypothesis 3: Parents' information and support needs will be met by the hospital after EPR/MyGOSH implementation.

Pre-implementation, we were interested in what parents wanted to know about what would be available to them in terms of information and support post implementation. At T_2 we then asked parents whether they had received the information and support they needed (Figure 6-5).

Figure 6-5: Information and support needs

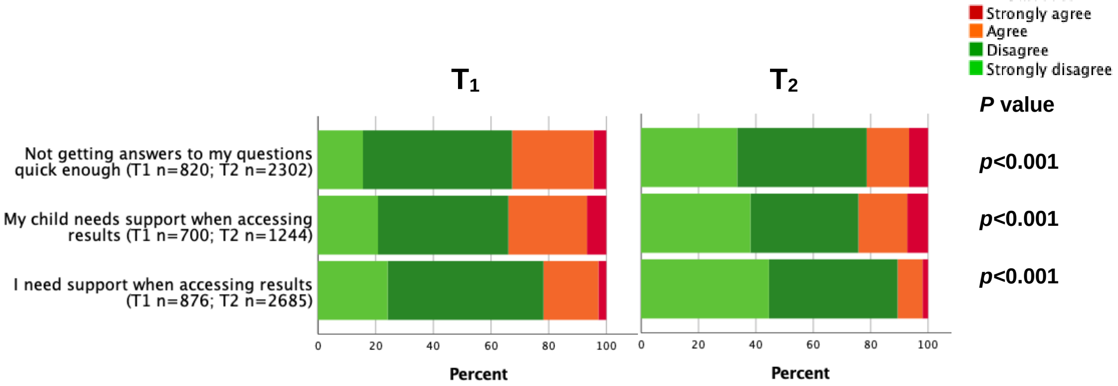


At T_1, the majority of parents indicated wanting to know what information and support they would get post-implementation in relation to each of the domains, but less so regarding emotional support.

At T_2 between 31-84% agreed that they got the information/support they needed, with lower rates reported in relation to knowing what happens when the system goes down (31%), emotional support (60%), who is looking at their child's health data (62%), and guidance and information pertaining to data safety. Therefore, parents had a level of unmet information/support needs, and the hypothesis was not supported.

Respondents were also asked whether they worried about getting answers to their questions quickly enough and whether they thought they would need support when accessing their results (T_1) and whether this happened (T_2; Figure 6-6):

Figure 6-6: Additional information and support needs



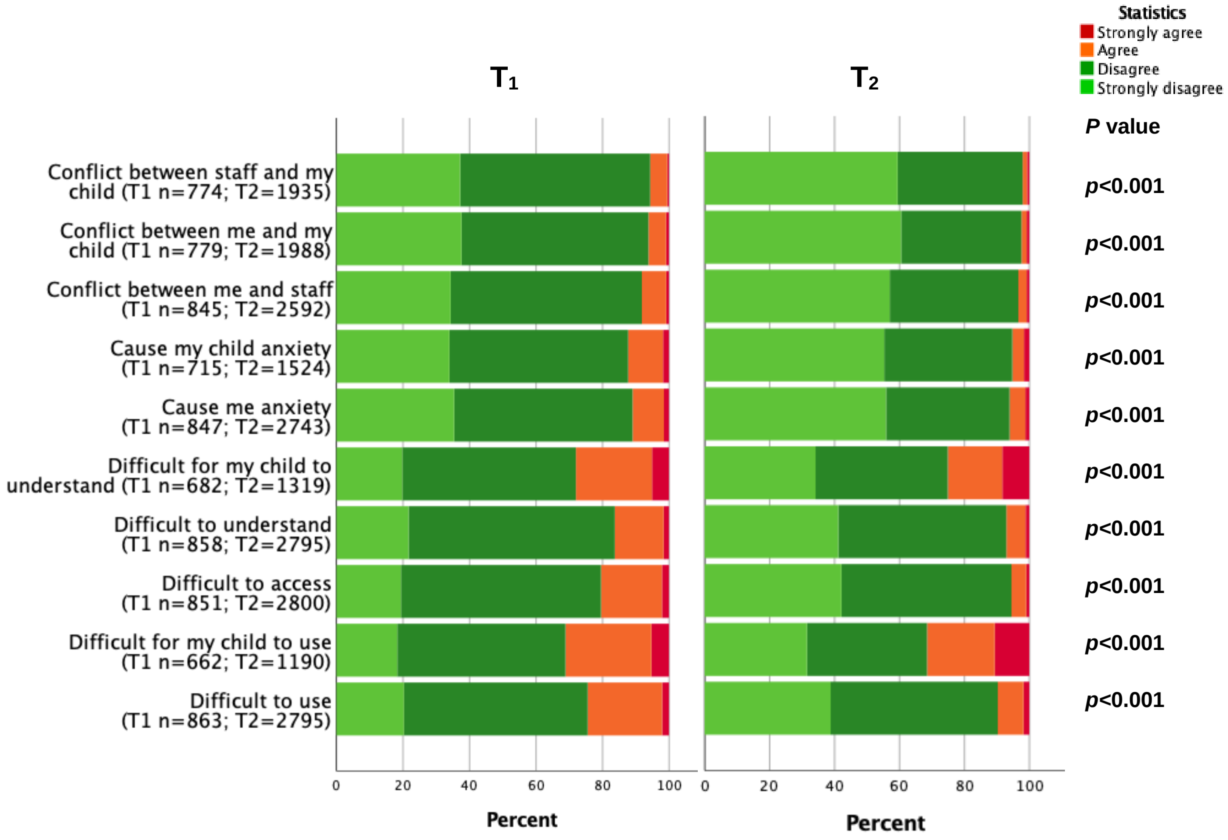
At T_2, there was a significant trend for a lower proportion of respondents to report they did not get answers to their questions quickly enough, and that they and their child needed support when accessing result at compared with respondents at T_1. However, a fifth of respondents at T_2 still reported not getting answers to their questions quickly enough, and felt their child needed support when accessing results.

6.4.3.5 Parents will have worries about using an electronic health system/patient portal

Hypothesis 4: Parents will have fewer worries at follow-up compared with baseline in relation to using, accessing, and understanding MyGOSH, MyGOSH causing anxiety and MyGOSH causing conflict.

Parents were asked if they worried MyGOSH would be difficult for them or their child to use or understand, would be difficult to access, or would cause any conflict (T_1), and the extent to which they agreed that these were experienced with MyGOSH use (T_2; Figure 6-7):

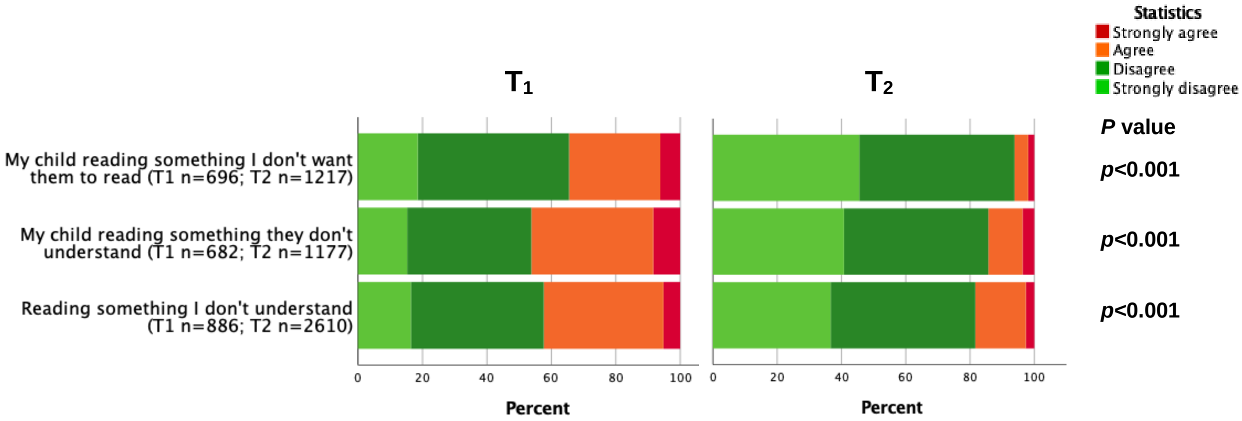
Figure 6-7: Worries about using MyGOSH



There was a significant trend for a lower proportion of respondents at T_2 to experience worries about using MyGOSH compared with the things that respondents at T_1 worried about, supporting the hypothesis. However, although less than at baseline, parents' worries regarding MyGOSH being difficult for their child to use and understand were still evident at T_2.

Additional worries related to them or their child reading information are shown in Figure 6-8.

Figure 6-8: Additional worries



There was a significant trend for a lower proportion of respondents at T_2 to experience worries about themselves or their child reading something they did not understand, and about their child reading something they did not want them to read, compared with parents who were asked this at T_1.

6.4.3.6 Parents' views on age limits for accessing MyGOSH, and whether they feel well informed about MyGOSH

Hypothesis 5: The majority of parents will:

- Think that the lower age limit of 12 years old for their child to access MyGOSH with their consent is acceptable
- Feel more informed about MyGOSH at T_2

Parents were asked their views on the age limit for accessing MyGOSH and how informed they felt about MyGOSH (Table 6-6):

Table 6-6: Parents' views – age limits/feeling informed about MyGOSH

Survey statement		**T_1 *n*=915 (%)**	**T_2 *n*=2787 (%)**	***P* value**
Do you think the lower age limit of 12 years old for being able to access MyGOSH with your consent is acceptable?	**Yes**	666 (72.8)	2056 (73.8)	*p*=0.52
	No	249 (27.2)	731 (26.2)	
Survey statement		**T_1 *n*=867 (%)**	**T_2 *n*=2799 (%)**	
I feel well informed about the EPR system	**Very**	167 (19.3)	947 (33.8)	***p*<0.001**
	Somewhat	460 (53.1)	1559 (55.7)	
	Not at all	240 (27.7)	293 (10.5)	

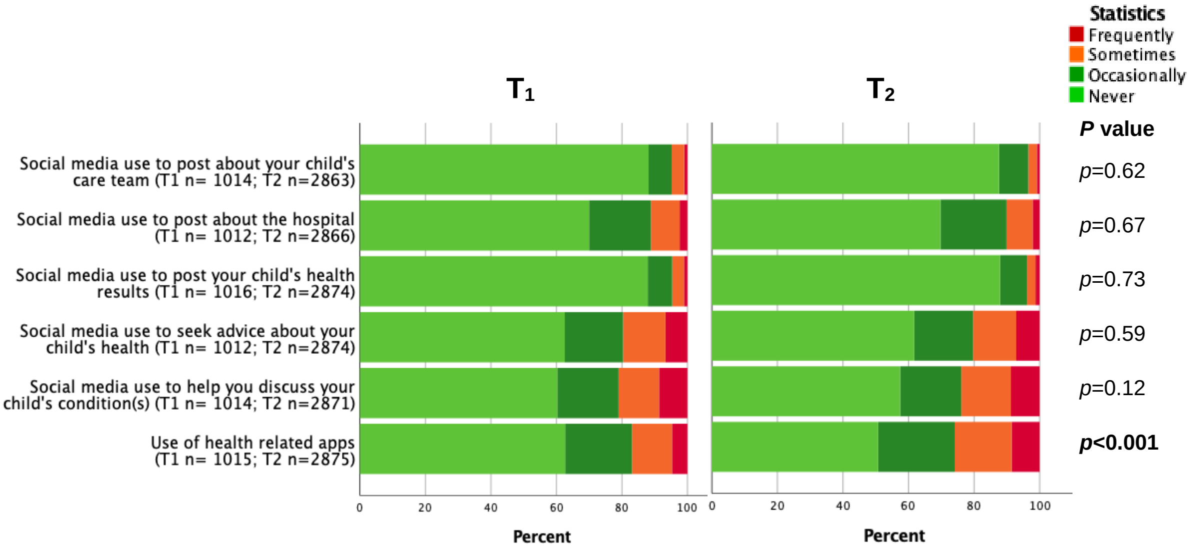
Although no trend was seen, a large and similar proportion of parents at both T_1 and T_2 reported that 12 years of age was acceptable for being able to access MyGOSH with parental consent. Parents' were asked their views about their child having sole at 16 years of age. Responses are represented in Table 6-7 below. There was a significant trend for a higher proportion of respondents to feel well informed about the EPR system at T_2 compared with respondents at T_1. These findings support the hypothesis.

6.4.3.7 Parents' perceptions of their own and their child's health-related app and social media use

Hypothesis 6: The proportion of parents using social media to discuss or seek advice from others about their child's condition and using health related apps will increase with the use of MyGOSH.

Respondents were asked about their social media use and health related app use (Figure 6-9).

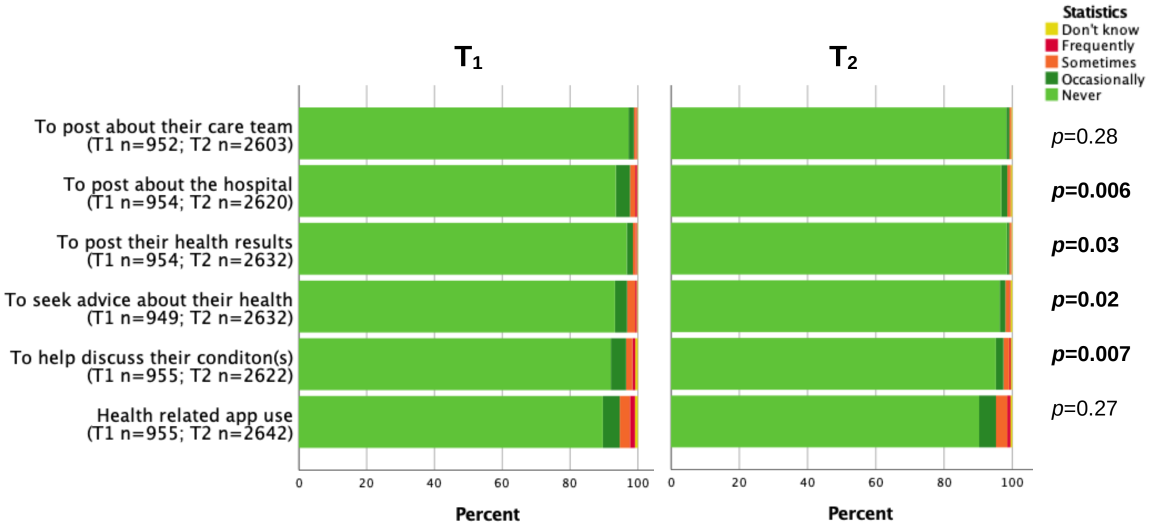
Figure 6-9: Parental social media/health app use



There was a significant trend for a higher proportion to report health related app use at T_2 compared with those asked at T_1. At both time points, parents reported low social media use to post about their child’s care team or the hospital, or post their child’s health results. A fifth of T_1 and T_2 respondents reported using social media to seek advice or discuss information related to their child’s condition(s), indicating how parents use social media related to their child’s health. No changes were seen over time regarding all of the aforementioned topics. However, an increase was seen over time related to parents’ health related app use. This hypothesis was partially supported.

Parents were also asked about their perception of their child’s social media and health related app use (Figure 6-10)

Figure 6-10: Parental perception of their child’s social media/health app use



Parents reported low social media use by their children at both T_1 and T_2, with the majority of parental responses about their child’s social media and health-related app use being ‘never’. A significant trend was seen for a lower proportion of respondents at T_2 to report that their child used social media to post about the hospital, post their health results, seek advice about their health, and used social media to help discuss their condition(s) compared with respondents who answered at T_1. No change over time was seen related to posting about the care team or the use of health-related apps.

Although we are only reporting parental views rather than fact, parents reported that their children never or rarely used social media or health apps for the above reasons, or were unaware of their use, the baseline and follow-up data were from two independent groups with results showing similar trends.

6.4.3.8 Parents’ views on their child accessing health data and sharing health-related information on social media

In addition to the questions about parents’ perception of their children’s social media use, parents were asked a series of questions about how happy they were with their child using social media for health reasons, accessing MyGOSH and potentially having sole access to MyGOSH when they turned 16 years of age. Parents ranked their answer on a scale of 1-10, with 1 being the lowest (extremely unhappy) and 10 being the highest (extremely happy). These questions were not applicable for parents with children under 12 because patients are only eligible for MyGOSH access from the age of 12 (with their parents' consent). Responses are presented in Table 6-7:

Table 6-7: Parent responses – their child accessing health data/sharing on social media

	T_1		T_2		***P* value**
Survey statement	***n*=**	**Median (IQR*)**	***n*=**	**Median (IQR*)**	
1) Accessing MyGOSH	*n*=515	8 (5-10)	*n*=1316	8 (6-10)	***p*<0.05**
2) Accessing their results online	*n*=509	8 (5-10)	*n*=1301	8 (5-10)	*p*=0.27
3) Being able to contact their care team through MyGOSH	*n*=507	8 (5-10)	*n*=1297	8 (5-10)	*p*=0.16
4) Being able to view some of their health data	*n*=510	8 (5-10)	*n*=1313	8 (6-10)	*p*=0.26
5) Posting about their condition(s) on social media	*n*=491	3 (1-7)	*n*=1188	3 (1-7)	*p*=0.55
6) Posting their health results on social media	*n*=498	2 (1-6)	*n*=1188	2 (1-6)	*p*=0.7
7) Having sole access to their health data at 16 years of age	*n*=503	6 (2-9)	*n*=1277	6 (2-9)	*p*=0.9

*IQR = Interquartile range

Significance testing was performed using two-tailed Mann-Whitney U non-parametric test

Parents at T_2 were happier for their children to access MyGOSH than parents at T_1, where a significant difference was seen over time. There was a wide range of responses from parents about their child having sole access at 16, and this did not change over time. Parents scored social media related questions low on the scale, with no change over time. The following boxplots visually present these findings (Figure 6-11).

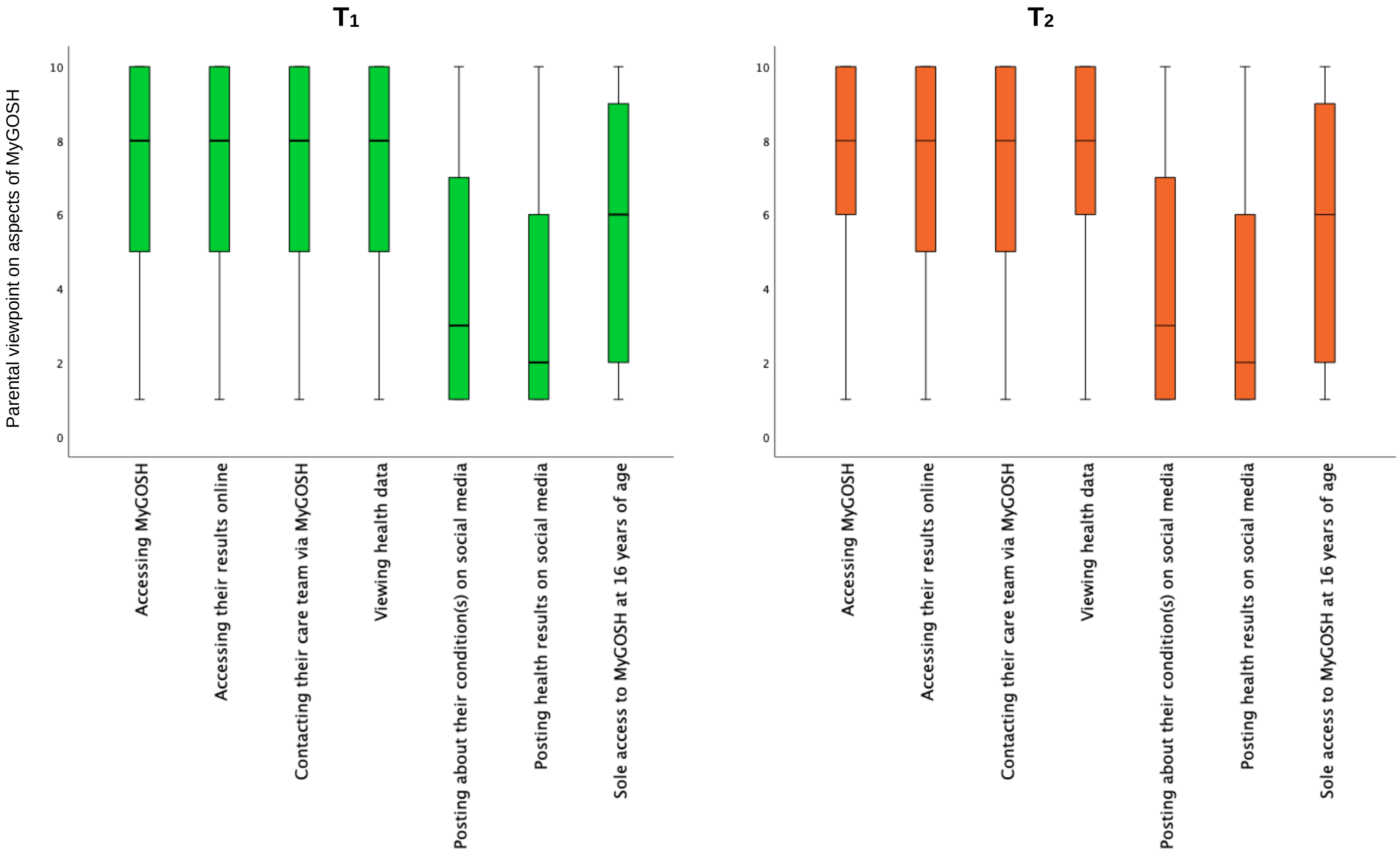


Figure 6-11: Parent responses from Table 6-7 at T_1 and T_2

6.4.3.9 Potential barriers to accessing MyGOSH

In addition, we were interested in understanding potential perceived barriers to parents and their children accessing MyGOSH.

Parents were asked whether any of the listed statements posed a barrier for them or their child being able to access MyGOSH (Table 6-8):

Table 6-8: Barriers to accessing MyGOSH

Survey Statement	**T_1 *n*=1040 (%)**	**T_2 *n*=2905 (%)**
English is not your first language	77 (7.4)	132 (4.5)
English is not your child's first language	21 (2.0)	48 (1.7)
You are not confident using a computer/electronic device	55 (5.3)	114 (3.9)
You have a learning difficulty or disability	20 (1.9)	41 (1.4)
Your child has a learning difficulty or disability	84 (8.1)	274 (9.4)
You have a sensory impairment (sight/hearing)	18 (1.7)	32 (1.1)
Your child has a sensory impairment (sight/hearing)	49 (4.7)	114 (3.9)
You have a physical impairment	8 (0.8)	20 (0.7)
Your child has a physical impairment	28 (2.7)	76 (2.6)
You may be too ill to use MyGOSH	10 (1.0)	33 (1.1)
Your child may be too ill to use MyGOSH	19 (1.8)	56 (1.9)

Although participants were only required to complete this if it applied to them, it is noted that a smaller percentage of respondents at T_2 were those for whom English was not their own or their child's first language, or those who were not confident in using a computer/electronic devices. For these respondents MyGOSH would pose additional barriers, which may mean fewer were able to access MyGOSH post-implementation, resulting in fewer responses where these issues were relevant at T_2. Barriers to access were also reported by respondents with a physical, intellectual, or sensory impairment, indicating an even greater barrier due to some form of disability, or multiple disabilities.

6.5 Discussion

Parents' views and perceptions from before (*n*=1040) and after (*n*=2905) EPR and MyGOSH implementation were sought and analysed.

6.5.1 How the key findings relate to the hypotheses and literature

In the same manner as the preceding chapter, each of the hypotheses, the key findings from the parent data, and whether each hypothesis was supported are summarised in Table 6-9. This is followed by a discussion relating our study findings to relevant research literature. Our investigations in this chapter sought to examine parental views and perceptions of how EPRs and patient portals improved aspects of care for families, in the same manner as we examined children's and young people's views in chapter 4.

Increased parental satisfaction following EPR and portal implementation and associated benefits are widely reported in the literature [82, 91, 93, 98]. Parents' satisfaction with care provision at GOSH was already high prior to EPR/MyGOSH implementation. However, significant improvements in satisfaction were seen following transition to the new system related to the management and coordination of appointments, the time it took to receive a clinic letter, ease of speaking to care team members, and overall communication from the care team. Our findings concur with a study by Ahlers-Schmidt et al. (2013) where parents reported the benefits of communication with the care team via the portal and viewing their child's medical record/health information [67]. A further study by Selvadurai et al. (2019) also described benefits experienced by parents when communicating with the care team and managing appointments via the portal [87]. However, our findings reported no improvements in satisfaction with how easy it was for parents to get questions answered, the mode of receiving test results, parental involvement in decisions about care and being informed of their child's care. This might be due to the amount of time it takes to embed a new EPR system into practice [97].

Table 6-9: Hypotheses, key findings and whether each hypothesis was supported

Hypothesis 1: Parents' overall satisfaction with current aspects of their child's care will increase from baseline (T_1) to follow-up (T_2) following experience of EPR, and use of the MyGOSH patient portal.	
• Baseline satisfaction was high • Significant improvements seen at T_2 only related to how appointments are booked/changed, coordination/convenience of appointments, time to receiving a clinic letter, ease of speaking to care team member, and overall communication from the care team • No change over time seen related to ease of getting questions answered, time to receiving test results, mode of receiving test results, involvement in decisions about child's care and informed about child's care	**Hypothesis partially supported**
Hypothesis 2: At T_2, parents will perceive that MyGOSH has facilitated benefits and improved aspects of care.	
• Parental expectations at baseline were high • Higher levels of disagreement were seen at T_2 in relation to feeling in control of their child's condition, informed about their child's care, communication with the care team, and regarding changing appointments online, meaning that parents' expectations were not met in these areas • Expectations of improved aspects of care after MyGOSH implementation were not met	**Hypothesis not supported**
Hypothesis 3: Parents' information and support needs will be met by the hospital after EPR/MyGOSH implementation.	
• Parents had a level of unmet information/support needs following EPR and MyGOSH implementation	**Hypothesis not supported**
Hypothesis 4: Parents will have fewer worries at follow-up compared with baseline in relation to difficulty in using, accessing, and understanding MyGOSH, MyGOSH causing anxiety and MyGOSH causing conflict.	
• Parents at T2 had fewer worries in relation using, accessing, and understanding MyGOSH, MyGOSH causing anxiety and MyGOSH causing conflict	**Hypothesis supported**
Hypothesis 5: The majority of parents will: • Think that the lower age limit of 12 years old for their child to access MyGOSH with their consent is acceptable • Feel more informed about MyGOSH at T_2	
• Parents agreed that 12 years of age was acceptable for MyGOSH access • Parents felt more informed about MyGOSH at T_2	**Hypothesis supported**
Hypothesis 6: The proportion of parents using social media to discuss or seek advice from others about their child's condition and using health related apps will increase with the use of MyGOSH.	
• No change was seen over time related to social media use to post, discuss, or seek advice about their child's condition(s) • Parents reported increased health related app use at T_2	**Hypothesis partially supported**

Parents have expectations that patient portals will improve aspects of care, especially in terms of parental involvement in care giving processes [97, 98], decision-making [98] and helping parents to manage their child's condition(s) [93]. We therefore asked parents about their expectations of the improvements to aspects of care MyGOSH would bring. Baseline responses were again positive, but rather than an improvement at T_2, there was a deterioration in the level of agreement, suggesting parents' expectations may not have been met following implementation.

Questions relating to portal functionality, yielded high numbers of 'Don't know' answers, especially in relation to 'change appointments online to a convenient day/time' and 'easier communication with child's care team' which, suggests that parents were unable or unaware of how to do this via the portal. Prior to implementation, the benefits and convenience of these functionalities were promoted by the hospital but were not realised. The research literature demonstrates mixed findings on these topics. Some studies demonstrated increased parent satisfaction when able to access their child's portal [67], with perceptions of improved care quality [75, 82]. However, our hypothesis that parents' overall satisfaction with current aspects of their child's care would be higher following experience of EPR and use of the MyGOSH patient portal was not supported. A study by King et al. (2017) reported slow increases in parental engagement over time [97], which suggests that further testing is required to determine whether improvements are seen after a longer time post-implementation.

Prior to implementation, parents wanted information about what happens when the system goes down; the safety and privacy of the system; who their child will see when they visit the hospital, and who is looking at their child's health data. Parents also wanted emotional and technical support, and guidance on accessing and using MyGOSH and InBasket messaging. However, the findings indicated that parents' information and support needs were not fully met in any of these areas, with less than one third reporting that they got the support needed, indicating a high level of unmet need. These findings are in contrast to those of Lee at al., (2017) who reported increased fulfilment of parental information needs after portal implementation [91]. This may be because our study included different populations who responded at each time point rather than the same participant group who responded to both time-points, as in at study by Lee et al. (2017) [91].

Despite improvements post-transition to EPR in terms of parental worries about their child using MyGOSH, concerns remained about how difficult it would be for them to use and understand the system, particularly in relation to access test results. This resonates with previous research, in which parental concerns about results being misinterpreted and causing the child anxieties has been highlighted, along with the need for clearer explanation of test results [93]. In another study, Kelly et al. (2017) identified that parents reported staff were not responding to messages promptly when communicating via a patient portal [75]. In our study, when parents were asked if they, or their child, needed support when accessing results, and whether they received answers to their questions quickly enough, approximately a fifth of parents reported they/their child still needed support when accessing results at T_2. This suggests that there will be families who need ongoing support in these areas.

Notwithstanding parents' expectations and information and support needs not being met, our results demonstrated parents had fewer worries at T_2 compared with T_1. This was in relation to difficulty in using, accessing, and understanding MyGOSH, MyGOSH causing anxiety or conflict, supporting hypothesis 4. However, parents' worries regarding MyGOSH being difficult for their child to use and understand were still evident at follow-up, albeit their worries were less than at baseline. In a study by Hong et al. (2016) parents had concerns about misinterpretation of medical tests or results that might lead to their child being anxious or upset [47, 96]. The provision of age-appropriate mechanisms for reviewing health data was advocated [47, 96]. Byczkowski et al.'s (2014) findings recommended clearer explanation of laboratory results/terminology with more links to resources/education, and easier web site access, log-in, navigation and use [47, 93]. Our findings indicate that parents and patients could benefit from the same approaches (described above) set out by Hong et al., (2016) and Byczkowski et al. (2014) to aid MyGOSH access, use, and understanding of portal content [93, 96].

Overall, parents who completed the survey at T_2 felt more informed about MyGOSH after having used it for a period of time. One area of concern, however, was that 10.5% of parents still felt 'not at all informed' about MyGOSH at T_2, indicating that communication from the Trust needs to be on an ongoing basis to ensure parents are kept informed and up to date. Hands-on demonstrations of health portals were advocated by Hong et al. [96] to raise awareness, encourage understanding and use, and introducing something similar at GOSH might help parents feel more informed and facilitate successful portal implementation. When parents thought about the age at which they felt it would be appropriate for their child to access MyGOSH with parental consent, a large proportion of parents from both time-points reported that 12 years of age was acceptable.

Respondents were asked about their own and their child's social media use and health related app use, and we hypothesised that the proportion of parents using these would increase with the use of MyGOSH. Overall, parents reported relatively low social media use. However, a higher proportion of parents reported using social media to seek advice or discuss their child's condition, and health related app use than they did to post about the care team, the hospital, or their child's results. At T_2, significantly more parents reported health related app use, but we do not know whether this was related to increased MyGOSH use or other health apps.

A study by van der Velden et al. (2013) reported low social media use by CYP related to posting health information or seeking advice or support about their condition(s) [152]. Their study revealed that social media plays an important role in teenagers' lives in maintaining normality, rather than always focusing on being sick [152]. Parents in our study reported very low social media use by their children at both time-points, concurring with van der Velden et al.'s findings.

We were also interested in understanding how parents felt about their child accessing and using MyGOSH, and potentially having sole access at 16 years of age. Parents at T_2 were happier for their children to access MyGOSH compared with those who responded at T_1. This may link to parents' worries being lower at T_2, as discussed above, after they had experience of using the system.

The topic of confidentiality for the young person in relation to allowing parents access to their medical notes is controversial, and may impact the young person's willingness to discuss or disclose information to their care team [34, 121, 144-146]. Most centres in the US automatically exclude parents from young people's medical records once they reach 16 years of age [121]. Traditionally, the approach at our hospital has been more collaborative, with parental involvement throughout the child's or young person's journey, so the prospect of parents potentially being excluded from MyGOSH when their child turns 16 years of age is daunting for them. Parents in our study reported a varied response to their child potentially having sole access at 16, but this did not change between T_1 and T_2. The need to work with the family early on in adolescence, to enable the young person to develop the necessary skills required for self-management of their condition(s), and prepare parents to gradually relinquish control is highlighted so that this process does not cause unnecessary anxiety for both parties. This approach is advocated in the literature around a young person's transition from child or adolescent services into adult services [164, 165].

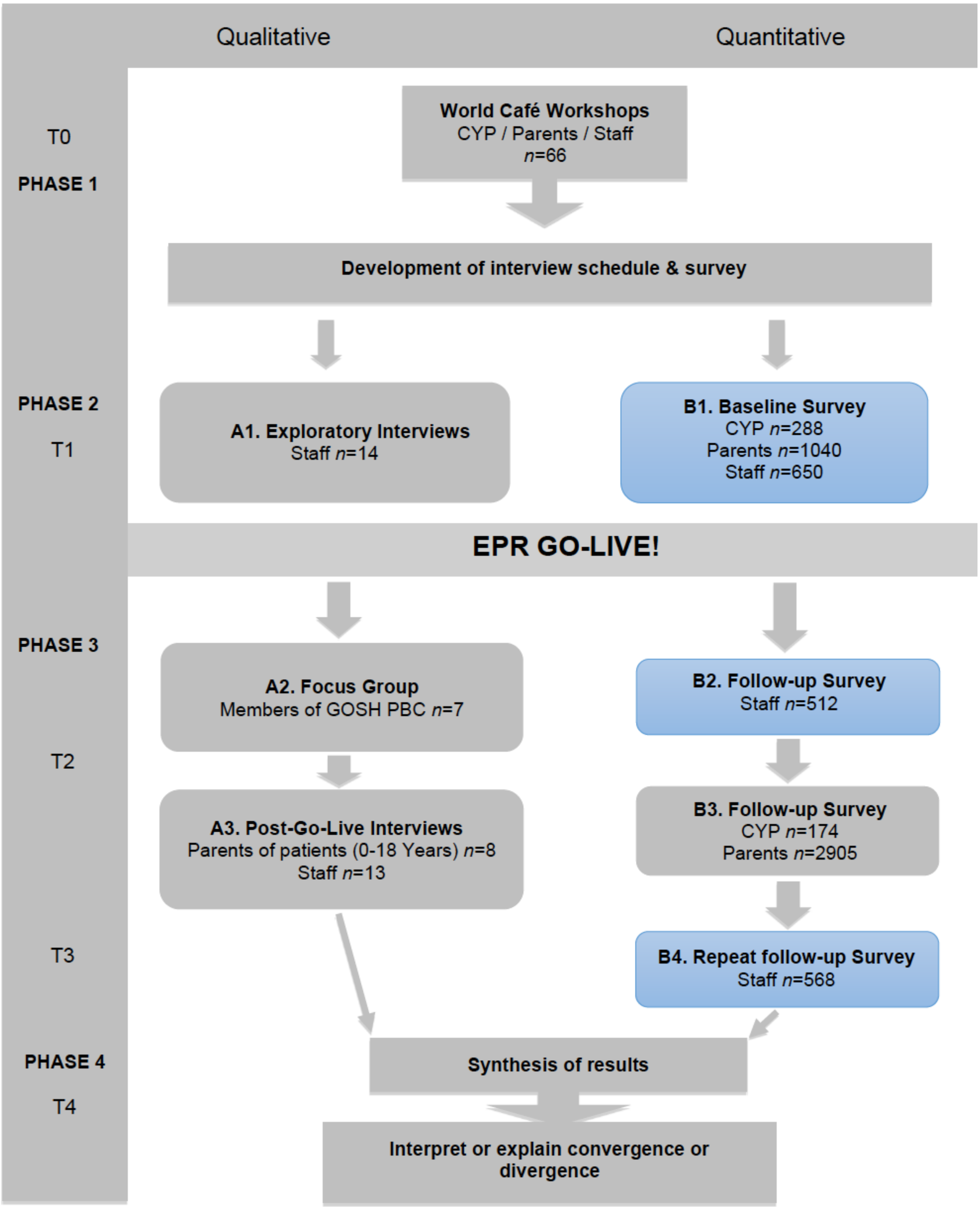
In an increasing digital age, accentuated by the coronavirus pandemic, rapid technological advancements in all aspects of life pose challenges for those who do not have the skills or the means by which to access online services [166, 167]. Families with a lower income are much less likely to have internet access than families earning more. In households earning between £6000-10,000, only 51% had home internet access, whereas households with an income of over £40,001, 99% had home internet [166, 167]. Ten percent of the UK's population overall are internet non-users [166, 167]. Furthermore, a study by Kumar et al. (2018) reported the major barrier to accessing the patient portal was the lack of computer/phone skills (81.8% of respondents) [168]. Potential barriers to accessing MyGOSH were confirmed in our study and should be highlighted so that efforts can be made by the hospital so overcome such barriers. Parents also reported that not being confident in using a computer/electronic device was a barrier to accessing the portal. Additional barriers to access included English not being the parents' first language, the parent having a learning disability or difficulty, a sensory or physical impairment or being too ill to use the portal. Children of parents who are not confident in speaking English are at risk of preventable adverse events whilst in hospital, due to the language barrier [169, 170]. Furthermore, parents for whom English is not their first language may ask their children to translate their health information for them, which may not always be appropriate [171]. These findings demonstrate that digital deprivation will and does affect families' ability to access the portal, and that some families may need special consideration. Adjustments may need to be made by the care team to enable equal and fair access to health information and services for those who are unable to access digital health services, for whatever reason.

6.6 Summary

Parents did not show increased levels of satisfaction with aspects of care post EPR/MyGOSH implementation as compared with before implementation, however, satisfaction was already high prior to this transition to an EPR system. Similarly, parents' expectations of the improvements MyGOSH would bring to aspects of their child's care were not met. The high number of 'don't knows' to some of the questions reveal that some parents are unsure of how to use the portal. Furthermore, parents' information and support needs were not met. These two aspects indicate the information provided to parents about how to access and use MyGOSH, and its functionality, was insufficient. More support is required for parents if they are to benefit from full portal utility. However, parents reported fewer worries during follow-up data collection once they had used the portal, suggesting that their anticipated worries around portal use were higher than the reality of using MyGOSH. Overall, parents were happy for their child to access MyGOSH from the age of 12 years old, with their consent, and parents reported a varied response to their child having sole access at 16, but this did not change over time. Despite parents not being happy about their children potentially sharing health information online, our results demonstrate that, in reality, this does not occur, which also aligns with the research literature on this topic. This study has identified that some families will experience barriers to accessing and using patient portals such as MyGOSH. Barriers are socio-technical rather than technical alone, with implications for equal and fair access to health services, which need to be considered by the clinical teams and the hospital as a whole. Measures put in place to ensure families who are unable to access MyGOSH are not disadvantaged [172, 173].

The findings from the staff surveys will be presented in the next chapter. The aim was to understand staff perceptions and experiences of the hospital transitioning to an EPR system with a linked patient portal (MyGOSH). The focus was on how EPR and MyGOSH impacted upon the provision of care for families, and staff perceptions of their ability to provide care.

Chapter 7 Staff Survey



7

7 Staff survey (phases two and three)

7.1 Introduction

The findings from the staff surveys that were also conducted during the quantitative aspect of phases two and three of the study will now be presented. This will follow the same format as the two preceding chapters. Methods will be described, along with the statistical analysis and significance of the results from the baseline to the follow-up surveys. The hypotheses will be stated, with presentation of the corresponding findings from the survey questions, followed by a discussion incorporating pertinent research literature and then a summary of the chapter.

7.2 Aim

The aim of this research activity was to understand staff perceptions and experiences of the hospital transitioning to an EPR system with a linked patient portal (MyGOSH). The focus is on staff perceptions of how EPR and MyGOSH impacted the provision of care for families, and staff perceptions of their ability to provide care.

7.3 Methods

7.3.1 Study setting and design

The study setting was the same as for the CYP and parents, however, staff experiences and perceptions were surveyed at three time-points pre and post EPR-implementation utilising a cross-sectional sample: (baseline = T_1), at six months post-EPR transition (first follow-up = T_2), and 18 months post-EPR transition (final follow-up = T_3).

7.3.2 Survey development

The staff survey was developed and piloted following two World Café workshops held with staff from the hospital. Questions covered themes including their expectations of how their experiences would change following EPR and MyGOSH transition; expected benefits; anticipated challenges; practicalities of using the new EPR system; the potential impact on their ability to provide treatment and care; how the patient experience may change; what information and support they felt they would need using the new system; and whether any ethical and legal considerations were raised. Questions measuring confidence were based on a 10-point scale ('Not at all confident' to 'Extremely confident'). Most other questions were based on a 4-point Likert scale ('Strongly disagree to 'Strongly agree'), with 'N/A' included for questions that might not have been applicable to all staff. Participants were also asked their job title and speciality to aid understanding of the impact, challenges, and benefits of the implementation of EPR throughout the Trust and what it meant to each person. No personally identifiable information was collected, meaning that the surveys were anonymous, and no-one could be identified from their responses, unless they volunteered their email address if they were interested in participating in other aspects of the study. Due to the specialist nature of the hospital, if participants were worried their job title would identify them they were encouraged in the invitation email to leave a generic response e.g. Clinical Nurse Specialist, Neurology.

7.3.3 Participant inclusion and exclusion criteria

The survey was open to all staff in the hospital and there were no exclusion criteria

7.3.4 Recruitment and survey distribution

Hospital staff were invited to participate via Trust-wide emails containing information about the study and a direct link to the online survey. During baseline survey distribution (T_1), paper copies were also left in staff-only areas of the Trust. Both of the follow-up surveys were electronic only, in keeping with the theme of ‘Going Digital’. Awareness of the study was raised through a range of internal communications such as the Trust Monthly Newsletter, EPR Newsletter (which was also accessible via ‘GOSHweb’ Intranet), banner n GOSHweb, posters in staff-only areas, a Trust screensaver, and through the EPR ‘Roadshow’ (Appendix 38 provides an example of the screensaver and banner). To increase participation, study information was also provided at departmental meetings, via Head of Department emails, emails from the Chief Executive and Chief Nurse, and via presentations at the Senior Leadership Team meetings. Return of completed surveys was taken as consent to participate.

7.3.5 Data collection

Study data were collected using REDCap electronic data capture tools hosted at UCL [136].

7.3.6 Sample size

Sample size was based on an estimated 20% response rate from a total of 3000 clinical staff members [137]. The required representative sample comprised 600 responses for each of the three time-points. Initially, this was calculated on a total population sample of all clinical staff working in the hospital during the data collection period. However, it was unfeasible to distribute just to clinical staff or only those who had contact with patients (as initially intended), due to needing to utilise an all-user email via the Trust email system. Furthermore, the decision to send to all staff was informed by the systematic review conducted as part of this study, in which it was identified that some staff groups were under-represented or absent from the research.

7.3.7 Statistical analysis

Survey data were exported from REDCap into SPSS (IBM SPSS Statistics for Macintosh, Version 27.0). SPSS was used for all analyses and a *p* value of <0.05 was taken as significant, and these will be marked in bold text. Findings from the survey are summarised with medians and inter-quartile ranges for continuous data, and frequencies and percentages for categorical data.

Pre/post differences in staff members' perceptions were compared using chi-square test for nominal data, and the Kruskal-Wallis non-parametric test for ordinal data to assess for differences between the three groups of respondents.

7.3.8 Missing data and not applicable responses

The returned survey completeness rate was high at T_1 (>84.5%) for all questions. At T_2, the completeness rate was lower (>69%), which may reflect the burden on staff soon after EPR implementation. At T_3, the survey completeness rate improved to >75%. See Appendix 39 for the number of missing responses for each question and the number of questions which were answered N/A.

7.4 Results

7.4.1 Demographic characteristics

Respondent demographics are presented in Table 7-1.

Table 7-1: Respondent demographics

	T_1	T_2	T_3
Staff group	***n*=650 (%)**	***n*=512 (%)**	***n*=568 (%)**
Nursing	196 (30.2)	130 (25.4)	131 (23.1)
Administrative/Clerical: Clerical, administration, Medical Secretary/ Personal Assistant, Clinician's assistant/Clinic assistant, Accountant/Accounts clerk, Analyst/ICT/ Data/Data scientist/steward/ DRIVE tech lead, Research, Lawyer/Paralegal, Workforce/Corporate, Coder	131 (20.1)	91 (17.8)	123 (21.7)
Expanded Allied Health Professionals (AHPs): Physiotherapist, Speech and Language Therapist, Dietician, Occupational therapist, Operation Department Practitioner, Orthoptist, Radiographer, Orthotist, Sonographer, Pharmacist, Audiologist, Optometrist, Social worker, Genetic counsellor, Family therapist, Teacher, Play specialist/worker, Clinical academic, Clinical psychologist/assistant psychologist/psychotherapist, Social scientist, Associate/advanced practitioner/transfusion practitioner, Perfusionist	89 (13.7)	76 (14.8)	77 (13.5)
Medical	87 (13.4)	73 (14.3)	70 (12.3)
Other (Patient-facing): Healthcare Assistant, Support Worker, Housekeeper, Chaplain, Porter, Patient experience, Patient liaison, Interpreter, Dental technician, Arts	33 (5.1)	20 (3.9)	41 (7.2)
Other (Non-patient facing/not clear): Resus Officer, Engineer, Facilities, Estates, Shift Technician (Mechanical), Technician (clean room), Clinical SIM technician, Student, Technical specialist, Clinical/Healthcare Scientist (Biomedical/Biochemical/Physiologist), Genetic technologist, Lab assistant, Managerial/ Team leader/Coordinator	95 (14.6)	103 (20.1)	108 (19.0)
Unknown/Not specified	19 (2.9)	19 (3.7)	18 (3.2)

7.4.2 Representativeness to the GOSH staff population

Representativeness of the staff survey participants to the GOSH staff population is presented in Table 7-2.

Table 7-2: Representativeness

	Staff at T_1	**GOSH Staff**	***P* value**
Staff group	***n*=650 (%)***	***n*=5074***	
Nursing	196 (30.2)	1619 (31.9)	Chi-square statistic 7.3 *p*=0.12
Administrative/Clerical	131 (20.1)	901 (17.8)	
AHPs	89 (13.7)	565 (11.1)	
Medical	87 (13.4)	723 (14.2)	
Other (Combined patient-facing/non-patient facing) and unknown/not specified (Staff at T_1 = 19; GOSH staff = 200)	147 (19.7)	1266 (21)	

Survey participants at T_1 were representative of the GOSH population.

7.4.3 Response rate

Table 7-3 presents the survey distribution and response rates across the three time-points.

Table 7-3: Survey distribution and response rate across three time-points

	T_1	T_2	T_3
Distributed	5445	6407	5879
Undeliverable	576	375	477
Total delivered	4869	6032	5402
Total responses	1065	524	591
Partial responses	415*	12	23
Submitted responses	**650****	**512**	**568**
Response rate %	**13.3%**	**8.5%**	**10.5%**

*The partial response numbers reported here were thought to be related to having unique study number/job title/speciality as mandatory fields in baseline survey (required for paired data analysis). This mandatory field was removed in subsequent surveys to promote completion of surveys, but may have resulted in far fewer partial responses.

**650 submitted baseline responses included 18 completed paper surveys from distribution in staff areas of the hospital.

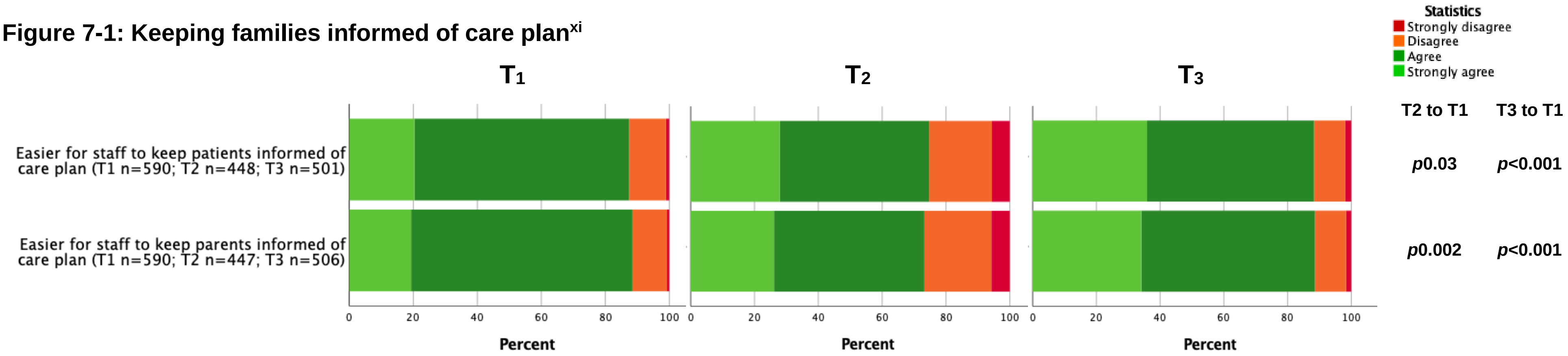
7.4.4 *Survey findings*

7.4.4.1 Keeping families informed of the care plan

Hypothesis 1: Electronic patient records will make it easier for staff to keep families informed of the care plan.

Staff were asked whether they perceived it would be easier (T_1), or was easier (T_2/T_3), to keep families informed of the care plan after EPR implementation (Figure 7-1).

Figure 7-1: Keeping families informed of care plan[xi]



[xi] This is to remind the reader that the colour coding used in the stacked bar charts reflects what is considered a positive or negative response for the question e.g. green represents a positive response; red represents a negative response. At times, this may mean that disagreement is a positive thing, and would be reflected in green, or that agreement is a negative, and reflected in red. It is acknowledged that people who are colour blind may find the chosen colours difficult to interpret but the aim is to present the results in a manner which conveys the voice of young people and their experience of transition to EPR and MyGOSH.

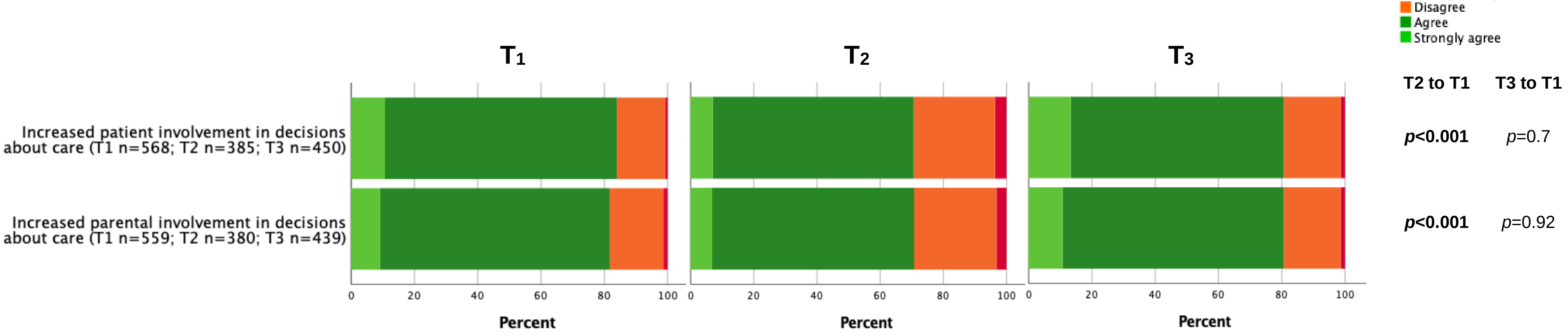
Although there was overall agreement amongst staff across all three time-points that following EPR implementation it would be, or was, easier to keep patients and their parents informed of the care plan, there was a significant trend at T_2 for less agreement from staff who responded at T_1. This means it was more difficult for staff to achieve this six months post-implementation. Therefore, the hypothesis was not supported at T_2, but was supported at T_3.

7.4.5 Family involvement in care

Hypothesis 2: Following MyGOSH implementation, staff will perceive that families were more involved in care.

Staff were asked whether they perceived MyGOSH would result (T_1), or did result (T_2/T_3) in families being more involved in decisions about care (Figure 7-2).

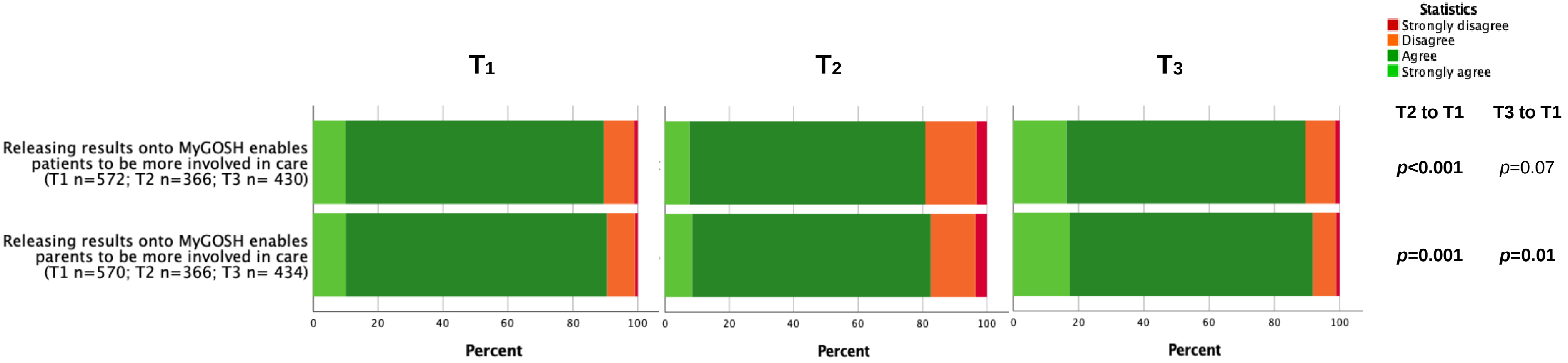
Figure 7-2: Increased family involvement in decisions about care



No change was seen over time to demonstrate that following MyGOSH implementation, families' involvement in decisions about care would be, or was, increased. Furthermore, there was a significant trend at T_2 for less agreement from those who participated than staff respondents at T_1. The hypothesis was not supported.

Related to this, staff were asked whether they perceived releasing results onto MyGOSH would enable (T_1), or did enable (T_2/T_3), families to be more involved in care (Figure 7-3).

Figure 7-3: Results release onto MyGOSH enabling family involvement



There was overall agreement amongst staff across all three time-points that releasing results onto MyGOSH would enable, or did enable, families to be more involved in care, however, a significant trend of less agreement from respondents was seen at T_2 compared with those who responded at T_1. At T_3, a significant trend of increased agreement was only seen related to parents' involvement in care.

Therefore, the hypothesis was not supported at T_2, and at T_3 this was only supported in relation to the perceived impact that releasing results on MyGOSH has on involvement in care for parents but not patients at T_3.

7.4.6 Support families

Hypothesis 3: Following EPR implementation, staff will feel more confident in their ability to support families in relation to care.

Staff were asked a series of questions about their expectations of how confident they would feel (T_1), or did feel (T_2/T_3), in their ability to support families to make a decision about care; answer questions; manage anxiety; and manage conflict (Table 7-4). Staff ranked their answers on a scale of 1-10, 1 being the lowest (not at all confident) and 10 being the highest (extremely confident).

Table 7-4: Staff confidence in their ability to support families

	T_1 n=650		**T_2 n=512**		**T_3 n=568**		**P value****
Survey statement	**n=**	**Median (IQR*)**	**n=**	**Median (IQR*)**	**n=**	**Median (IQR*)**	
1) Support patients to make a decision about their care	455	8 (8-9)	301	8 (6-9)	359	8 (7-9)	**p=0.001**
2) Support parents to make a decision about care	465	9 (8-9)	310	8 (6-9)	362	8 (7-9)	**p=0.001**
3) Answer patients' questions	494	9 (8-9)	342	8 (7-9)	393	9 (8-9)	**p=0.001**
4) Answer parents' questions	510	9 (8-9)	360	8 (7-9)	415	8 (8-9)	**p=0.001**
5) Manage patient anxiety	475	8 (7-9)	315	8 (7-9)	374	8 (7-9)	**p=0.02**
6) Manage parent anxiety	490	8 (7-9)	333	8 (7-9)	389	8 (7-9)	**p=0.01**
7) Manage conflict	542	8 (7-9)	345	8 (6-9)	398	8 (7-9)	**p=0.001**

*IQR = Interquartile range; **Significance testing was performed using the Kruskal-Wallis non-parametric test

Statistically significant differences were seen for all survey points. The differences suggested a decrease in confidence in each domain This hypothesis is not supported.

Below are box plot representations of the above findings, which more clearly shows the distribution of the data (Figure 7-4).[xii]

[xii] Box plot representation of these data show the upper and lower quartiles (the rectangle), with the median demonstrated as the horizontal line. Variability outside these quartiles is represented by the vertical lines (whiskers) either side of the rectangle, with outliers plotted as individual points.

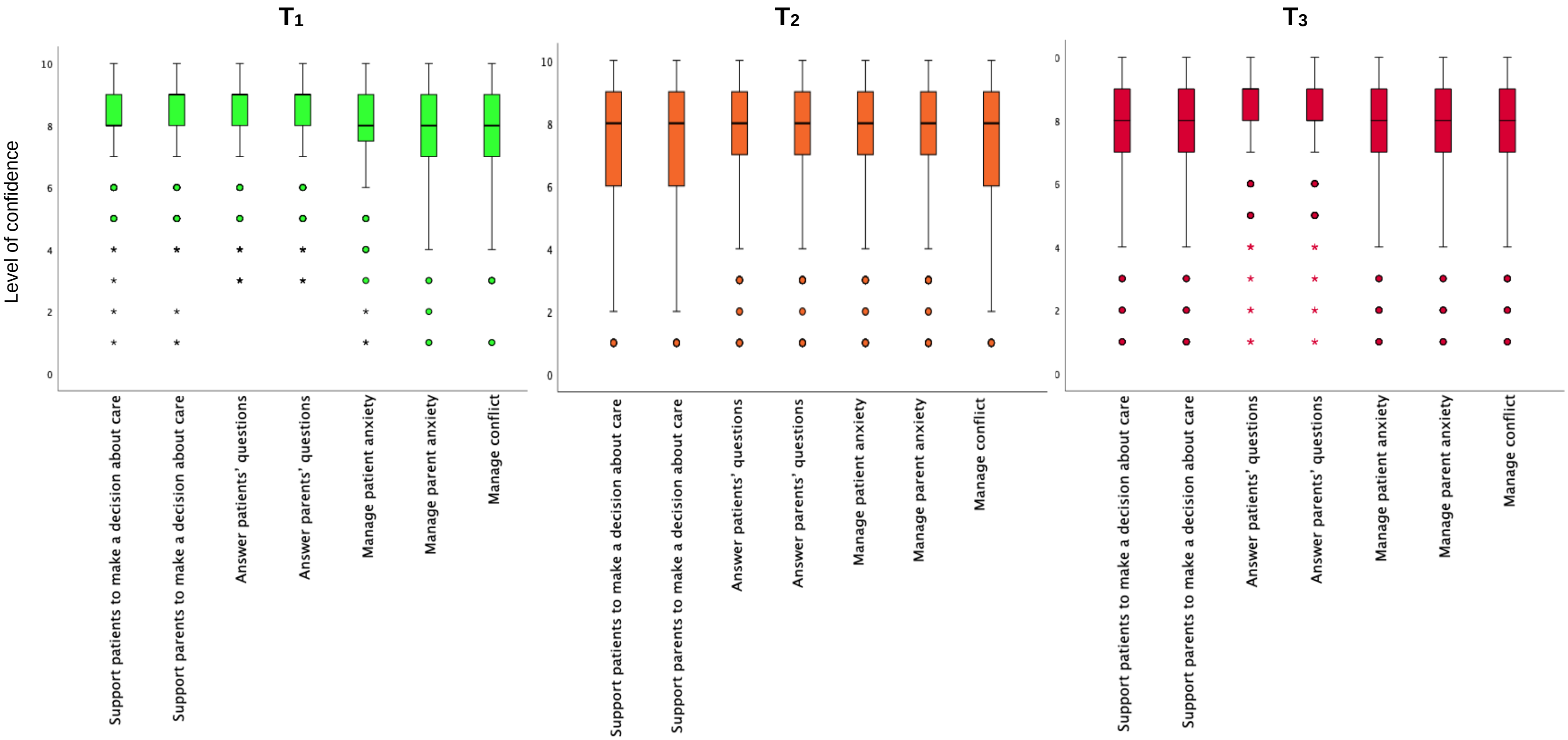
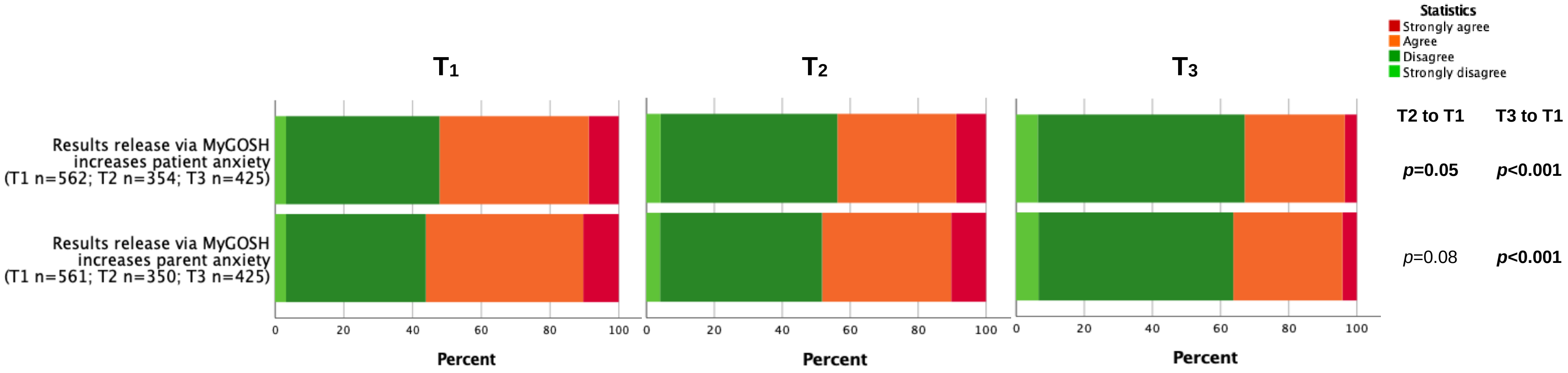


Figure 7-4: Staff confidence in their ability to support families

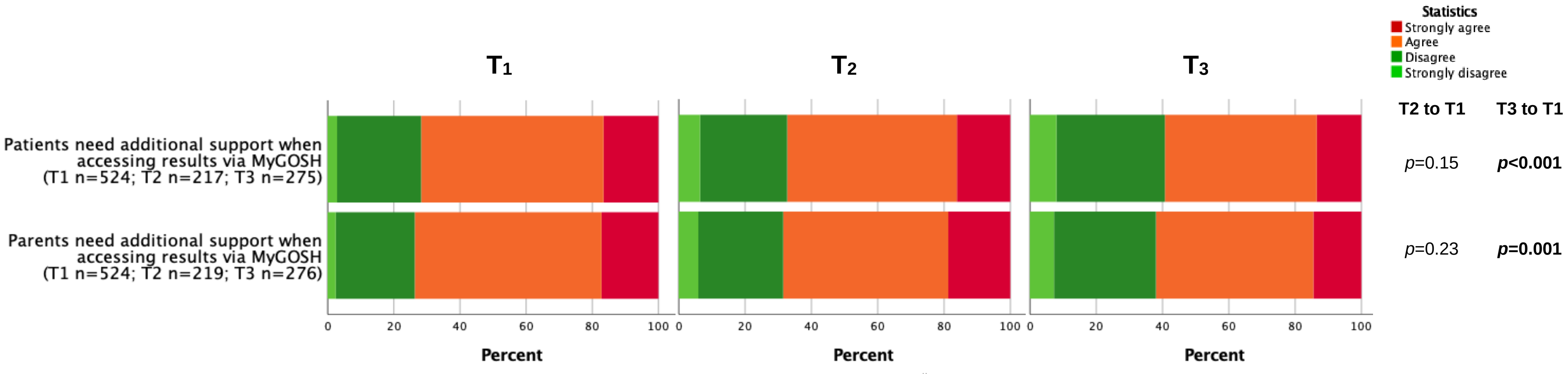
Related to supporting families, staff were asked whether they perceived releasing results onto MyGOSH would increase (T_1), or did increase (T_2/T_3), anxiety for families (Figure 7-5), and whether families would need (T_1), or did need (T_2/T_3), additional support when accessing results (Figure 7-6).

Figure 7-5: Results release via MyGOSH and family anxiety



These results demonstrate that at T_1 staff felt that releasing results onto MyGOSH would increase patient and parent anxiety. Although the proportion of respondents reporting this reduced over time from T_1 to T_3, with a significant trend for a higher proportion to disagree with this notion, approximately a third of respondents still perceived results release via MyGOSH caused patient and parent anxiety at T_3, 18 months after system implementation.

Figure 7-6: Family support when accessing results via MyGOSH



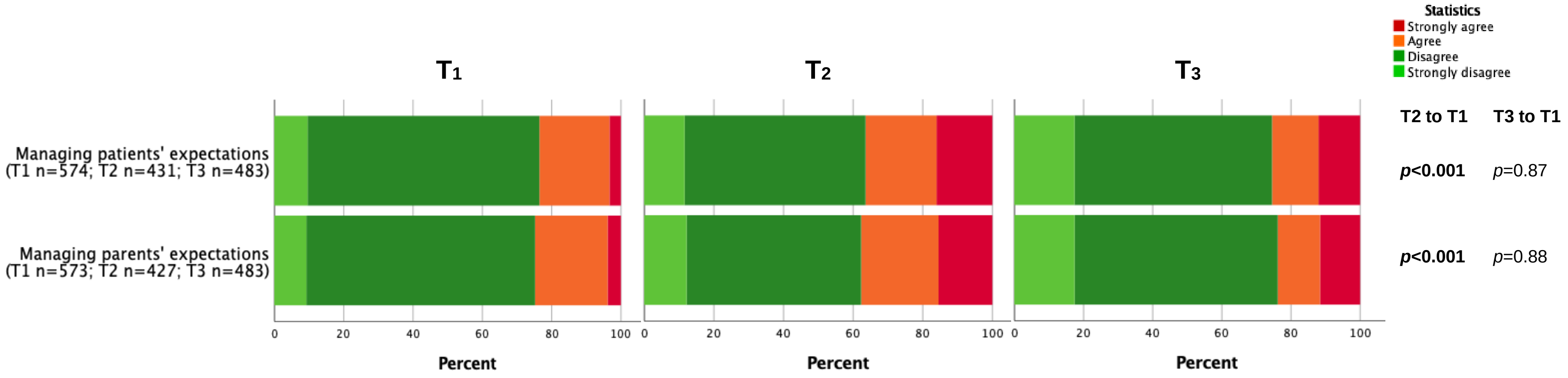
Also related to releasing results onto MyGOSH, the majority of staff agreed that families would need, or needed, additional support when accessing results via MyGOSH. Similar to Figure 4, there was a significant trend for a lower proportion to report families needing support at T_3, but approximately 60% of respondents perceived this still to be the case at this time, 18 months after system implementation.

7.4.7 Managing families' expectations

Hypothesis 4: Electronic patient records use will make it more difficult to manage families' expectations.

Staff were asked if they perceived EPR use would make (T_1), or did make (T_2/T_3), it more difficult to manage patient and parent expectations (Figure 7-7).

Figure 7-7: Managing families' expectations



	T2 to T1	T3 to T1
Managing patients' expectations	***p*<0.001**	*p*=0.87
Managing parents' expectations	***p*<0.001**	*p*=0.88

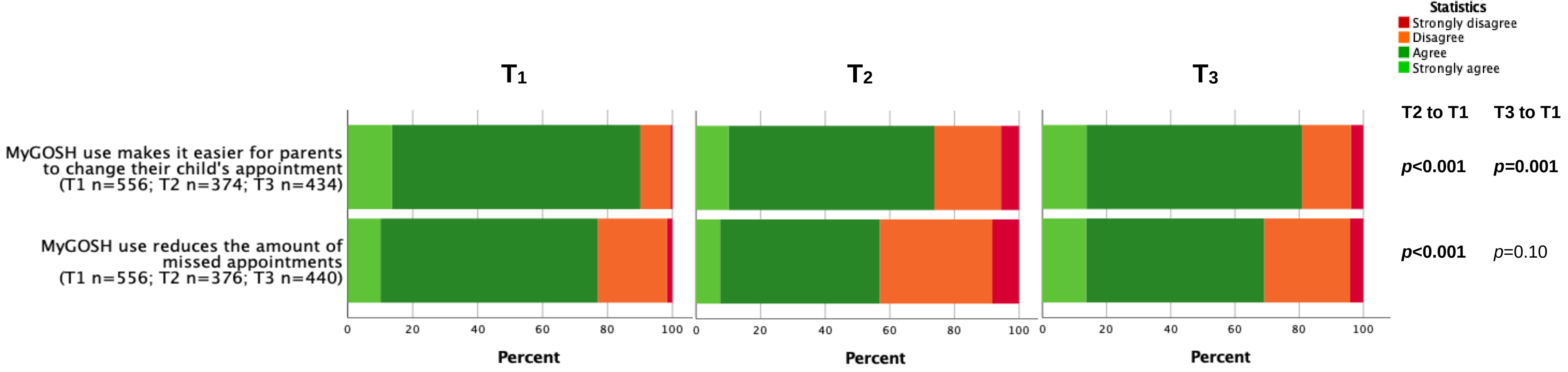
Over two thirds of staff respondents at T_1 did not perceive EPR use would make it more difficult to manage families' expectations. However, there was a significant trend at T_2 for respondents to report more negative responses than those who responded at T_1. This may suggest that it was more difficult to manage families' expectations in the early stages after EPR implementation rather than when staff were more practised at using the system. Therefore, this hypothesis was supported at T_2, but not at T_3, meaning that overall, EPR made it more difficult to manage expectations.

7.4.8 Managing appointments

Hypothesis 5: Following MyGOSH implementation, staff will perceive that it will be easier for parents to change their child's appointment.

Staff were asked if they perceived MyGOSH would make it easier (T_1), or it was easier (T_2/T_3), for parents to change their child's appointment. Related to this, staff were asked whether they perceived MyGOSH use would reduce (T_1), or did reduce (T_2/T_3), the number of missed appointments (Figure 7-8).

Figure 7-8: Ease of changing appointments via MyGOSH, and whether MyGOSH use reduces missed appointments



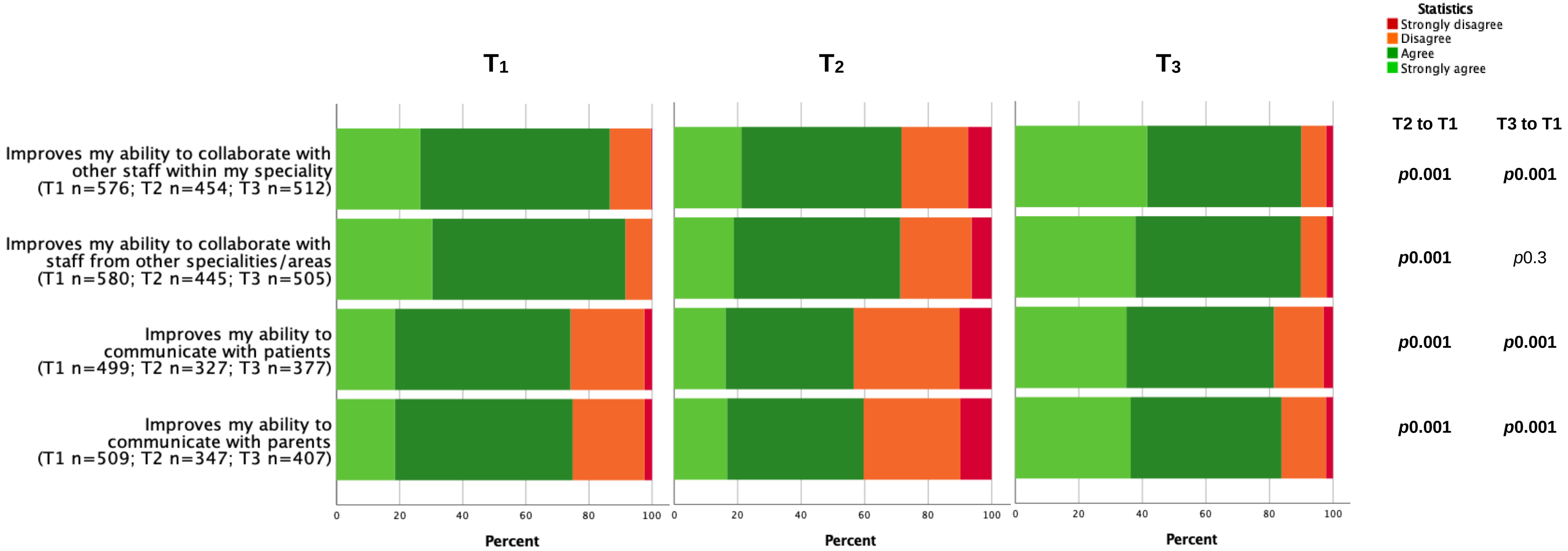
Whilst the majority of staff agreed or strongly agreed that the portal would make it easier for parents to change their child's appointment and it would reduce the number of missed appointments, levels of agreement were higher before implementation than afterwards. At T_2 in particular, a significant trend was seen for a higher proportion to report disagreement than those who responded at T_1. Furthermore, at T_3, there was a significant trend for a higher proportion to report disagreement compared with T_1 related to ease of changing appointments. The hypothesis was not supported.

7.4.9 Communication

Hypothesis 6: EPR/MyGOSH will improve staff's ability to communicate with other professionals and families over time.

Staff were asked a series of questions about whether they perceived their ability to collaborate with other staff, and communicate with families would improve (T_1), or did improve (T_2/T_3), after EPR implementation (Figure 7-9)

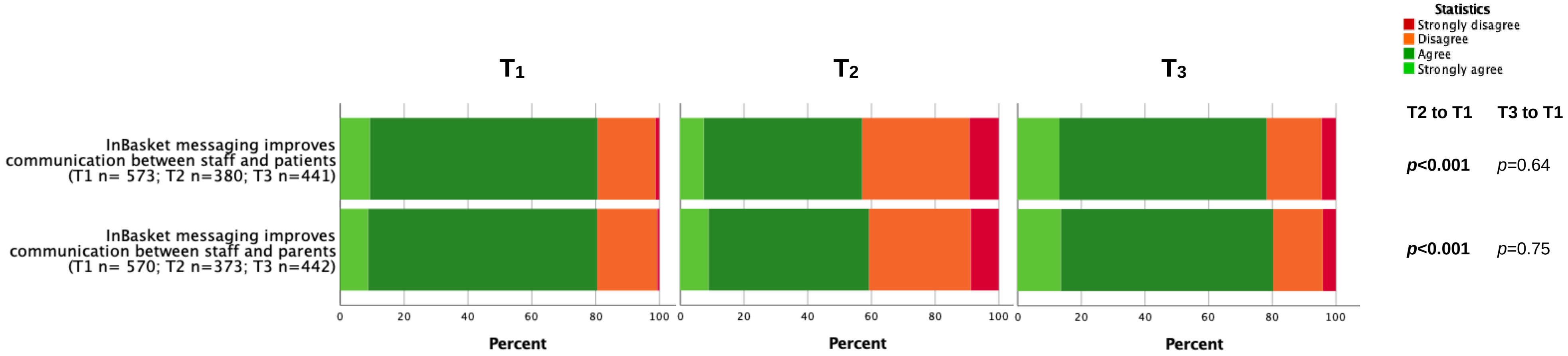
Figure 7-9: Improvements in communication and collaboration



At T1, responses were mostly positive >70% selecting agree/strongly agree for each question. However, T2 demonstrated a significant trend for a lower proportion of respondents to report agreement than those who completed the survey at T1, reflecting that it may have been harder to achieve these improvements in collaboration and communication in the early phases after system implementation. At T3, there was a significant trend for a higher proportion to report increased levels of agreement related to in-speciality collaboration, and improved communication with both parents and patients. This hypothesis was partially supported.

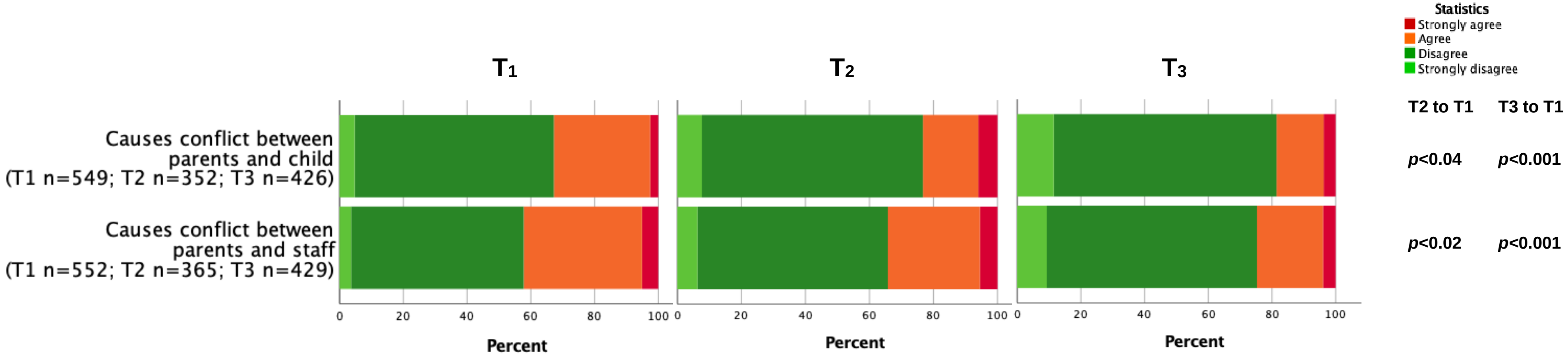
Related to this, staff were asked whether they expected the InBasket messaging function via MyGOSH would improve (T_1), or it had improved (T_2/T_3), communication (Figure 7-10), and whether it would cause conflict (T_1), or caused conflict (T_2/T_3), between staff and families (Figure 7-11).

Figure 7-10: Improvements in communication via InBasket messaging



Agreement levels were high at T_1 related to the expected improvements in communication via InBasket messaging. However, a significant trend for a lower proportion reporting agreement was seen at T_2, demonstrating it may have been harder for staff to determine whether ‘InBasket’ messaging improved communication at this early-stage post-implementation.

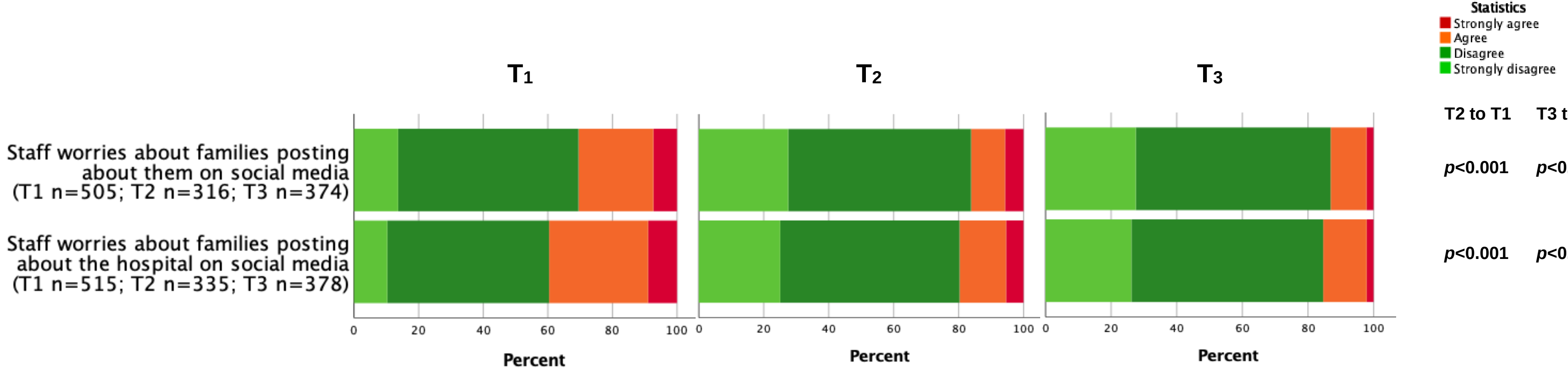
Figure 7-11: The messaging function via the portal (InBasket messaging)



Staff members' perceptions of InBasket messaging having the potential to cause or causing conflict between parents and their child and between parents and staff were highest at baseline than post-implementation. Responses at both T_2 and T_3 demonstrated a significant trend for a lower proportion report negative responses, which may mean that with use, staff perceived InBasket messaging to not be a cause of conflict.

Related to the topic of communication, staff were asked if they were worried about families posting about them or the hospital on social media (T_1/T_2/T_3; Figure 7-12), and whether they perceived MyGOSH use would make it easier (T_1), or it was easier (T_2/T_3), for families to share health data on social media (Figure 7-13).

Figure 7-12: Staff worries about families posting on social media

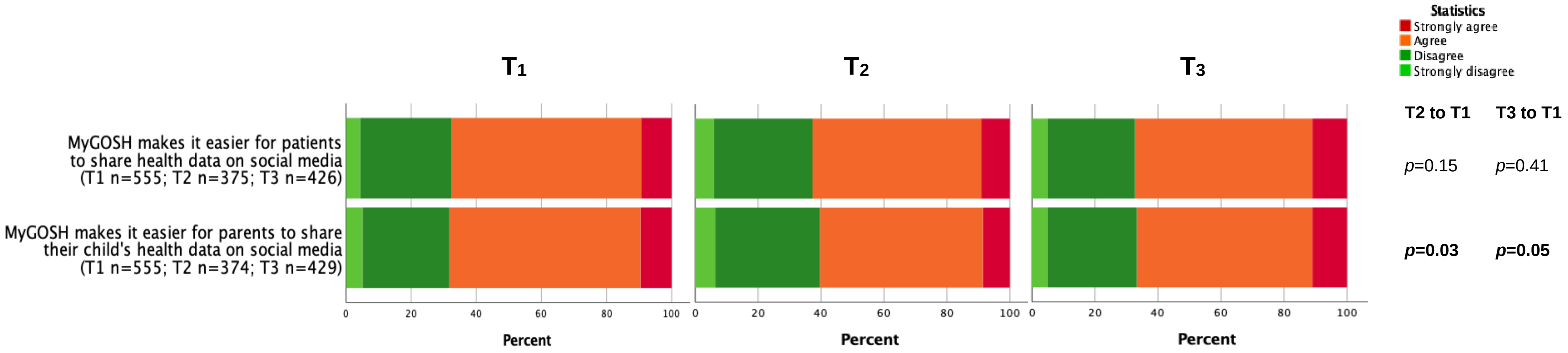


T2 to T1	T3 to T1
p<0.001	*p*<0.001
p<0.001	*p*<0.001

Staff worries about families posting about them or the hospital on social media were highest at T_1, with worries reducing over time with EPR/MyGOSH use. Overall, a significant trend was seen at both T_2 (as compared with those who responded at T_1) and at T_3 (compared with those who responded at T_1) for a lower proportion to report negative responses, suggesting that staff worries reduced over time after the use of EPR/MyGOSH.

Staff were also asked about MyGOSH making it easier for patients and parents to share health data on social media (Figure 7-13).

Figure 7-13: Staff perceptions of whether MyGOSH use makes it easier for families to share health data on social media

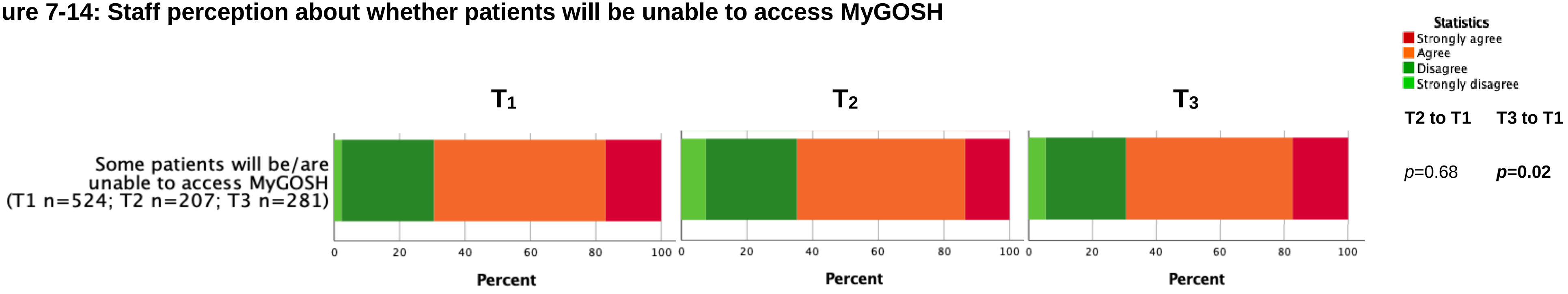


There was an overall consensus among staff at all three time-points that MyGOSH would, or did, make it easier for families to share health data on social media. No changes over time were seen related to patients. Regarding parents, however, a significant trend was seen for a lower proportion to agree/strongly agree at T_2, compared with T_1 respondents; and again at T_3, a significant trend was seen for a lower proportion of respondents to agree/strongly agree compared with T_1 respondents.

7.4.10 Barriers to accessing MyGOSH.

We were also interested in staff perceptions of patients’ ability to access MyGOSH. Staff were asked if they agreed or disagreed that some groups would be (T_1), or were (T_2/T_3), unable to access MyGOSH (Figure 7-14).

Figure 7-14: Staff perception about whether patients will be unable to access MyGOSH



There was overall agreement amongst staff across all three time-points that some patients would be or were unable to access MyGOSH, with >64% of respondents agreeing or strongly agreeing with this statement. At T_3, there was a significant trend for a lower proportion to answer positively, demonstrating that staff perceive barriers to patients accessing MyGOSH continue to exist 18 months after implementation.

7.5 Discussion

Staff members’ views and perceptions were captured from before (T1; *n*=650), at six months after (T_2; *n*=512), and 18 months after (T3; *n*=568) EPR and MyGOSH implementation. Survey participants (at T_1) were representative of the GOSH population.

It is acknowledged that the number of surveys distributed at T_1 (*n*=5445; Table 7-3) does not match the GOSH staff population number (*n*=5074; Table 7-2). This is believed to be because the staff list provided at the time was not 100% up to date with those staff members leaving or on leave for other reasons as this is accurately collated retrospectively (which is explained by the number of undeliverable emails). This means that the GOSH staff population figure will be an accurate reflection.

Hospital staff members’ views and perceptions of transitioning to an electronic patient record system with an EPR-tethered patient portal were sought on a wide range of topics at all three time-points. The results presented in this chapter relate only to the impact EPR and MyGOSH had on staff members’ ability to provide care and support for families. Each hypothesis, the related findings and whether the hypothesis was supported is presented below in Table 7-5. A discussion will follow relating the hypotheses and findings to the relevant research literature.

A study by Kelly et al. (2017) reported that healthcare team members perceived parents felt more in control and more involved in their child’s care after patient portal use [76]. In another study by Chung et al. (2018) it was reported that parental access to their child’s EPR during hospitalisation encouraged parental involvement [70]. Giving parents access to their child’s medical records was reported to result in parents feeling they had a better understanding of their child’s illness [70, 93]; medical tests/results [82]; and medical terminology [91, 97]. This led to parents feeling empowered to advocate for their child [70]; manage their child’s condition [93] and feel less reliant on staff [47, 75].

Table 7-5: Hypotheses, key findings and whether each hypothesis was supported

Hypothesis 1: EPR will make it easier for staff to keep families informed of the care plan.	
• Staff perceived it was more difficult to keep families informed of the care plan 6 months after implementation • At 18 months after EPR implementation, staff perceived EPR made it easier to achieve this	**Hypothesis partially supported**
Hypothesis 2: Following MyGOSH implementation, staff will perceive families being more involved in care.	
• Following MyGOSH implementation, staff did not perceive families to be more involved in decisions about care	**Hypothesis not supported**
Hypothesis 3: Following EPR implementation, staff will feel more confident in their ability to support families in relation to care	
• Following EPR implementation, staff did not feel more confident in their ability to support families in relation to care	**Hypothesis not supported**
Hypothesis 4: EPR use will make it more difficult to manage families' expectations	
• Staff perceived EPR use made it more difficult for them to manage families' expectations in the early stages post-implementation • No change over time was seen at follow-up, meaning that it remained difficult to manage expectations	**Hypothesis not supported**
Hypothesis 5: Following MyGOSH implementation, it will be easier for parents to change their child's appointment	
• Following MyGOSH implementation, it was not easier for parents to change their child's appointment and it did not reduce the number of missed appointments	**Hypothesis not supported**
Hypothesis 6: EPR/MyGOSH will improve staff's ability to communicate with other professionals and families over time	
• Staff perceived it was more difficult to communicate with other professionals and families 6 months after implementation • At 18 months post-implementation staff perceived EPR/MyGOSH improved their ability to communicate with families • At 18 months after implementation, staff perceived EPR/MyGOSH improved their ability to collaborate with other staff within their speciality but not with staff from other specialities/areas	**Hypothesis partially supported**

Following EPR implementation, our findings demonstrated that staff did not perceive families to be more involved in decisions about care. However, staff reported it was easier for them to keep families informed of their care plan once they had been using the system for 18 months, however, it was more difficult to achieve this in the early stages after implementation. There was agreement amongst staff at all three time-points that releasing results onto MyGOSH enabled parents to be more involved in care, but it was again more difficult to achieve this soon after implementation. Staff also anticipated that results release via MyGOSH would increase patient and parent anxiety, and despite staff perception of this decreasing over time, this worry was still evident 18 months post-implementation, meaning families needed additional support when accessing results via the portal.

The systematic review in Chapter 2 identified that staff members required support post-EPR implementation to understand new EPR-related terminology [68], navigate system complexity [68, 89] and learn EPR functionality [47, 74]. Cognitive challenges also existed for staff, including increased cognitive workload [71, 100] and information overload [100]. These were especially evident in the early phases post EPR/portal implementation [71], abating at differing rates post-implementation [47, 71]. This was also evident in our study. Aspects of care relating to keeping families informed of the care plan, increased family involvement in decisions about care, results release enabling family involvement, managing family expectations, collaborating and communication were more difficult for staff to fulfil six months after system implementation (T_2), as opposed to 18 months post-implementation (T_3). Furthermore, burdens on staff were also described in the literature and systematic review including the impact of EPR and portal use on time and increased workload [68, 70, 73, 74, 76, 79], with time-consuming data entry processes [68] and time spent on computers [79], both affecting workflow [47, 76]. These factors were reported to negatively impact staff's ability to provide patient care [68, 74, 76], and reduced face-to-face patient interaction in the clinical setting [73, 76, 79]. A lack of IT support could create barriers to staff system use and usability [89], further detracting from patient care [68]. Consequently, extended periods of technical support may be required for some staff members when transitioning to a new EPR system [71], which can also disrupt workflow and normal ways of working, creating additional burdens on staff, particularly in the early phases post-implementation [47].

For families and patients, a benefit of portal access is being able to manage appointments easily via the portal [87], and a reduction in missed appointments has been demonstrated after portal utilisation [174]. However, our findings did not concur as staff reported it was not easier for parents to change their child's appointment following MyGOSH implementation, and it did not reduce the number of missed appointments. A confounding factor which may explain the lack of reduction in missed appointments may be attributed to the transition to virtual care during the pandemic [175].

The communication-related benefits of using an EPR and patient portal are well documented including improved communication between clinical teams, and improved communication between parents and the care team [70, 76, 82, 85, 87, 93, 97]. Furthermore, staff members' ability to collaborate with others within their speciality, and with staff from other specialities is also reported in the literature as the EPR systematically integrates patient data from different specialties, resulting in a shared and comprehensive health record [176]. This promotes a mutual understanding amongst health professionals, facilitating the coordination of care [176]. Our findings indicate improvements over time in staff's ability to communicate with families, as well as improvements over time in collaboration within the same speciality but not with staff from other specialities. Vos et al. (2020) also reported EPR-related hinderances to collaboration among healthcare professionals [176]. These were related to different specialities within the hospital using EPR functions such as problem lists or medical histories in different ways, with reports of staff members experiencing information overload trying to decipher pertinent clinical details if numerous individual notes were entered into the system [176].

With an era of widespread use of social media, and following high profile cases surrounding limiting or withdrawing life-sustaining treatment from children [177-180], staff members who attended the phase one workshops worried that MyGOSH access may make it easier for families to post on social media. Families would have easier access to health-related information and messages from professionals. Staff members worried about families posting about them or the hospital, or sharing health data on social media. Our findings confirmed that staff members perceived it would be easier for families to share health information on social media across all three time-points. Worries stemmed from the rise in the populist rhetoric to vilify medical and professional expertise and public funded healthcare, and the promotion of the lay-expertise from behind the shield of social media [177]. However, the survey findings demonstrate that staff worries about families posting about them or the hospital on social media reduced over time, with more use of MyGOSH.

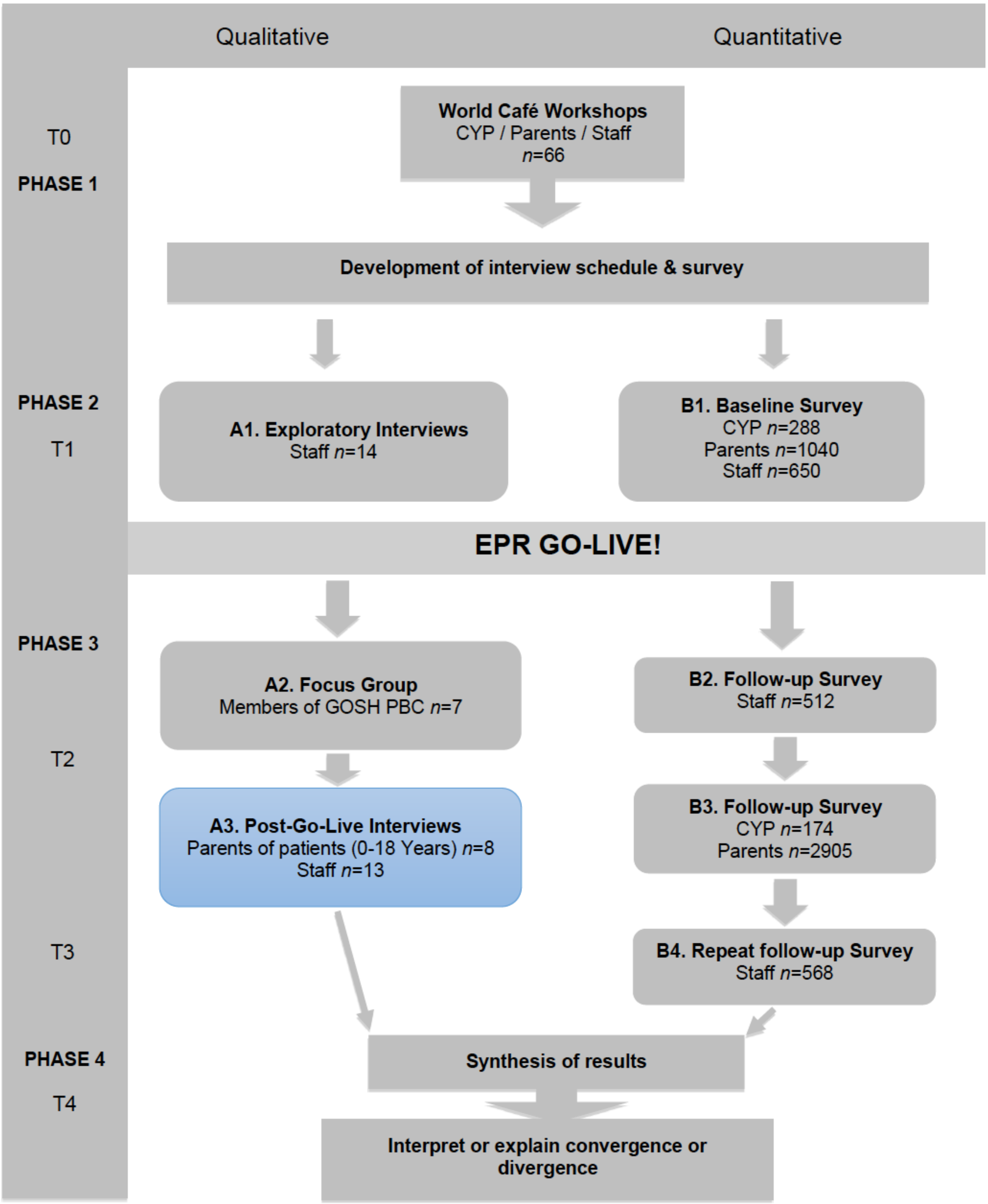
As the use of patient portals increase, with the potential for increasing health quality and efficiency, it is important to acknowledge that some families will be unable to access or use them, with the potential worsening of health disparities [154, 181]. In our study, staff reported a high level of agreement across all three time-points that some patients experience difficulties accessing MyGOSH (>64%). Although this is not explored in any further detail in the staff survey findings, the barriers to accessing and using patient portals are well documented [37, 154, 155, 181, 182] and relate to age and race [37, 154, 155, 182], functional impairment [182], income [37, 154], internet equality [37, 154, 181], and health literacy [182], with the need for patient portals to be available across multiple platforms to reduce disparities in access [154]. What our findings do show is that, unlike some other findings where worries or concerns lessened after using the new system, there was no significant change over time, indicating that this was a persistent concern, and action needs to be taken to reduce barriers to accessing MyGOSH.

7.6 Summary

Challenges exist for staff members to meet the needs of those within their care, especially in the earlier stages after EPR and MyGOSH implementation, leaving staff not feeling confident in their ability to provide support and care to families. Additional burdens were evident around results release via the portal. Although staff perceived that releasing results onto MyGOSH enabled families to be more involved in care, it also increased family anxiety, resulting in additional support being required during a time of already increased burden for staff members. These additional burdens on staff need to be factored in when resource planning system implementation in terms of the provision of additional staff members to manage the workload. However, despite these challenges, staff reported improved communication with families and improved collaboration amongst professionals. Although staff members consistently perceived MyGOSH would make it easier for families to share health related information on social media, their worries about families posting about them or the hospital reduced over time, with MyGOSH use. Staff perceived there to be ongoing barriers to their patients being able to access MyGOSH.

In the next chapter, the parent interviews conducted during the qualitative aspect of phase three of the study will be presented.

Chapter 8 Parent Interviews



8

8 Parent interviews

8.1 Introduction

The focus of this chapter is the parent interviews that were conducted during the qualitative aspect of phase three of the study. Firstly, the methods are described including interview schedule development and participant recruitment, followed by data analysis. The results are presented, with key themes illustrated through parent quotes, and a discussed in relation to pertinent research literature. Finally, the chapter will be summarised.

8.2 Context and setting

As part of the post go-live exploration of stakeholder views, parents were invited to participate in interviews approximately 18 months after Great Ormond Street Hospital (GOSH) transitioned to an electronic patient record system (EPR) and MyGOSH patient portal. The interviews were initially planned for 12 months post-implementation but due to the Coronavirus 2019 (COVID-19) pandemic, they were delayed until after the first wave (August 2020).

8.3 Aim

The parent interviews aimed to understand participants' perceptions and experiences of GOSH's transition to EPR and MyGOSH patient portal and how this affected the care of their child, including: communicating and interacting with healthcare professionals; their involvement in decision-making; viewing results; and managing their child's care.

8.4 Methods

8.4.1 Interview schedule development

The interview schedule was developed based on relevant literature and the results of workshops held with all stakeholders during phase one (see Appendix 32).

8.4.2 Participant inclusion and exclusion criteria

8.4.2.1 Inclusion

- All parents of children of all ages who were patients at GOSH and who had signed up to MyGOSH

8.4.2.2 Exclusion

- None

8.4.3 Sampling strategy

During phase three of the study, parents were able to express an interest in participating in the study interviews by leaving their contact details upon completing the parent survey. Out of 2905 parents who completed the survey, 180 parents volunteered their contact details. A process was put in place to manage this response sensitively and systematically. First, respondents were grouped according to how many specialist teams the child was under and the child's age. Second, a random number generator selected a sample of parents from each group, with the aim of inviting a range of parents caring for children of different ages with a variety of clinical needs. Groups of only ten parents were invited at a time, to ensure that everyone who came forward could be interviewed.

8.4.4 Participant recruitment and consent

Selected parents were sent an email inviting them to participate in the interviews. A reminder email was sent one week after the initial invitation. Those who responded were sent a participant information sheet (Appendix 40), with researcher contact details in case participants had any questions, and with the option to talk via zoom or telephone prior to the interview if required.

Parents who agreed to participate were sent the informed consent form (ICF) via email (due to the coronavirus restrictions limiting interviews to virtual methods; Appendix 41). Parents completed and returned the ICF prior to the interview. At the start of the interview the researcher answered any questions and verbal consent was re-confirmed and recorded.

8.4.5 Sample size

Choosing an appropriate sample size in qualitative research is debated in the literature, and is an area of practical uncertainty [183]. According to Sandelowski (1995), a sample size in qualitative research ought to be of a size that makes the material manageable, yet big enough to ensure 'a new and richly textured understanding of experience' (p.183) [184]. This may be guided by the research aims, researcher experience [185] and qualitative methodology. A sample of 8-10 participants was considered as being sufficient for capturing rich, in-depth parental experiences and perceptions, whilst manageable in the context of the multiple strands of data being collected.

8.4.6 Data collection

Originally, the interviews were planned to be face-to-face in a suitable location in the hospital at a time convenient to the parent. However, due to the pandemic, submission of a non-substantial amendment enabled interviews to be conducted virtually or over the telephone, providing some choice to participants. With participants' permission, interviews were audio-recorded for transcription accuracy and transcribed verbatim. Secure and anonymous data storage was in accordance with the Data Protection Act [103].

8.4.7 Data analysis

Qualitative data generated from the interviews were analysed using thematic analysis. Taking a reflexive thematic approach enabled patterns of meaning across the dataset to be identified [122]. This focused on understanding and interpreting the participants' reality from the data, in this case the perceptions and experiences of parents in relation to EPR and MyGOSH use during the first 18 months' post-transition and how this affected the care of their child [122]. Coding and theme development were conducted using an inductive approach, driven by the data, coding without trying to fit a pre-existing coding framework [122, 186]. Codes and themes were identified through a rigorous six stage process: familiarisation; generating codes; generating initial themes, initial theme review; defining and naming themes; producing the report [186]. As part of the interpretation of the data, during the writing of each theme, the transcripts were revisited to check the parents' intended meaning. Each stage was checked and confirmed with a second researcher, one PhD Supervisor. The above processes gave rise to a thorough and robust approach to data analysis. Furthermore, the model of trustworthiness, advocated by Lincoln and Guba (1985), was used to assess research rigour within the qualitative research context [187]. This model, argued by Whittemore et al. (2001) to be the gold standard, is comprised of the criteria of credibility, transferability, dependability and conformability [187, 188].

Credibility refers to the extent to which research findings are an accurate representation of the participants' experiences insofar as the accounts are believable, and recognisable by those who share the same experiences or circumstances [189]. In this study, parents were valued as experts in their own lives, the care of their children and their experiences. They were given maximum opportunity to express their experiences, feelings, worries or concerns. The value of silence was also reinforced, as this gave thinking time for the participant and often elicited more explanation, expanding on their initial thoughts. This resulted in richer interview data and also enabled the researcher to understand the full meaning of participant experiences, which promoted credibility [188].

Transferability refers to the extent to which research findings are generalisable or applicable to other settings, beyond the context in which they are collected [190]. However, assessment of the transferability of the study findings is argued to be outside the realm of the researcher's judgement, meaning that it is up to others to judge whether the findings are applicable to other populations or settings [191, 192]. The provision of detailed, thick description of the research process and the study findings throughout the relevant chapters of this thesis aid assessment of transferability of the study findings by others [190, 191].

Dependability, also referred to as auditability, pertains to the degree to which another party is able to follow the researcher's decision trail [193]. Throughout this study, a reflexive diary was kept which included decisions made, challenges experienced and learning from each encounter. Field notes were also completed following each interview to capture immediate thoughts and feelings of the research activity, and notes were also kept throughout. These were essential due to the fast-moving pace of this large study.

Confirmability, meaning to confirm or corroborate the study findings. The researcher is said to demonstrate confirmability by engaging in the reflexive process, acknowledging their preconceptions and biases, and recognising their possible impact on shaping the study's findings [193]. This was done by keeping and referring back to my reflexive diary and through ongoing discussions with the PhD supervisory team. I was particularly mindful of my interest in ethics and was careful not to let this interfere with my judgement or impact the study's findings.

In addition to the above concepts, care was taken to ensure anonymity of the participants and their children by removing all identifiable information from quotes. This was especially important due to the specialist nature of GOSH, and due to patients with rare diseases being cared for at the hospital, making them potentially easy to identify.

8.5 Results

8.5.1 Participants

A total of eight semi-structured interviews were conducted, out of 71 invited parents: seven via zoom and one via telephone using the interview schedule in Appendix 32. Interviews lasted between 25-62 minutes, and were between 11 and 25 pages long. Parent demographics are represented in Table 8-1.

Table 8-1: Demographic details of interview participants

Demographic	Specifics
Gender	8 mothers
Ethnicity	3 White British, 1 White British Other, 1 White American, 3 Non-white
Age of Child	4-17 years
Number of GOSH teams child was under	1 team = 2 participants 2 teams = 3 participants 3 teams = 0 participants 4 teams = 1 participant 5+ teams = 2 participants
Number of children with an intellectual disability	3
Number of children with a physical impairment	2

8.5.2 Themes

Three themes with sub-themes were identified: 1) transitioning to an EPR system – lack of preparedness, lack of standardisation, and unfulfilled expectations; 2) Benefits – internal and external communication, practical benefits, and additional benefits; 3) Parental sense of responsibility for the child's health and well-being – promoting the child's autonomy, and reluctance to relinquish responsibility for child's health and well-being (Figure 1)

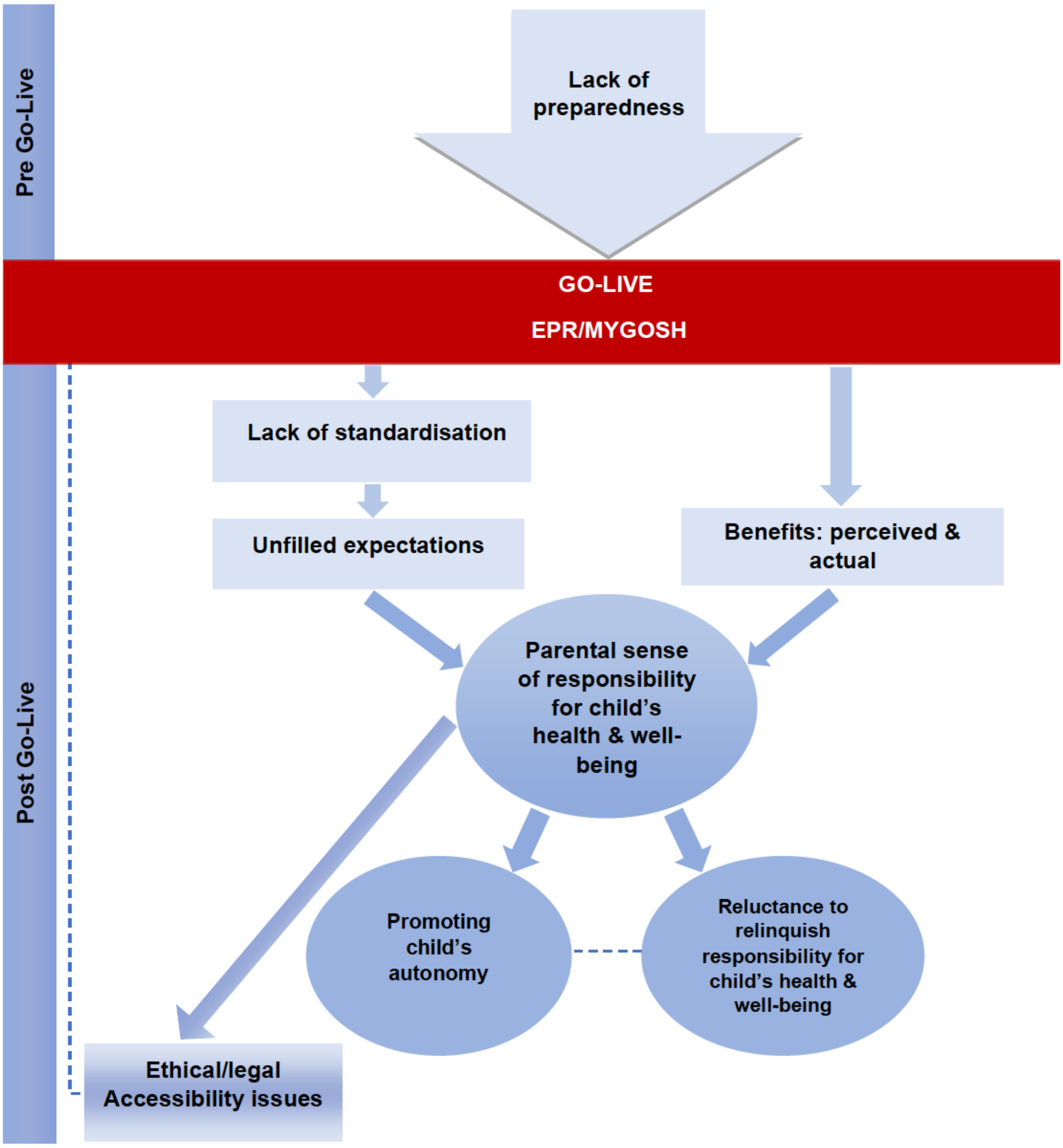


Figure 8-1: Parent interview findings

8.5.2.1 Transitioning to an EPR system

As previously highlighted, GOSH formally transitioned from paper and other numerous separate electronic systems and databases (over 500) to a single EPR system during the third week of April in 2019. Intensive support for staff from super-users (those trained to have a deeper understanding of the new system to give support to other staff) was provided for two weeks after go-live. Support thereafter was given from the EPR help desk, with an anticipated 'business as usual' from June 2019 [194]. The parent interviews revealed that, in practice, the process from implementation to 'business as usual' took much longer than anticipated. The interviews highlighted parents did not know when MyGOSH was coming into effect, how long it would take to be fully functioning, and what they would be able to do via the portal, creating anxiety and frustration. These factors meant that parents were not adequately prepared for GOSH moving to an EPR system with MyGOSH patient portal, resulting in some challenges being experienced during this transition period. In addition to the impact on parents from a lack of preparedness, parents perceived that staff were also unprepared, which affected their experiences of both face-to-face encounters and via MyGOSH.

8.5.2.1.1 Lack of preparedness

Parents were informed about the upcoming transition to EPR and MyGOSH at the end of clinic letters, which were sent to families in the post. Posters were also visible throughout the hospital and leaflets were accessible in the clinical areas. Despite two parents reporting feeling, "*well informed*" (P2), and that, "*they had* (been) *given a lot of information*" (P3) about the upcoming change, most parents did not feel well informed. Parents felt that the advertising was insufficient, for example, "*I didn't really see it in the hospital when I was last there"* (P4) or "*the advertising was very localised*" (P1). The parent of a 17-year-old described as having, 'special educational needs and disabilities' reported being completely unaware the portal was being implemented, "*I can honestly say I missed it*" (P1). She goes on to highlight:

> *"To put it in with appointment letters, it's wasted really … when you're busy and you've got a million things on your plate, you literally just open a letter, see which department it's from and when the date is, and you really don't read anything else. So, it's very, very easy to miss (P1).*

The degree of unpreparedness that parents could experience was highlighted further by one mother who did not find out about the hospital's transition to EPR until after the system had been implemented:

> *“We learned about it incidentally from clinicians looking bemused in appointments, and just every member of staff talked about Epic, the whole thing was Epic,- all saying they're struggling with systems. I mean, even from reception staff, everybody. So, that was the first knowledge that there was a new system” (P7).*

Lack of preparedness also impacted on parental decision-making about signing up to the GOSH portal in the first place:

> *“There were these signs all over the hospital and sheets to fill in and the receptionist by each of the clinics asked us if we wanted to join but that was about it. There wasn't really much information given about how the system would work” (P8).*

Some parents took the initiative themselves to find out more about the portal, *“I had to … find the information by myself”* (P4) and, *“I went online* (myself) *to register”* (P2). Parents expressed that much clearer communication was needed about any upcoming changes within the hospital, with parents wanting to know in advance, *“If there was anything they're still planning to roll out”* and wanting, *“a heads up”* (P3).

One parent provided feedback on the MyGOSH help desk, highlighting that when she called them to assist her, *“They say that it's not their* (responsibility) *-, it's always this blame game and pass the buck on to somebody else”* (P8). This parent felt that they had taught themselves how use, troubleshoot and resolve issues on MyGOSH, *“I think that at this point I probably have learned my way through MyGOSH”* (P8).

Parents offered suggestions for how best to communicate such changes to families, highlighting that, *“If you want to get information across, you've got to do it in the right way and in the right format”* (P1). As well as more advertising generally, the use of a factsheet and discussions from direct care team members were suggested. The timing of information giving, when staff had parents’ full attention was also viewed as important, for example, *“in the waiting room, because sometimes you can be waiting an hour for an appointment”* (P1).

Further to the need for improved communication about upcoming changes, parents felt that the hospital could have communicated MyGOSH functionality to families more effectively. Participants described how, in terms of functionality, *“Nothing has ever been explained … it was a case of go on and see”* (P7), and how *“It's definitely not very clear at all.”* (P8). Some interviewees were unaware of certain aspects of MyGOSH functionality prior to their interview:

> *Moderator: “… if there was a need for GPs to know, then yourselves and the clinical team can arrange for them to be sent a link, a time limited link. The GP can login and view whatever they need to view”.*
>
> *P4: “That's interesting. That is very good and that's something I didn't know, and that will be helpful”.*

Some parents were also unaware that they would be able to access their child’s results:

> *“I didn't realise I was ever going to get access to these results and then I had this little flag two weeks after clinic saying: 'You've got a new message on MyGOSH,' and I was, like, 'Oh, what's that?' It was blood results” (P5).*

Locating the ‘app’ on personal phones was also not necessarily straightforward due to it being called ‘MyChart’ rather than ‘MyGOSH’:

> *“I think there's such a disconnect between MyChart and GOSH … for ages, I couldn't find it. Perhaps because I couldn't remember what it was called” (P1).*

Parents reported being confused, anxious and frustrated by the challenges they faced with finding, accessing, utilising, and understanding the patient portal when it was implemented. Better information and clearer communication well in advance of any future process of change was consistently requested by parents.

Parents also felt that staff were unprepared. They reported on their own reflections that departments took up to 12-18 months to get used to using the system. This included enabling parents' access to results via the portal and communicating effectively with them via InBasket messaging. Parents shared frustrations related to staff members' unfamiliarity with the system, staff not knowing how to change information on the system, appointment cancellations or, conversely, seeing additional appointments on the system that were not a usual part of their child's care. One parent described finding erroneous appointments on the system:

> *"For some reason there were extra appointments, like he'd been put on as a new patient, and also his normal follow up appointment, and* (on) *different days … it was very confusing, … it turned out it was just somebody's error" (P3).*

Adding to parent frustrations during this period, care teams did not return parents' calls, and some parents were only able to see full results via MyGOSH 18 months after the system was implemented. The parent of a young person with physical and intellectual disabilities, requiring intervention from multiple agencies, and needing to book flights to attend appointments at GOSH felt extremely frustrated when their appointment was: *"cancelled ten times"* (P1). She went on to explain:

> *"There seems to be a lot of disorganisation and not knowing things … you will end up with people missing appointments … or people turning up for appointments that aren't valid" (P1).*

The extent of the impact of a poor experience of transitioning to EPR/MyGOSH was particularly highlighted by this parent, who revealed that in response to her experience, she was subsequently seeking treatment for her child at an alternative hospital.

When attending face-to-face outpatient appointments, it was apparent that staff members' lack of preparedness impacted on the experience for families. Parents reported how appointments were taking longer due to staff trying to navigate the new system, being unfamiliar with its functionality or trying to multi-task. One parent, for example, described how staff members were distracted by technology, with a resultant loss of face-to-face contact:

> *"They're typing away. You say one thing and then they continue typing, typing, typing and then sometimes when you interrupt … they don't like it" … it was a bit difficult* (with) *lots of silence and clicking and clacking going on … you just have to remain there, sitting quiet" (P4).*

Parents understood, however, that change takes time to implement, *"It's a massive change so of course we knew it was going to take time"* (P3). It was observed that as, *"clinicians are starting to get more comfortable with it, I see them … using it more effectively"* (P7). As discussed in a later section (8.5.2.2) despite the challenges experienced during the first 18 months post-transition, parents felt there were benefits and as one parent said, *"It's been worth it, really, to get this in place"* (P3).

8.5.2.1.2 Lack of standardisation

The interviews also revealed a lack of standardisation in departments' use of MyGOSH to manage patient care. This resulted in a lack of consistency in what information parents had access to, what health information was released onto the portal including *whether* results were shared, and methods of communication via InBasket messaging. This lack of consistency was most noticeable to parents of children under more than one speciality, creating feelings of frustration:

> *“How does it get decided what's enabled and what isn't, and why does it vary by specialty? That is the sort of thing that is very difficult in a patient experience if in one specialty you can do something,* (and in another) *you discover you can't” (P7).*

Whilst one parent with a child under multiple specialities experienced an overall improvement in communication, they recognised that this may not be solely related to the new system, *“I think that that it depends on the team. I think it's much more doctor-dependent”*, because *“when I send the team messages, they often don't reply”* (P8). One parent was unable to message the care team at all through MyGOSH because the function was not activated, and another participant described how it was by trial and error that they communicated with their care team with mixed responses from the teams, *“The XXX team are pretty good at picking up the messages, better than picking it up on email”* (P5).

A lack of consistent communication filtered through various aspects of parents’ experiences. They described variations in how test results were communicated to them, with different teams communicating using different approaches, including via MyGOSH, by telephone or in clinic prior to release onto the portal. Variations were also noted by staff within the same team. For one parent, a constant struggle seemed to be getting access to the results, *“Results don't go on automatically, they have to be released by the clinician … And it seems very hit or miss as to what is released”* (P7).

When thinking about communication between teams looking after their child, parents described how they anticipated EPR and MyGOSH would facilitate easier communication between teams, *“My daughter, she's under the care of three teams, and I feel like it would be easier for them to talk”* (P2). This participant also felt, *“more reassured that they're able to see everything in one place”* (P2). However, it was confusing for parents to receive information via MyGOSH and then also in the post, *“Everything seemed to be coming through* *the app and then I'd get a hard copy of that a week, sometimes two weeks, later"* (P1). Parents held the view that the release of information and communication via the portal were department and clinician specific, with a lack of standardised approach to communicating with them. However, a unified, standardised approach was desired by parents not only to reduce confusion but also, *"because that's what's going to make it* (MyGOSH) *really viable. Otherwise, you're still going to have two systems in place. So, it just defeats the purpose of having it"* (P1).

8.5.2.1.3 Unfulfilled expectations

It was apparent that a perceived lack of preparation of parents and staff for 'Going Digital', and an ensuing lack of standardisation in how the new system was utilised, contributed to unfulfilled expectations. All but one interviewee felt that there was a mismatch between what was promised, in terms of what the portal could do, and the reality of when the system went live. It took time for: a) features to become available; b) departments to utilise such functionality; and c) departments to get used to using the system. One parent, for example, described how it would have been helpful if the hospital had set their expectations in advance:

> *"It seemed like beforehand they were saying how much we were going to be able to do on it. And I wish that they had communicated that …, 'You're going to eventually be able to do all of this.' Because then I felt like my expectations would have been more realistic" (P3).*

Although, MyGOSH is a snapshot of the child's health data, this was also not communicated to parents in advance, resulting in their frustration and disappointment at not seeing the whole record. One parent described how they, *"thought it was going to be implemented or used more openly than it is."* (P7). The same parent describes how they:

> *“Certainly, expected that test results, factual information would be there, so hospital letters, I expected to be able to see all the referral letters, I expected to be able to see test results (P7).*

Another parent described how the information about her child’s recent unplanned admission could not be seen on MyGOSH, when she had expected it to be:

> *“So, she was admitted to our local hospital and transferred down to GOSH, and that one* (unplanned admission) *just hasn't appeared electronically at all. There's no record of it on the parent side of MyGOSH whatsoever. I've got no discharge summary, no anything. It just doesn't exist” (P5).*

Despite feeling that information was missing from her child’s story held on MyGOSH, this parent continued to have confidence that the records were complete in the wider EPR system, *“I'm sure it's on the hospital side. It's just not on the parent's side”* (P5). The same parent did not initially realise that there was a two-week delay in results being released onto the portal, *“It's somewhere in the fine print in one of the FAQs about why there is a two-week delay. It's fine now I know”* (P5).

Whilst some parents indicated the system was meeting their expectations, for others this was not the case. When parents were asked whether there were any aspects of the system, they needed support with – accessing information or results, or contacting the care team – one of the interviewees responded, *“So, actually, I haven't used MyGOSH for any of those things. I've probably just used the phone number to call”* (P8), suggesting that she was not using MyGOSH to its full potential.

There was also a consistent thread throughout the interviews of parents’ need for health information about their child(ren). One parent felt that she knew her son’s results better than the clinicians because she had a complete overview of her child, *“I can join the dots whereas the clinician is looking here and now”*

(P7). This parent had been used to having access to information, which enabled them to be prepared for meetings with the clinician:

> *“Because we've been in private medicine for the last ten years and have got used to being able to see full data before we have our appointment, it's so much better. We actually understand what's coming up, we've had a chance to think about what the results are, we have any questions and thoughts, there isn't that great denouement of the consultation” (P7).*

However, despite this parent *thinking* MyGOSH would enable easier access to the information she wanted, actually *getting* the required information was not without its challenges. This parent felt that MyGOSH, *“hasn't got round the problems of trying to get full information … Now we have an extra layer whereby asking for things to be released and then, not managing to do it”* (P7), describing how she felt the clinician was unwilling to release results onto MyGOSH. For this parent, having to balance persistently asking for information and not being given it impacted her greatly, causing distress. This parent resorted to putting in, *“a subject access request … because I'm fed up of it’”* (P7), describing feelings of frustration. The need for cultural change about the release of health information dominated the interview for this participant:

> *“These are complex children, if I have an understanding, it's much better. We have better conversations with the consultants, much better conversations when we actually know the detail … However, … most of them aren't used to sharing information, and even the mere mention in the consultation asking for it, they look incredibly threatened” (P7).*

These changes in practice and how parents accessed information impacted on the relationship parents had with professionals, especially if there were issues relating to clinicians’ willingness to share information. For example, this parent felt that, *“Great Ormond Street seems further behind other organisations I'm* *dealing with"* regarding openness to share the child's information with the parent, and that the, *"old, rather paternalistic culture hasn't gone"* (P7). Parents felt that MyGOSH can play a role in helping fulfil their need for information, keeping them informed about their child's condition(s) and care, giving them a sense of control, and helping to promote parental autonomy. However, parents felt strongly that clinicians need to overcome their reluctance to share information. The advent of MyGOSH had left this parent with unfulfilled expectations and feelings of frustration with the current processes.

The challenges parents experienced after EPR and MyGOSH implementation, due to a lack of preparedness and standardisation, led to frustration and confusion, with some parents feeling this may have implications for the hospital in maintaining its reputation.

Despite the interviews being held 18 months post-EPR and MyGOSH implementation, when asked about the benefits of MyGOSH parents talked about what they expected the potential benefits to be more than what the actual benefits were, as if they were still under a transition period. This contributed to parents' unfulfilled expectations as they were still looking to the portal's future potential rather than benefits already experienced. Potential benefits included time-saving benefits for the hospital and its staff including increased efficiencies for doctors from dictating clinic letters straight into the EPR; not having to print out paper notes (time and cost-saving benefits), both resulting in freeing up secretary time; and reducing the wait time for notes being sent between departments. Perceived environmental benefits were also noted by parents as the hospital will eventually cease sending out clinic letters or 'After visit summaries'.

Parents also saw the potential in MyGOSH's development for the future, for example, *"There's definitely potential there to do a lot more"* (P1); *"I think there's a lot that could still be done with the app … it needs more advancing, more developing"* (P2); and*, "I think MyGOSH is potentially great, I think because I much prefer dealing with everything online* (P7). Potential was also seen in using MyGOSH for inpatient communications from parents to care team members.[xiii] One parent described how useful it would have been during a lengthy admission with one of her children:

> *I think being there for five and a half months, it really would have helped in a lot of things where the communication was quite difficult, … because you have to go and speak to a nurse, and then they have to wait for a doctor, who then has to wait for a consultant (P2).*

Despite the challenges experienced from transitioning to EPR and MyGOSH and the sense of having unfulfilled expectations in relation to these, parents did identify some emerging benefits.

8.5.2.2 Benefits

The actual benefits experienced by parents were described under the categories of communication, both internally and externally, and practical benefits of MyGOSH functionality. The benefits of virtual care were highlighted, and time-saving benefits for families and staff were reported. Other benefits were also described such as reassurance that their messages were looked at, improved confidentiality of medical records and hospital overview of parental involvement in their child’s care.

8.5.2.2.1 Internal and external communication

Parents were able to identify communication related benefits from using MyGOSH. All but one interviewee reported they experienced overall improved communication with their child’s care team via the ‘InBasket’ messaging function through MyGOSH. Communicating with the care team this way was described as, *“easier and faster”* (P2), with the ability to, “*communicate our problem faster”* (P2), compared to trying to call the hospital, *“I think the communication with the team is actually better via MyGOSH than it was*

[xiii] It is hoped that inpatients will have this in the future in the form of “MyGOSH bedside”. Implementation of this has been delayed due to the pandemic, with difficulties piloting this due to COVID-19 restrictions and infection control measures.

previously" (P3). Furthermore, parents deemed communicating solely through the portal was beneficial for care teams when communicating with families because all team members can see the same information, giving an overview of the patient's needs. Although parents worried about making more work for staff when contacting them with a query, parents described how they perceived communication via InBasket messaging to be less intrusive, and more cohesive:

> *"When you send an email, although they're always really good at replying, you always feel like oh, I'm really sorry, I'm interrupting you, I know you're really busy. Whereas now … it just feels like that's the way they want you to do it* (via MyGOSH)*, that's the way they want to get back to you .... It doesn't feel like you're contacting them in a way that is going to make more work for them"(P6).*

This example highlights a change in views about the sense of burden parents placed on professionals when contacting them about their child. Interviewees also described the benefits of having access to their child's medical information on MyGOSH when communicating with other professionals, outside of the hospital. Having all the relevant information in one place, and the ease of accessing MyGOSH were seen as beneficial:

> *"*(MyGOSH is) *very helpful when we are at our local hospital, like in A&E, where I do try to take all the most recent clinic letters and everything but to just have it on my phone … to* (show) *the A&E doctors or to the paramedics or whoever right away, that is really, really helpful" (P8).*

The parent of a young person with physical and intellectual disabilities felt one of the benefits of MyGOSH was having access to health information whilst managing discussions with her child's school, *"If I'm discussing something with school, I can't obviously take all the paperwork. But the fact that you've got that* *at your fingertips is a real plus"* (P1). Similar benefits were also described in relation to sharing test results in a timely manner:

> *"If he gets sick and we need to go to our local hospital … they often ask about most recent bloods and what his results are like, what's his normal? … So, it helps that I have it in the app" (P3).*

8.5.2.2.2 Practical benefits of MyGOSH functionality

Parents describes practical benefits of MyGOSH functionality. The portal was reportedly easy to use, and intuitive. Parents reported it was easy to order repeat prescriptions via the portal and that this saved time. The quick access to information was deemed beneficial. Parents liked being able to view their child's appointments via the portal, and that appointments can synchronise with their calendar on their phone or device. Appointment reminders and other notifications, such as a text message or email to notify them of an item was on MyGOSH for review, were seen as useful. A parent described how the notifications were reassuring to her, "*the fact that you get a text message notifying you is … a good thing. Because I'm not looking at it all the time. So, you get the heads up that there's something on there that you might want to review* (P1). Parents with more than one child at the hospital reported the useful functionality of being able to link their children's MyGOSH accounts to their parental access:

> *"My daughter is also under GOSH under the same team (as my other son), it really helps that I now have both of them linked on my account and so I can see appointment times and easily know which is (which), and to get the appointments lined up (P3)*

Regarding the InBasket messaging functionality within MyGOSH, a parent expressed that, *'Now I actually prefer it* (using InBasket messaging) *because I like that I can see if they've seen my message or not"* (P3). This functionality, much like WhatsApp, was seen as helpful. Another parent described how she liked, “*having a look at what each specialist says*” (P4), so having communication from all specialities visible to them, was beneficial.

8.5.2.2.3 Additional benefits

Although it was recognised that InBasket messaging should not be used for emergencies, parents felt reassured that, *“If I've got an urgent-ish message to get into the team, that clearly is monitored, it does get to somebody”* (P7). The confidentiality benefits of MyGOSH over paper notes were also recognized, *“Before, the files were left outside the room … and anyone potentially could've picked it up and gone through it*” (P4). Increased awareness of parental involvement in their child’s care, monitored through parents’ MyGOSH use, was perceived to be beneficial for the hospital. According to one parent, *“You can see that the parents are joining in and how much participation parents have in a child's care, how interested they are and whether they're reading the letters you send out”* (P5). This may be especially important when there are safeguarding concerns, enabling hospital oversight of parental involvement.

Overall, participants highlighted that MyGOSH can improve communication between families and the care team, and virtual methods of care were a welcome development to parents, superseding the traditional approach of regular face-to-face appointments. Furthermore, virtual care was seen by parents to promote an emphasis on individualised care. According to one parent, it has, *“helped the team realise … that it's possible to not have to do it* (the same) *for everyone”* (P3), insofar as face-to-face appointments are not required by all, all of the time. Nevertheless, parents advocated consideration of appropriateness of the mode of appointment, balancing the risks of virtual care versus coming to the hospital for face-to-face appointments, and the recognition that barriers exist for some families to interact virtually.

8.5.2.3 Parental sense of responsibility

From the interviews with parents, their overwhelming sense of being the person who is the architect of their child’s care and wellbeing, and the responsibility that this brings, was communicated. Parents felt they were the expert carer for their child, and were used to having control before EPR was implemented.

When EPR was introduced, they understood the benefits of promoting their child’s autonomy through access to MyGOSH, however this led to challenges around the reluctance to relinquish responsibility, creating a tension between these two concepts.

8.5.2.3.1 Promoting the child’s autonomy

Parents were used to managing their child’s care until the advent of EPR and MyGOSH, which then gave their child access to their health data electronically from the age of 12 years, with parental consent. Parents were asked how they felt about this being the age limit for their child(ren) accessing MyGOSH. A range of views was shared on this topic. One parent, for example, felt that, *“twelve just feels a bit too young”* to have access to MyGOSH (P2), and another parent explained why she too felt the same:

> *“I could appreciate that, probably, for the majority of parents, they would probably feel that twelve years old is a good age for them to give their child, like, a smart device … I think it's also that I wouldn't want my children to have a device like that, probably, until they're sixteen, seventeen, eighteen maybe … we're a religious family, we're more insular” (P8).*

Other parents, however, felt that each parent would need to, *“assess what their twelve-year-old is like and if they think that they're ready for it or not”* (P3). It was felt that this was a conversation for the parents and children to have and was a decision to be made by the family. The legal process to promote young people’s agency was also acknowledged, *“It's all about Gillick competence … It's what needs to happen”* (P5).

Overall, it was felt that MyGOSH, *“Will empower young people to take responsibility for their own health”* (P3) but that this may not be the right approach for *all* families. This family wanted to protect their child after experiencing a child bereavement, but it was acknowledged that each family will have individual and unique experiences bringing them to the hospital, which may affect the stage at which they feel MyGOSH access is right for their child.

Irrespective of whether or not parent’s felt that their child should have access, parents perceived that their children had little or no interest in using MyGOSH, apart from the daughter of participant 1, who was a young person with physical and intellectual disabilities. A parent of a 13-year-old described how her child is, *“Very bright, very able, but she has no interest in doing it”* (P7). This parent goes on to explain:

> *“So, although she's got great interests and abilities in many things, the dealing with her health, where she is at the minute, it's still something that Mummy does and takes the lead on. I increasingly show her, … but at thirteen that's not her priority … it's just not interesting” (P7).*

Portal use was thought by parents not to be relevant for *all* children or young people cared for by GOSH. Despite CYP being of the age to be granted MyGOSH access, their portal use varied according to the child’s interest and medical needs. However, although some CYP had little or no interest in using the portal, parents thought it was useful when it came to transition, *“twelve is perfect because it's also the age where you're looking for transition services or transition to adult services”* (P4). Related to this, another parent described how she encouraged her child to take more of a lead in his health during appointments, *“He goes into all of them on his own and he has done for as long as I can remember. That was something that we were really keen for him to do as soon as we felt that he was open to that”* (P6). This parent felt that children should be given the opportunity increase their autonomy and to, *“get a grip, if you like, of what's going on earlier rather than later”* (P6) in the hope that:

> *“It will be a very natural move across to patients wanting to access and, yes, everyone's going to be used to using it, aren't they, so it will be very familiar, unlike a National Insurance number dropping through the door.” (P6).*

The importance of gradually preparing young people over time was emphasised by parents, led by the child’s readiness to be involved, rather than the sudden expectation of having to become an adult. Parents described trying to balance gradual preparation:

> *I would hope that it would help him slowly take responsibility for it, … maybe even if he's not twelve when he gets access. If he decides that he's fourteen or fifteen, he gets access with us, then we can work on things together … this is when you need to communicate with your team, this is how you can see your appointments, this is how you can see your blood results and they can tell you what you need to do with your medication” (P3).*

With this came the consideration from parents about how much they thought their child could reasonably take on board:

> *“He has taken on as much responsibility that he needs to at the moment, until either he says, 'Oh, actually, I'll answer that.' Or 'I'll contact them and let them know.' Or until, maybe, as part of transition, the doctor may say, ‘I think I'd like to contact you directly now' (P6).*

This parent also openly talked about how she did not understand the results that were released onto MyGOSH, and that she waited for the clinical team to contact her to advise whether an increase or decrease in essential medication was required, raising the issue of risk. This raises the question of whether Is there an assumption from staff that parents understand the results that are released onto MyGOSH. This needs consideration if young people are to take increased responsibility for their own health because additional support may be required when preparing both young people and parents for transitioning to adult services. This parent worried about how adult services will compare with GOSH. This interviewee described GOSH as:

> *“A warm blanket of reliability, they never put a foot wrong, everything you need is there, there's never been a moment with GOSH where I've been thinking, 'God, what about-, who have I got to phone to organise this?'” (P6).*

The same parent goes on to say, *“GOSH is so good, they're so on the ball, they're so patient-centric, you think oh, are they going to do this, and you turn around and it's been done”*. This parent worried whether, *“we're being lulled into a false sense of security, and then when we go onto adult services, how good- … Will your adult service be as good as GOSH?”* (P6). Parents also worried about going to other hospitals that do not have EPR, and whether the transition would be a smooth process.

A parent of a child with a life-limiting condition shared their view on why it is important for families to involve their children in their care at a younger age, *“I completely understand parents wanting to protect their children for as long as they can”* but:

> *“I do think to make parents aware that this opportunity of getting children involved younger is as much for parents' and families' wellbeing … it's really important because, at the risk of sounding really mean spirited, it's not my problem. I don't mean it's not my … but it's not happening to me, what's happening to me is different, I'm his mum, and it's different, it's his thing, it's his monumental thing that he's living with, but I also think, sort of selfishly, I've got a life away from this and, potentially, beyond this as well, and I know my husband feels the same, that you've got to have a bit of self-preservation” (P6).*

This parent wanted to promote her child’s own sense of responsibility and autonomy, but also draws attention to the individual and distinct experience of each family member throughout the child’s journey with a life-limiting condition.

The possibility of their children sharing health information online, and the potential future impact this may have, was considered by parents. One of the interviewees worried about, *“Getting information into the wrong hands”* (P2). Another interviewee highlighted the importance of educating CYP about sharing their information online:

> *“The amount of coaching that they're getting at school about how to be safe on the internet, what you share and, certainly with us at home really early on, thinking about whatever you share, the implications of anything that you might share on social media and actually a great deal of caution about doing it because it's there for life. Do you want to do it?” (P7)*

Although parents recognised the need to promote their child’s own responsibility and autonomy, they had so many challenges they found it difficult to relinquish responsibility for their child and their care, creating conflicts for the parents. This will now be discussed.

8.5.2.3.2 Reluctance to relinquish responsibility

A lack of preparedness for EPR implementation, a lack of standardisation and unfulfilled expectations resulted in an anxious and confusing time for parents. Despite understanding and wanting to promote their child’s autonomy, many challenges existed, resulting in a reluctance to relinquish responsibility.

Thinking about the possibility of their child potentially having sole access to MyGOSH at 16 years of age, if they have the capacity to do so, accentuated this reluctance to relinquish responsibility for some parents. Whilst the majority of parents were positive about this, parents *still* wanted some form of oversight of their child’s care. Whether the child was mature or deemed responsible enough to have sole access seemed key to parents. According to one parent, *“I think that's fair enough. I think that they do at some point need to start taking responsibility for themselves”* (P3). However, another parent felt that, *“sixteen would be too young … I would still want to be able to access it as a parent”*

(P4), advocating that joint access was important for her. This parent's reasoning was as follows, *"I don't think every sixteen-year-old would be responsible enough or able to understand everything"* (P4). This parent felt it was, *"good to give access, but I don't think sole access should be given for children"* (P4), with responsibility and understanding of information on the part of the child being key for this parent. Another parent strongly felt that, *"parents should have it* (MyGOSH access) *until the child is eighteen, because the parent has responsibility"* (P7), linking the age at which the child could have sole access to the age at which parental responsibility (PR) ceases.

Trust seemed important to parents insofar as trusting their child to reveal information when needed, and to, *"discuss things that they need to discuss"* (P1). Parents understandably remained concerned about their child's wellbeing despite recognising that they would, "*have to respect and appreciate their privacy"* (P2). This parent described how, *"I think just being a parent you just always would want to know how they are, and to make sure that they're keeping on top of their health and their appointments,"* regardless of their age. Related to respecting privacy, a parent acknowledged that:

> *"There might be things that they want to discuss with their doctors, and they don't want their parents to know about and I wouldn't want him to not ask a question because he was afraid that I would find out about it" (P3).*

Another perspective raised by a parent was how having a good relationship with the care team may impact on parental willingness for their child to have sole access to MyGOSH:

> *"I know the team well enough, and I would be comfortable for them to tell me, 'this is not right' … I would be comfortable to drop them an email every so often and go, 'I just want to check, … are you happy that he is responding the way that he should be?" (P6).*

However, this scenario potentially conflicts with respecting the privacy of the child or young person. Furthermore, parents had always been custodians of their child’s health information and wanted reassurance of how the privacy and security of their child’s medical record would be promoted. On the practical aspects related to data safety, one parent reported how the system, *“Locks you out … automatically so it's a fairly safe system,”* and that this safety feature was important because, *“A child may or may not be reliable at logging themselves out to keep the records secure”* (P5).

Parents wanted to have some control over who had access to their child’s health data, advocating that access was limited, *“to the direct* (care team) – *the secretaries and the actual consultants, and the clinical team”* (P4). Parents also wanted some control over where information about their child was sent, for example, one parent reported, *“we're getting a lot of private information going to the school, and we don't know where it's ending up”* (P1). Parents wanted reassurances that those accessing it had a legitimate reason. They struggled with the potential of not having oversight of their child’s health data and who has access to it.

Worries existed about the possibility of the EPR system or MyGOSH being hacked or there being a data breach. One parent felt that, *“Some people won't be downloading the app for privacy reasons … You hear about ransomware attacks,”* and they wanted to know, *“So just how secure is it? Where is the data being held? It's just about data protection and making sure that data is safe, and not liable to be hacked or leaked”* (P4). Another interviewee revealed how despite hacking being, *“such a big problem at the moment … it wouldn't stop me from using the system”* (P1) yet reassurance from the hospital was required about security of data was still needed:

> *“I think … to have a little bit more reassurance that this is a very specialised system, that you have good encryption, that you have this back-up and that you have systems within that that tell you if it has been breached … that kind of information would be helpful to know (P1).*

Another parent was more confident in the system’s security, *“I feel like it's very secure, so I'm not really worried about any kind of data breaches”* (P5). Reassurances were also sought about continency plans during system downtime:

> *“There needs to be a plan in place, if it does fall over … Would you tell parents what was going on? How would you do that? … So, even if it's the next appointment just gets texted to your phone, as an automatic back-up, so that you know that that is the next time that you need to make contact” (P1).*

Parents wanted reassurances from the hospital about their ability to protect their child’s health data, and contingency plans for if a breach did occur or if the system failed.

Parents identified that their child’s ability to manage their own care and make appropriate decisions were important factors when thinking about whether their child was ready to take responsibility for their health independently. A parent worried whether their child would, “*contact the hospital or their care team, or* (be) *changing their course or line of treatment, I guess, without consulting the doctors*” (P2). Another parent described how the child’s ability to manage their care determined whether MyGOSH access was appropriate, and at what point the parent would intervene:

> *“If you're going to let children have access, or young people have access to it … at what point do you limit or stop that access if you're having problems with children ringing up and cancelling appointments, or doing things like that?” (P1).*

Clearly some parents wanted oversight of their child’s healthcare, wanting to know that they can be responsible for their health and well-being as they mature. Furthermore, young people’s ability to understand the health information on the portal, the possibility of them reading something potentially distressing, and the language used by clinicians were also important to consider. One parent described how one of her children was found reading their sibling's paper medical notes:

> *"A helped herself to B's paper folder at one point and read one of the letters which was very explicit about heart transplants and survival … 'If you don't get a heart transplant you die' … and yes, it was an interesting conversation then to try and retrieve" (P5).*

A worry for this parent was if this sort of information was accessed inadvertently online then it would have been less obvious that her child had seen it. As a result, having a conversation about it would be more difficult, with possible deleterious implications for the sibling reading that information. This illustrates a further point, that the language used by clinicians in after visit summaries (clinic letters) is often not written in a style that is accessible to young people:

> *"The clinic letters especially are just not filtered … Some of the things that are on there, they're very medical. As medics are, they're very black and white about death" (P5).*

This quote emphasises a requirement for clinicians to shift their thinking in the way they communicate with families, writing in a way that is accessible to and understandable by young people, matching their level of ability. However, a parent who was a healthcare professional recognised the difficulty of writing clinic letters in such a style*, "It's hard enough trying to write it in non-medical language for an adult, but to translate it into children's language? That would be a big ask"*, but it was also recognised that, *"It's their record and they have a right to know"* (P5). Until parents have the confidence that their children will receive clear and understandable information about their health, parents are reluctant to relinquish responsibility as they may be needed to translate medical jargon for their child.

As MyGOSH access will result in the child or young person accessing the information on the portal, this may invoke some difficult conversations if they are not adequately informed or prepared. A parent of a child with a life-limiting condition revealed:

> *"It's very hard because we don't know-, we're very open with him when it's required, when it comes up, we don't really know how much of a handle on his long-term prospects he has and it's very hard to ask because if the answer is, 'I don't know what you're talk about.' You've got to be prepared that the next question is going to be, 'What are you talking about?'" (P6).*

For this family, information giving is led by their child's readiness to receive information about their condition and, potentially, their prognosis.

There was a sense from interviewees that they worried about being labelled as difficult parents when they wanted access to their child's health information. Furthermore, when advocating for the child's best interests, parents sometimes felt others perceived them as wanting to be in control:

> *"As parents you're always very conscious that people feel like you're trying to maintain control, but actually what you're trying to maintain is the best interest of your child … I'm never going to stop doing that … Sometimes I think, as parents, you almost feel like that's what you get accused of" (P1).*

This parent related this worry about being seen as wanting to be in control to her experiences of advocating for her child in the educational setting, *"You know, certainly in education, it's almost, 'Well, what does she want? That's what you want'. 'Well, I'm telling you what she wants because I've spent years with her and I know what she wants'"* (P1), highlighting again the parent as the expert in their child.

Parents identified potential conflict between them and their child relating to the parents' potential difficulties in relinquishing control of the portal to their children. According to one interviewee, *"I could see there being some conflict there of parents still wanting access when … the children don't want* (them to have) *access"*, but it was recognised by this parent that this might, *"be an issue even outside of just the MyGOSH app"* (P3). Another parent said, *"It depends how much of a control freak their mother is and I think my two might have more of a problem because I won't want to let go* (P5).

Families with children with physical or intellectual disabilities may have additional considerations for their children with regard to accessing and using MyGOSH. A parent described her experience in depth of her 17-year-old daughter trying to navigate MyGOSH and the complexities that have arisen:

> *"At the moment, she will just review things with me … Not on her own … because she would be pressing all of the buttons. I didn't want to lose any of that information … So, it was really important to keep everything I needed. So, I haven't really let her loose on the app. She's a bit mischievous when she goes on to the computer. She wants to know what everything does. So, she would be messing around with things and probably sending messages to GOSH and all sorts" (P1).*

Supervised access is facilitated by this parent to enable her child to participate, but also to prevent any inadvertent use or data loss. The same parent goes on to describe what her daughter finds difficult:

> *"I think she does struggle with the way it's set up. And I know a lot of children with their conditions have visual issues, as well ... she would definitely be interested, I think, if it was more user-friendly for her" (P1).*

Complexities also exist on the topics of consent, security issues and vulnerabilities when granting MyGOSH access to a young person with physical and intellectual disabilities. The same participant describes her worries on this:

> *"I totally respect the law, and being able to take control at sixteen, but I think the danger is that with children with SEND, you might think a child has that ability, even if they're coming across as very eloquent, and they can vocalise, and say what they feel, … there could be things they're masking. There could be other issues that aren't obvious to people" (P1).*

This parent highlighted how, *"There are always going to be security issues because of her understanding and her level of ability"* and likened unsupervised MyGOSH use to the use of a bank account, *"I wouldn't allow her access to a bank account, because she'd probably just go and empty it out … either she would give somebody the PIN or give somebody the card"* (P1). Moreover, worries existed about other people's understanding of her child's abilities:

> *"I think that's quite a scary thing from a parent's perspective, … there are very grey areas in terms of what people's understanding is of the child's, or the young person's, level of ability. So, for me, that's quite a difficult one … I know there have been incidents at school where, certainly, older children have requested things that the parents would not have condoned, and the school have said that, because the child is of that age, that they can make those decisions" (P1).*

The importance of supporting young people with physical and/or intellectual disabilities to make the right decisions was highlighted, *"There needs to be a little bit more flexibility even within the scope of the legislation to allow those not so black and white areas to exist, and people to make decent decisions".* This parent felt that, *"There has to be safeguarding within that structure … in terms* *of their wellbeing, … a framework within that to make it work properly, and not do more … harm to that young person"* (P1).

This parent was clearly struggling with the thought of being made to relinquish portal access, *"Up until that point, you've done everything for your child … to say that at that point that you can just relinquish … any kind of influence, … it concerns me a bit, to be honest, it's something that I worry about for the future"* (P1). Another parent, with a child with autism also described her reluctance to relinquish portal access,

> *"I know the hospital obviously doesn't go over 18 or 19, except in exceptional cases, but education health and care plans go up to 25. I think in that instance it (sole access) would be better, but even for a neurotypical teenager, sole access I think for sixteen would be too young, personally speaking. I would still want to be able to access it as a parent" (M4).*

The prospect of relinquishing access to their child's health records was clearly anxiety provoking for some parents.

8.6 Discussion

Data revealed how unprepared parents were for the hospital's transition to EPR and MyGOSH. Parental experiences were also affected by staff unpreparedness, which not only impacted them, but also impacted the way they perceived the clinical teams were caring for their child(ren). Such unpreparedness led to a lack of standardisation, with parents reporting varied approaches taken by different care teams, or even from members of the same team. Consequently, the transition period was much longer than anticipated (12-18 months). Parents felt that their expectations of what MyGOSH could do, or the ways in which MyGOSH would change or enhance care delivery remained unfulfilled. Benefits were reported but these were overshadowed by the extended transition period, with parents more readily describing perceived potential benefits rather than actual benefits. Parents took it upon themselves to find out about MyGOSH, taking a proactive stance in managing their child's care, and important issues relating to their child accessing and using MyGOSH were raised. These often involved ethical and legal considerations, and parents may have benefited from early discussion of these issues prior to system implementation.

Preparedness, or lack of, was clearly an overriding concern for parents. It is acknowledged in the literature that a long preparation period is required to facilitate successful EPR implementation [79], requiring preparation and support for all prospective users. Although it is difficult to specify an exact timescale required for preparation as this will depend on numerous factors, targeted system design is required based on user needs to facilitate and promote prolonged user engagement, utility, user satisfaction, and digital literacy for implementation success [47, 77, 79, 86, 97, 98, 110]. At GOSH, pre-go-live preparation was primarily with hospital staff members to ensure implementation readiness, however, this meant that families were relatively unaware of the huge change until it happened or had already been implemented. How the change to EPR/MyGOSH was communicated and advertised by the hospital to families, its functionality and where to go to for support could have been clearer and more comprehensive. Families often missed the communication on the bottom of the clinic letters. Staff members did not provide adequate information when parents asked about the proposed functionality and potential benefits of using MyGOSH. Consequently, parents did not have the information required to make an informed decision about whether to sign-up for MyGOSH, or allow their child access. This highlights the need for improvements in these areas. The importance of setting expectations and understanding end-users' expectations and perspectives when implementing a new EPR system is well documented [195-197]. Parents need to be prepared so that they have realistic expectations of what they will be able to access via MyGOSH. Early preparation for when a major change is happening in the hospital is crucial to families' understanding of the process, and will improve patience with, and understanding of, any challenges encountered during the change process. Staff training and monitoring of how the information is delivered to families is imperative [198]. These are important ongoing for GOSH, as well as for other children's hospital implementing a patient portal.

Parents were able to describe benefits of the hospital transitioning to an EPR system with a patient portal, but these were overshadowed by the extended transition period. Parents more readily describing perceived potential benefits rather than actual benefits, which aligns with findings by King et al. (2017), especially the potential in improving communication with professionals and engagement in care [47, 97]. In our study, although improvements were seen to communication overall, diversity was seen in the approach taken by teams when communicating with parents, and the use of EPR and MyGOSH, leading to a lack of standardisation. Families under more than one specialist team reported a greater variation in practices and they found this anxiety provoking and confusing. Diffin et al. (2019) advocate that a personal health record, such as a patient portal, can benefit both CYP with complex health conditions, and parents, in terms of improved self-advocacy and enhanced communication with HCPs [199]. Consequently, CYP can be empowered to be more involved in decision-making about their care [199]. It seems likely that, due to the prolonged period of time required for staff to become familiar with using the system, benefits will be experienced by parents but perhaps later than anticipated. Further investigation is needed to see if this is the case, as advocated under “Recommendations for future research’.

Parents emphasised the need for teams to take a more standardised approach via EPR and MyGOSH in terms of communication, virtual appointments, and results release, yet balancing the need for an individualised approach to care according to the child’s specific needs. Leading on from this, there was an overwhelming need for information by the parents, and the need for a culture change was highlighted in terms of information release onto the portal. In a study by Lee at al. (2017), which looked at families’ satisfaction with a generic portal and a disease-specific portal, information needs were significantly more fulfilled in the disease-specific portal group [91]. This emphasises the importance of an individualised, disease-specific approach to care. Furthermore, if the hospital is to utilise MyGOSH fully, enabling and fostering partnerships in care, then health information and results should be released via the portal in a standardised manner, not dependent on speciality or clinician preference. This also applies to other hospitals that use patient portals. In a study by Byczkowski et al. (2014), parents recommended clearer explanation of laboratory results and terminology, the ability to add or edit data, more links to resources and education, and personalised medication specific information [47, 93]. These additions would enhance the individualised approach to care via a generic patient portal for all users, such as MyGOSH.

Parental anxiety around children accessing and using MyGOSH was evident, even though they wanted their children to gradually take on more responsibility for their health. Reassurances were required on the safety of their child’s health data, that only the appropriate professionals directly responsible for their child’s care were accessing the data, and the desire to be able to control where the data is sent, for example, not sending unnecessary information to other parties involved, such as the school. This is in contrast to the study by Byczkowski et al. (2017), where parents were not overly concerned with confidentiality or what their child would read on the portal [47, 93]. In our study, emphasis was placed on discussion within the family as to when the most suitable time for the child or young person to access the portal may be, dependent on factors such as age, maturity, severity of condition, and prognosis. Clinical teams need to work with families early on to prepare young people to be more involved in managing their own care. Children and young people living with a complex health condition are reported to have a high perception of need for personal health record access, and a “high level of desire for self-management” (p.313) [199]. As the young person’s independence increases with maturity, and their capacity to make informed decisions about their health increases, a shift to sole portal access by the competent young person should be considered [200]. Parents will require preparation and support to help them relinquish responsibility when their child can manage their own health, and to prepare them for when their child is ready for sole portal access, as this is a contentious issue [164, 165]. The issue of parents being required to relinquish responsibility for their child’s health predates MyGOSH, however, with the prospect of access being denied to them when their child is 16 years old, if this is the wishes of the young person, this adds to burden of what parents have to cope with. Although, arguably this is an issue that is not solely related to MyGOSH, the portal adds another layer of complexity for parents of children with complex needs [199]. It is well documented that continued parental access to their child’s medical records or their health information impacts the young person’s willingness to discuss or disclose information to their care team [34, 121, 144-146]. Whilst shared access by CYP and parents was mostly welcomed by families in this study, this remains a contentious issue in guidelines for professionals and literature [200-205].

The concept of parental self-preservation was a very honest reflection from one parent, and is an example of a deviant case insofar as they reject in part the theme about parents struggling to hand over responsibility and wanting to keep control [206]. However, it is important to highlight that there will always be exceptions to the majority, and it is important to consider everyone’s unique viewpoint. It must also be acknowledged that patient portals may not be relevant for all CYP, nor will all be interested. Those with more severe disease or conditions are more likely to engage [207], which concurs with our findings.

Barriers exist for some families that may inhibit MyGOSH use or access. This may be due to cultural or religious preferences, limited or no access to the internet [167], a lack of technical skills to navigate the portal [168], or language barriers. Every effort should be made to ensure this does not mean reduced access to care. Families with children with physical and intellectual disabilities may need additional support for their child to be able to access patient portals such as MyGOSH, with a more user-friendly design suggested and an individualised approach to competence and capacity assessment. Individualised competence and capacity assessment applies to all CYP accessing patient portals [202, 208], guided by the principles of the MCA [31] and Gillick competence [32].

Parents’ experiences were complex and heterogeneous, depending on which team their child was being looked after by, how many specialist teams their child was under, and the needs of their child and severity of illness. Parents’ past experiences also influenced their perceptions and experiences of EPR/MyGOSH implementation. Conducting interviews 18 months after EPR system implementation meant that all participants had some experience of these new ways of working prior to the pandemic, but parents could not separate their views about the transition to a digital hospital from their experience of the pandemic. Parents were positive about the rapid transition to virtual care, driven by the pandemic, and advocated keeping such developments in place going forward due to the improvements in the quality of life for the family. These quality-of-life improvements included less time travelling to and from the hospital, less school missed for the child, and less time off work for the parent. Moreover, parents reported their child’s condition dominated family life less. Notwithstanding, reassurances were required by parents that their child’s treatment would not be compromised, and with the guarantee of access to face-to-face care, as the child’s condition dictates.

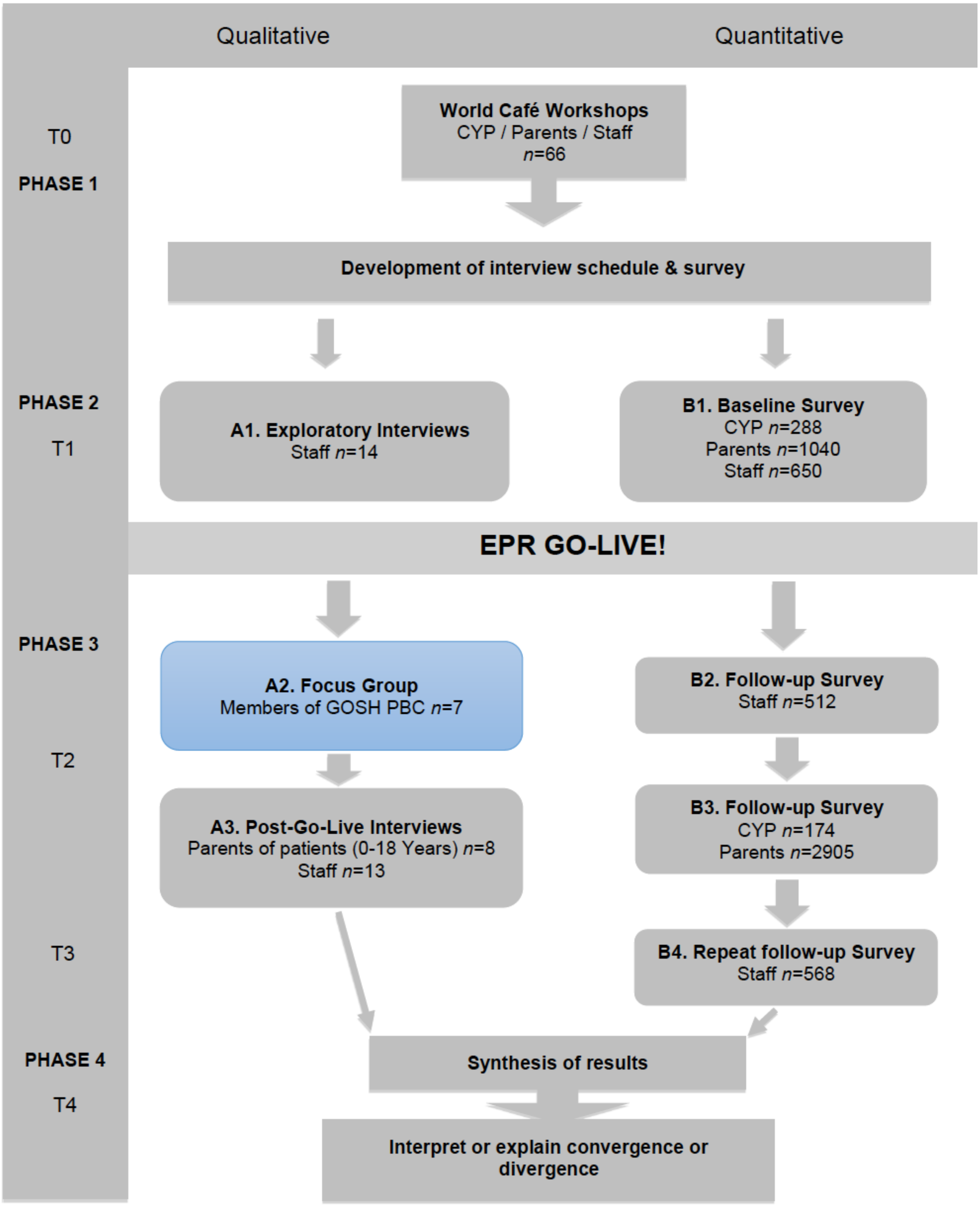
8.7 Summary

Parents were unprepared for the hospital’s transition to EPR and MyGOSH. Parental experiences were also affected by staff unpreparedness, which not only impacted them, but also impacted the way they perceived the clinical teams were caring for their child(ren). This unpreparedness led to a lack of standardisation across the hospital. Parents reported varied approaches taken by different care teams, or even from members of the same team, and the transition period from implementation to parents feeling that the new system was being used reasonably effectively took *much* longer than anticipated (12-18 months). Although benefits were reported, parents felt that their expectations of what MyGOSH could do, or the ways in which MyGOSH would change or enhance care delivery, were unfulfilled. Parents had to be proactive to find out about MyGOSH and its functionality, often by trial and error. Important issues relating to their child accessing and using MyGOSH were raised, often involving ethical and legal considerations, which should have been identified and discussed with families prior to system implementation. Despite being experts in their child, and used to being the person responsible for their child’s care and wellbeing, they understood the benefits of promoting their child’s autonomy through access to MyGOSH. However, they experienced many challenges, which led to reluctance to relinquish responsibility over their child’s care, which may be a cause of potential conflict when their child is old enough to manage their care independently. Clinicians must work with families early in adolescence to guide both the child and the parents through this potentially difficult time, taking into account a multitude of factors such as child’s willingness and ability to engage, parent and child literacy, access issues, data security concerns and impact of sharing test results online.

The findings from this research activity were overshadowed by COVID-19. Parents found it impossible to distinguish the hospital’s transition to an EPR system without the influence of COVID-19 as this had been such an overbearing part of their reality, especially living with the worries about having a sick child and the unknowns at the time about COVID-19.

In Chapter 9, the findings from a focus group held with members of the GOSH Paediatric Bioethics Centre nine months after EPR/MyGOSH implementation will be presented. The aim of this research activity was to explore the ethical and legal considerations related to MyGOSH, and of CYP and their parents using the portal and accessing their digital health data.

Chapter 9 Focus Group Discussion



9

9 Focus Group Discussion

9.1 Introduction

In this chapter the reader is presented with the findings from a focus group held with members of the Great Ormond Street Hospital (GOSH) Paediatric Bioethics Centre (with expertise in clinical ethics) nine months after EPR/MyGOSH implementation, during phase three of the study. The context and aim are presented, followed by the methods, including focus group topic guide development, participant recruitment and consent, and procedures. The results are presented through participant quotes, which are critically analysed throughout the discussion, related to relevant literature. Finally, conclusions drawn from these findings.

9.2 Context

There has been an exponential evolution of digital health innovation [12], accelerated by the COVID-19 pandemic through the rapid shift to tele-medicine and virtual care [209, 210]. Never has it been more crucial for CYP and their families to access their health data via digital means. Despite the numerous potential benefits of providing portal access for families, as previously described, ethical and legal complexities exist. However, these are rarely reported in the literature, as demonstrated in the systematic review (Chapter 3). Some of these considerations were anticipated prior to commencement of the study and were outlined in Chapter 1. However, as the study progressed, ethical and legal considerations relating to CYP and their parents accessing their digital health data and using a hospital patient portal became regular topics raised by participants. Responding to these emerging issues during data collection, the study was amended to include a formal exploration of current related ethical and legal considerations, what these were and their implications for CYP, their parents, clinicians, and the hospital as a whole. This was a deviation from the original protocol and required submission and approval of a substantial amendment (Appendix 42).

9.3 Aim

To use a single focus group to explore the ethical and legal considerations related to MyGOSH, and of CYP and their parents using the portal and accessing their digital health data from the perspective of those with clinical ethics expertise.

9.4 Methods

9.4.1 Focus group methodology

The focus group is a qualitative research methodology which involves a group interview of a purposively selected rather than statistically representative sample [211]. Ideally it consists of six to eight participants, and is used to gain rich insight into attitudes and behaviours to a specific predefined topic [212]. According to Krueger and Casey (2014), the focus group discussion should comprise the following characteristics: “1) a small group of people, who, 2) possess certain characteristics, 3) provide qualitative data 4) in a focused discussion 5) to help understand the topic of interest” (p6)[213].

9.4.2 Why choose to conduct a focus group?

Focus group methodology was primarily chosen over individual interviews because we wanted to elicit ethical and philosophical debate amongst the participants [214]. We wanted to draw on participants’ perceptions and experiences, beliefs and attitudes towards the chosen topic [211], bringing in their particular expertise and knowledge, from their practice. Furthermore, this methodology is described in the literature as a useful method for studying organisational change, in this case a change in practice which allowed children and their parents to access their medical records and related health data via MyGOSH patient portal [215, 216]. Barbour (2011) advocates that focus group methodology can “provide unique access to the range of perspectives and experiences of participants in a situation where individuals are involved in defending, explaining or even constructing their views through the interactive process” (p.7) in response to the change [215]. Focus group discussion has also been advocated as an economical, fast and effective method for obtaining data from multiple participants [213], which was a consideration in this large, time-sensitive study. A further benefit is that focus groups are often described as creating a non-threatening environment in which participants can share their views [217], thus enabling those who would perhaps not feel comfortable undertaking an individual interview to share their experiences as part of a group. The known benefits added further confidence in the method. However, members of the Paediatric Bioethics Centre are familiar and comfortable with this method of discussion due to frequently debating ethical and legal issues that arise within the hospital, or that are related to CYP in the wider health context.

9.4.3 Topic guide development

A topic guide was developed to inform the focus group discussion, based on relevant literature, and the results of the World Café workshops held with CYP and parents during phase one. The topic guide utilised a semi-structured approach with pre-defined open-ended questions, and follow-up probes for use when more detail was required [218]. An overview of the topics covered can be found in Table 9-1, and the full topic guide can be viewed in Appendix 43.

Table 9-1: Overview of topic guide

Topics covered in focus group discussion
• Concerns around supporting young people and parents when accessing their health data • Assessing capacity • Non-disclosure of diagnosis/prognosis to CYP • Inequitable access • Concerns about data being kept safe • Access to health data and sharing health data on social media • What young people worry about

9.4.4 Participant inclusion and exclusion criteria

9.4.4.1 Inclusion

- Members of the GOSH Paediatric Bioethics Centre

9.4.4.2 Exclusion

- Non-members of the GOSH Paediatric Bioethics Centre

9.4.5 Participant recruitment and consent

Members of the Paediatric Bioethics Centre are a team of experts and lay members who provide clinical ethics support to staff, parents and patients in managing ethical dilemmas that arise in our hospital [219]. Members were purposively sampled due to their specialist knowledge in medical ethics and law, and involvement in matters arising within the hospital related to these topics. Potential participants were sent study information in advance of the focus group (Appendix 44). All participants were informed about the voluntary nature of participation in the focus group and the right to withdraw at any point without giving a reason. Written informed consent was provided by all participating members (Appendix 45).

9.4.6 Data collection

The focus group was conducted in January 2020. Two researchers moderated the focus group: one acted as the moderator, whilst the other acted as the assistant moderator taking discussion notes and clarifying any EPR-related queries. The moderator and assistant moderator met prior to the commencement of the focus group to review the questions and prompts from the topic guide, clarifying any queries. The focus group discussion was planned to precede the Paediatric Bioethics Centre’s monthly committee meeting, in a non-clinical building that was part of the hospital premises, lasting 1 1/2 hours. The participants were welcomed, the moderators were introduced, along with an introduction to the research activity and a brief overview of the purpose of the research activity, and verbal consent was checked prior to commencing [213]. Ground rules were set, and audio recording was commenced, with permission. The moderator commenced with the opening question, kept the discussion on track, yet allowed for everyone to talk, probing for clarification when needed [218]. Once the focus group discussion had concluded, the moderators met to debrief and summarise the session [213]. The recording was transcribed verbatim. Secure and anonymous data storage was in accordance with the Data Protection Act [103].

9.4.7 Data analysis

Data were analysed using a reflexive thematic approach [122]. The active role the researcher takes in the production of knowledge is highlighted [220, 221]. Themes and codes are recognised to "represent the researcher's interpretations of patterns of meaning across the dataset" [220]. Reflexive thematic analysis is described as being "a reflection of the researcher's interpretive analysis of the data" [220], "produced at the intersection of the researcher's theoretical assumptions, their analytic resources and skill, and the data themselves" [221]. Patterns of meaning across the dataset were identified that addressed the research aims, within a constructionist framework [122]. This focused on how a certain reality was created from the data, in this case the perceptions and experiences of participants in relation to the ethical and legal considerations of CYP and parents accessing their digital health data and using a patient portal [122]. Analysis was completed using a through a rigorous six stage process: familiarisation; generating codes; generating initial themes, initial theme review; defining and naming themes; producing the report [186]. During familiarisation of the data, the transcript was read numerous times, which gave an overall sense of the discussion. As the focus group was specifically related to the ethical and legal considerations, coding and theme development were conducted using a deductive approach, directed by existing concepts or ideas, in this case findings from phase one workshops [186]. Line-by-line analysis was performed by highlighting relevant quotes in the transcript, with annotations written in the margins. Quotes belonging to the same category or code e.g. assessing competence, were grouped together in a table within Microsoft Excel (2021; Excel version 16.54), and initial themes were generated. These themes were then reviewed and refined by two researchers (PS and FG) thinking about concordance or discordance within each category, or any crossover with any other categories, and a consensus was reached on the theme/sub-themes names.

9.5 Results

9.5.1 Participants

Seven of the 18 members of the Paediatric Bioethics Centre participated in the focus group.[xiv] Membership includes several disciplines within and external to the organisation, including medicine, nursing and allied health, philosophy and bioethics, law, chaplaincy services, academia, safeguarding and social work. As members can easily be identified with a more detailed description, no further information about participants will be provided to maintain their anonymity.

9.5.2 Theme development

Four themes, with sub-themes, were identified: 1) granting access – complexities of assessing competence/capacity, transparency of information to CYP; 2) inequalities resulting in inequities – complexities of inequity in access; 3) responding to change – providing support and managing expectations; 4) engagement, empowerment and understanding – empowering CYP to take ownership of their health data, and a one-size-fits-all system may not meet the needs of all families (see Figure 1 for the thematic map). Each of these themes will be presented with illustrative committee member (CM) participant quotes.

9.5.3 Granting access

Granting MyGOSH access to CYP required much consideration by the participants, raising ethical considerations on the topics of the complexities of assessing competence or capacity, the potential for exclusion of CYP from MyGOSH due to non-disclosure of diagnosis, and the importance of telling the truth to CYP. These sub-themes will now be presented.

[xiv] The focus group had been rescheduled from a previous date due to unforeseen circumstances, meaning that the first planned date could not go ahead. The initial date had more members who had agreed to attend, however, in retrospect it was felt that the smaller number of participants was advantageous. A larger group may not have yielded such deep thinking or allowed each person within the group to participate fully.

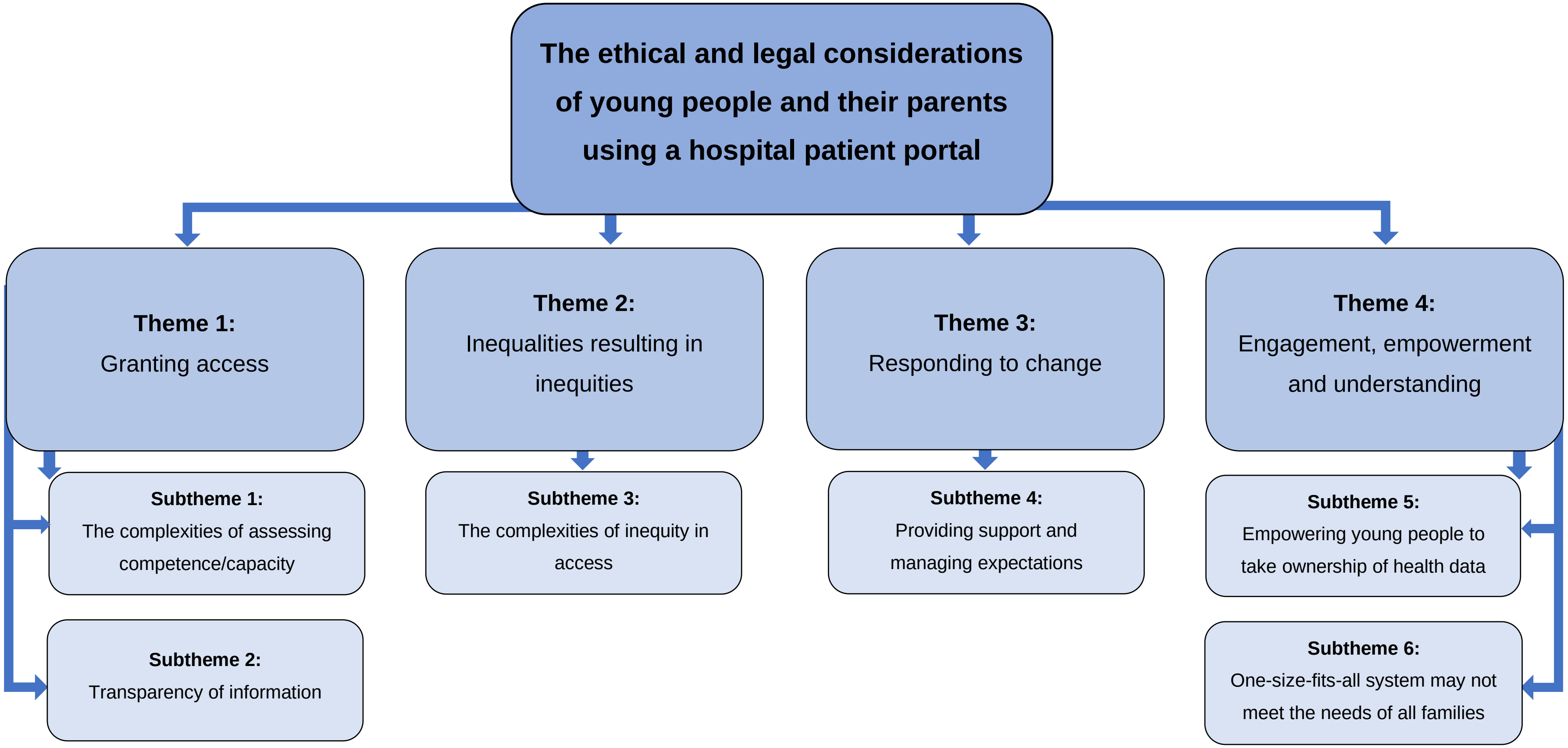


Figure 9-1: Thematic map: themes and subthemes

9.5.3.1 The complexities of assessing competence or capacity

The complexities of assessing a CYP’s competence (if under 16 years of age) or capacity (if 16 years of age or older) to access MyGOSH was highlighted by focus group participants. There was a presumption of capacity for those aged 16 years old or above, as per the Mental Capacity Act 2005 [31]. When considering decisions about portal access, it was difficult for participants to define the criteria for permission to be granted, but importance was placed on:

> *“Assessing the young person to see how much they understand about their condition, how much they understand about treatment, investigations, whether they can retain the information and whether they can take part in decision making” (CM2).*

Notably, participants identified a difference between a patient who has a chronic condition and is medically stable accessing online health information, and a patient who has a deteriorating condition, for example, relapsing leukaemia, particularly in terms of how information is delivered, with further complexities if the CYP has fluctuating capacity, *“It will depend both on the individual and the circumstance, … the individual and their level of understanding generally, but also depending on what their disease processes are”* (CM4). It was felt that some information will be more upsetting than other information, necessitating an individualised approach to both assessment for access to be granted and how health information is delivered. Participants also discussed whether CYP’s understanding is key to granting the portal access:

> *“I’m finding this difficult … if the concern is the information might be distressing or difficult for an individual to deal with then the competence in question is not about understanding, because really, if they do understand it then it distresses them. If they didn’t understand it, it wouldn’t actually distress them” (CM1).*

It could also be argued that if portal information is *mis*understood, then it could distress them, making this a complex issue. Moreover, the threshold for granting MyGOSH access was not considered comparable to the threshold for making decisions about medical treatment, meaning that normative judgements relating to competence assessment may need to be reconsidered:

> *"Standard assessments of competence are in order to allow a minor to make a decision, but this is merely to allow them access to* (MyGOSH)*. So, they're not making a decision, you're providing them with access to personal information … The threshold for competence drops immediately, if we're talking about making a crucial or critical medical decision then the threshold goes up" (CM1).*

Participants expressed worries about clinician ability to assess capacity, *"There are a lot of people who I come across … who are not confident with the assessment of capacity. Should they be? Yes. Are they? Not consistently"* (CM7). This identified a need for ongoing training and support for clinicians in the assessment of capacity.

9.5.3.2 Transparency of information to CYP

It was acknowledged by participants that being transparent with CYP was crucial if they are to take more responsibility for their health as they gain independence. Historically the hospital has tended to focus on consulting with parents, but it was acknowledged that clinicians need to be thinking more about, *"How do I empower the sixteen, seventeen-year-old where the law requires you to, or the under sixteen-year-old, where the law encourages you to, but doesn't require you to"* (CM7). Participants identified benefits from earlier involvement of CYP and their families in discussions about their care and it was recognised that failing to do so could be problematic for a young person turning 16, with the legal right to access their medical records (including MyGOSH). If they are not fully informed and do not fully understand their condition(s), there is the possibility of, *“A sixteen-year-old getting access to medical records is getting access to those records that cover periods throughout their childhood rather than just their current condition”* (CM1), which could lead to, *“Possible mental health implications for the young person, and potential for legal claim against the Trust for psychiatric damage”* (CM7) if they find out previously undisclosed and upsetting information.

Participants suggested that health information may be better received at a younger age rather than during adolescence, *“If you’re advocating from the child’s point of view … these things can be explained in quite a reasonable way when they’re nine or ten and they’re able to take it on, maybe that’s easier than when they’re a teenager”* (CM3). It was suggested that when MyGOSH access is requested, a crucial question that the clinician should ask is, *“Does this child know their diagnosis?”* (CM3).

The importance of truth telling to CYP was highlighted throughout the discussion, and how MyGOSH may promote greater transparency of health information, and between those involved. Whilst recognising parents’ good intentions for wanting to protect their child, the effects of not telling them the truth was considered:

> *“You can see lots of reasons why parents might want not to tell a child certain things and then face the awful consequences when they’re now going to be able to find out … The evidence is children are most distressed to learn that information is being kept from them. So, it’s not the fact of itself that’s distressing, it’s that they were lied to by their parents or had something concealed from them that was devastating” (CM1).*

The group concurred that, *“All of this surely tells us that if the patients remain ours as they’re hitting their adolescence, we need to be being up front with them, and however that is managed”* (CM3).

9.5.4 Inequalities resulting in inequities

Participants identified inherent inequalities in relation to having an EPR system with a patient portal, with complexities related to inequity in access which raised ethical issues.

9.5.4.1 The complexities of inequity in access

Participants highlighted inequalities inherent in EPR and portal provision, and barriers to access including those for non-English speakers when using an English-only system, and not having the technical knowledge to navigate the portal. Participants agreed that the hospital and its clinicians strive to provide equitable care but a mismatch in the provision of an equitable service and equal resourcing exists. Some families will need more support and clinician time than others, whilst the clinician is trying to balance care provision. Participants also highlighted disparity between those who do not have computers, smartphones, or regular access to the internet. Furthermore, they acknowledged that some families may not want internet access. There was concern that assuming that people *do* have access when they *do not* may be, "*Marginalising them in some way*" (CM7), and that those who lack technical knowledge will immediately be at a disadvantage. Conversely, having access and being articulate and 'tech-savvy' could help parents get what they needed for their child. As one participant said:

> *"If you think the internet is empowering, it is in a very unjust and unfair way … Any right is only as valuable as the means you have to exercise it. So, if the only way you can exercise your right to know personal information is through means that are not generally available, then it's problematic" (CM1).*

An additional challenge identified by the participants that poses a risk is that the portal can only provide one view for all those accessing it. So, if for example, one parent requires their address to be kept secure from the other parent, by court order, because they are at risk of harm from them, this is not currently possible via MyGOSH:

> *“There are potential inherent risks in not having a bespoke system that secures one view for one, but is able to reflect the fact that in this situation the other should not be accessing all of the information that the other can, even where they both have parental responsibility” (CM3).*

Currently, the secure address can only be protected by not granting access to the parent whom the court order is against, thereby creating inequity in access to their child’s health information, whilst minimising the risk to the other parent.

Participants felt that inequity was increased due to the EPR system only being available in English (apart from the functionality to translate after-visit summaries into Arabic). As a result, some families will, “*receive a less fluent means of communication with the Trust than others*” (CM7). Despite the concerns voiced by participants, they thought that the level of inequity may depend on portal utility and benefits experienced by families:

> *“If it makes a big difference … the inequity is far greater. If it’s just the ‘icing on the cake’, here’s a bit more information, then, actually, I don’t personally see it as particularly problematic” (CM1).*

Participants described difficulties related to CYP or siblings being required to translate health information at home, creating potential psychological burden if they are privy to information that is upsetting or may impact them or family members in the future (such as genetic or familial information). A best practice model of interpreter use was advocated by participants wherever possible, avoiding the use of family members to translate medical information.

9.5.5 Responding to change

Challenges were described related to responding to the changes brought about by the hospital's transition to the new EPR system, especially the provision of support to families and managing their expectations.

9.5.5.1 Providing support and managing expectations

Participants expressed worries about how best to manage families' anxieties around seeing blood results online, "*We had parents hugely anxious because there's a red, it's out of range, but it's not something we would worry about … If you'd been in clinic you would have said, essentially those blood tests are fine*" (CM2). The change from interpreted to raw results being released onto the portal was highlighted. Participants acknowledged this required new ways of thinking and working, recognising, "*We have to think carefully about how the information is put on there, so that it's not misinterpreted"* (CM2). The discussion revisited the complexities around competency and understanding of information and its implications:

> *"It's not a simple matter of age-related competence to understand, because it looks like that'll vary according to the condition, some people whatever their age have better or worse understanding of their condition. So, it's presumably the risk of providing people with raw data and information that's not interpreted for them, but that's a problem across any age" (CM1).*

Participants concurred that support for CYP and parents whilst accessing their results via MyGOSH was important. Concerns were also raised about responding to questions in a timely manner via 'InBasket' messaging, especially if worrying information was posted. So, managing families' expectations in how quickly they get a response via MyGOSH was important.

It was evident from the discussion that committee members who were clinical staff were uncertain about standard operating procedures. This may impact their ability to provide support and manage families' expectations. For example, when thinking about MyGOSH and what can be viewed, the participants had uncertainties around whether the parent and child can log in separately, and whether what the child views is the same as their parent's (separate logins, same view). One participant was uncertain about what specific information could be viewed via MyGOSH, *"I don't know what else is available for parents/children to see in terms of, is it diagnosis, clinical letters, appointments, investigation results? I don't know"* (CM2). Participants with a clinical role recognised that, *"We're going to be learning as we go along"* (CM2), suggesting that the transition period for clinicians and families alike to get used to using the new system may span a considerable length of time post-implementation.

9.5.6 Engagement, empowerment and understanding

Under the theme of engagement, empowerment and understanding, earlier and increased engagement with young people and their parents was advocated, as was empowering young people to take ownership of their health data. Aspects of data safety were considered important, and it was identified that a one-size-fits-all system may not meet the individual the needs of all families.

9.5.6.1 Empowering young people to take ownership of their health data

Participants recognised the potential benefits of empowering CYP to understand their condition better, to help develop their autonomy, and the importance of being able to access their health information. Helping them take ownership of their health data was advocated. Participants also felt that both CYP and their parents need support during the process of adjustment with it being, *"… a gradual process of acquiring those skills, so we're aiming that when they get to 16 or 17, they can be fairly independent with their understanding of their condition, making decisions, knowing how to get medication etc.,"* (CM2), something that would also help CYP on the journey of transitioning into adult services.

Related to this, there was an overwhelming consensus among participants about the need to engage more and earlier with CYP, directing the discussion much more towards them. This was viewed as particularly pertinent in a number of different circumstances: when the diagnosis has not been disclosed to the child or young person; where they have been excluded from portal access; when needing to prepare them to become the consenter; or allowing time to apply to the court for deputyship if they lack the capacity to make decisions for themselves.

When it came to maintaining the confidentiality of young people's health data, they were regarded by the members of the PBC as being vulnerable, for example, due to the ease of access to health information, their level of maturity, or the potential for others to misuse their information. Although it was acknowledged that these issues are not isolated to EPR/MyGOSH, it was thought that having easier portal access through a smartphone/electronic device could lead to information being less confidential than it should be, "*Young people maybe not be thinking through what might happen to the information they've got if they let other young people access it, you know their peers*" (CM2). The group concurred that this could be problematic: *"I think there are enough kids sending photos of themselves topless to prove that they don't necessarily think through these things*" (CM4), and that if private information is indiscriminately shared, there is a risk of it being: *"Spread across social media like quick fire, to hundreds and hundreds of people, that's unbelievably harmful and destructive"* (CM1).

Participants perceived MyGOSH to provide better data security and confidentiality than letters being posted to families, *"MyGOSH is one of the safer aspects, because it'll be username and password protected. Letters could go anywhere … What's probably a greater risk is the whole EPR system itself getting hacked*" (CM4). There was agreement around wider aspects of data safety, *"So, it's part of having a society where you use so much media, isn't it? People have to decide whether to balance that … risk of information going out to the wrong people, versus wanting the information"* (CM2).

The complexities of trying to educate CYP in the responsible use of social media were discussed, "*Even if you spelt out formally what the risks are, I doubt that anyone would really understand what it might mean …"* (CM1). Young people may not understand, '…*how long this information is stored, even though sometimes you delete it from social media'* (CM6). One participant likened health data to a gift to be kept private, *"Perhaps we just don't emphasise it enough, it's yours, it's your gift, it's your private thing, be really careful before you give it away because anything you give away you may never be able to take back again"* (CM5).

The issue of 'sharenting' (parents sharing information) such as photographs, videos, or confidential health information on social media without their son's or daughter's knowledge, was discussed by the group. The possible future implications for CYP were worrisome for the participants; guidelines for CYP and families were advocated to ensure they were aware of the possible harms from sharing their data online.

9.5.6.2 A one-size-fits-all system may not meet the needs of all families

MyGOSH access and content is not bespoke to CYP's individual needs and condition, or the needs of the family. It was felt that a generic one-size-fits-all approach, "*Isn't particularly helpful or useful, and certainly isn't reflective of an individual and family's circumstance"* (CM3). Writing letters to the child or young person, in addition to the parents, was a suggested method of individualisation, but it was recognised that thought is required as to what information this should contain, "*Because we want children and young people to be more engaged*" (CM2). The child's or young person's condition and/or developmental level needs to be considered rather than using the, "*Standard adult letter*" (CM2). For example, if diagnosed with a developmental disorder such as autistic spectrum disorder, *"We could design a report for that young person summarising their assessment* (in language) *so they can read it"* (CM2).

9.6 Discussion

Complexities exist when giving young people access to digital health data via a patient portal, but this does not mean that access should be denied. Participants in this focus group emphasised the need for individual assessment when making access-related decisions. Participants proposed that competency assessments for portal access may not carry equal weight to making a complex decision about medical treatment, concluding that when gaining access to health information, the threshold for granting portal access may therefore be lower. Although, empirical observations have no direct normative bearings, these perspectives can be used to inform normative judgements. Every effort should be made to ensure each young person is as involved and as autonomous as possible, within their capabilities, with the aim of empowering them to manage their own health. This echoes findings by Hong et al. [96], who reported young people felt increased confidence in managing their health whilst using MyChart [47].[xv]

Early engagement with CYP was viewed as important, with emphasis on preparing them for becoming the consenter, particularly when they are unaware of their diagnosis or prognosis. Fostering a culture of truth-telling was also considered important by the participants, and as advocated by Pergert and Lützén (2012), 'is a prerequisite for trusting relationships' (p22) [222]. This requires collaboration between clinical teams and parents, as well as open communication and involvement of CYP in all aspects of care, as advocated by Hudson, et al. [223]. Clearly, a one-size-fits-all system may not meet the needs of all CYP. Central is timely preparation to ensure a CYP-focused approach, in terms of discussions being directed towards them, using terms about their diagnosis they can understand, and letters written to them in a readable format. These steps in engagement should correspond with age and cognitive abilities, reflective of an increasing understanding as they approach transition from child into adult services, which links to their cognitive ability and competence to be able to comprehend what is being asked of them if providing consent (or assent) [224]. Therefore, preparation is the key to successful transition [225,

---

[xv] MyGOSH is MyChart, renamed by GOSH after consultation with the Young People's Forum.

226], including empowering CYP to take increasing ownership of their health data as they increase in autonomy and decision-making [164, 227]. This also includes support for young people to understand privacy concerns and the impact of their digital footprint on their futures, as they become more autonomous [228].

Families need ongoing support whilst adapting to digital health technologies, including adapting to new ways of thinking with raw data (results) being released onto the portal. Communication with families prior to results release is advocated to reduce anxiety. These findings concur with those of Krasowski et al. (2017) where significant patient anxiety was created as a result of accessing results via a portal prior to discussion with the care team [229].

The provision of equitable patient portal access is important to support equitable health outcomes [47, 117]. However, it is clear that the use of an EPR system and patient portal creates inequalities which lead to inequity for some families. Equity relates to “social justice and fairness, and reflects a concern to reduce systematic discrimination and marginalisation” (p.580) [230]; in this case access to health information and the benefits of the portal to “social groups who have different levels of underlying social advantage or disadvantage” (p.580) [230]. The ethical principle of equity denotes that,

> *“… selective priority should be given to improving the situation of the most socially disadvantaged groups in a society, which may mean the readjustment of strict rules or structures, or the redistribution of the resources, and other processes that drive a system of inequality”*
>
> Wiles and Kobayashi (2009) [230].

With digital transformation, the disparity gap is widened. According to Rawls, inequality of opportunity, in this case access to MyGOSH, and the priority of efficiency and welfare, is only acceptable if it enhances the opportunities of those with lesser opportunities in society; and/or the extent of hardship for those who do not traditionally benefit are lessened [231]. When related to the inequalities inherent in EPR/MyGOSH, these inequalities would only be acceptable if those who would usually have less opportunities, such as those with limited access, benefitted from the transition to digital health, meaning that the disparity gap would be lessened. However, although inequity may, to some extent, be dependent on portal utility – the greater the utility, the greater the inequity – it does appear that inequities are increased for some families. The distinction between formal and substantive equality of opportunity is acknowledged. Formal equality in the digital health context would mean that everyone is treated consistently or fairly at all times. Substantive equality in this context would recognise the equality of everyone, but would also identify those who may have difficulty accessing digital health means, with the aim of greater understanding of what is required to promote equality. All patients have a right to healthcare information, which is more important and fundamental than the specific inequity assumed to follow the introduction of EPR and the patient portal. This needs to be considered by healthcare providers. Furthermore, there is a legal obligation to make reasonable adjustments for those with disabilities, and to incorporate these into digital health transformation [232]. Reasonable adjustment flags can be incorporated into patient records to alert healthcare staff to the needs of the patient but further work is required to promote accessibility by all to their records [233]. As stated by Watts, “Any healthcare development that doesn't rapidly become available to all individuals has the unintended but inevitable consequence of fuelling health inequality” [161].

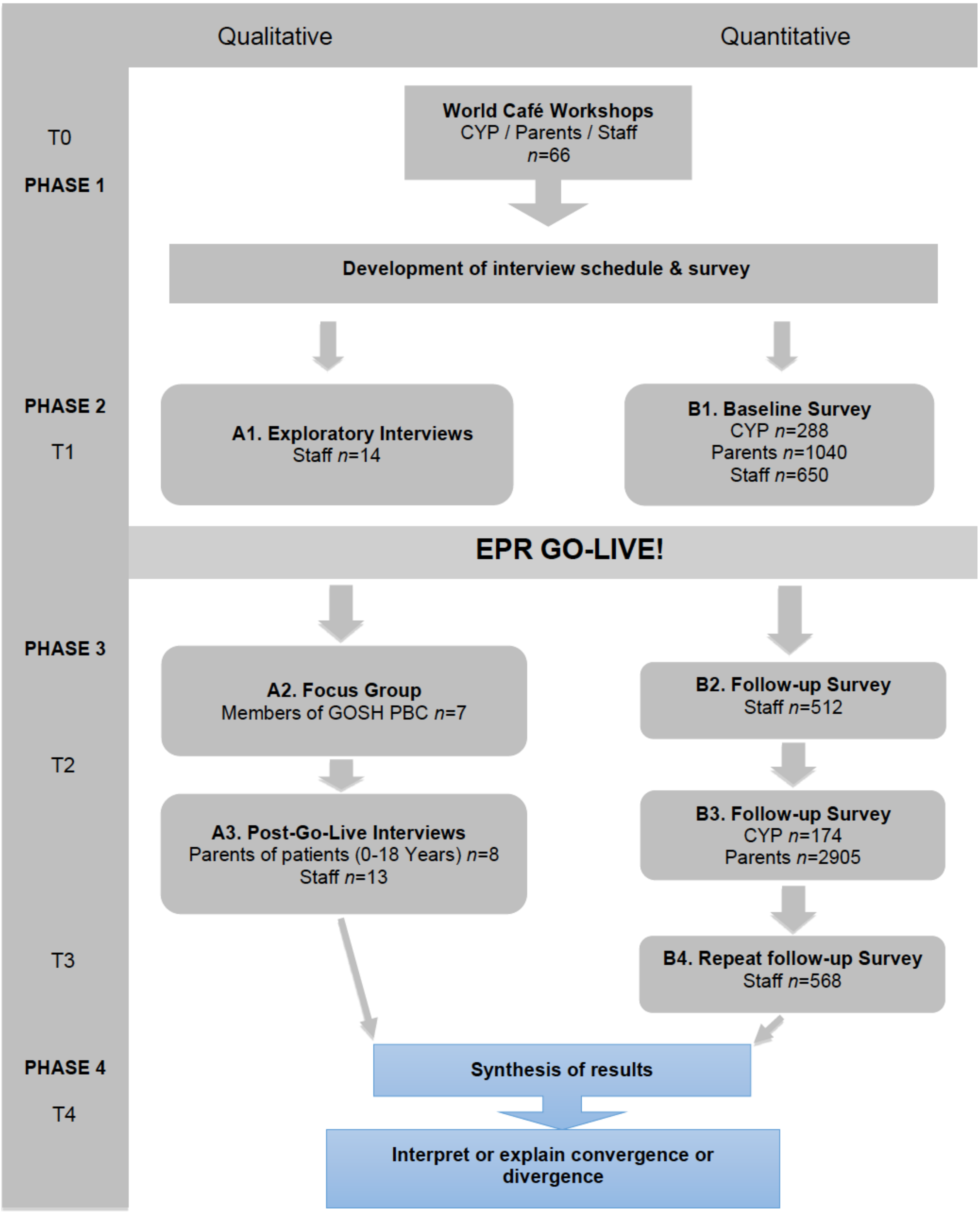
The widespread issue of the digital health divide related to patient portal access is well documented [154-156, 201]. This has been widened during the COVID-19 pandemic [160, 162], increasing barriers between some families and the hospital. There is a need to ensure those who do not have access to MyGOSH receive equal access to health information and care, including those who choose not to have MyGOSH access. Resolution of the secure address issue is also required to eliminate the risk this poses, and to facilitate appropriate portal access for both parents with PR. There is work to do at clinician, management and executive level, locally and nationally, requiring initiatives across policy, practice, research and implementation to maintain equal access to healthcare whilst going digital, and thus, promoting distributive justice [118, 201]. The promotion of inclusion and equity are essential if CYP are to fulfil their right to ‘the highest attainable standard of health’ under Article 24 of the United Nations Convention on the Rights of the Child [234].

9.7 Summary

These discussions are pertinent to understanding the complexities around CYP and their parents accessing their digital health data; digital health innovation is shaping the future of healthcare. Promoting inclusion is essential to lessen, rather than widen, the digital divide. This requires adequate resources and support at a national level, enabling clinicians to ensure all families can access health information and the care they need, and CYP are empowered to embrace their health needs. Ongoing support is required for all relevant stakeholders to navigate the ethical and legal complexities of digital health systems. Continued commitment is needed on multiple levels to balance the benefits and burdens, ensure portal utility for patient benefit, whilst maintaining an individualised approach to care.

In the next chapter, the quantitative and qualitative will be integrated and synthesised, to discover the overall findings from the study. The unique contribution of the study, the implications for healthcare services beyond GOSH are highlighted, implications for practice, recommendations for future research, and dissemination are then presented. This research’s strengths and limitations will be discussed and conclusions will be drawn.

Chapter 10 Synthesis



10

10 Synthesis, implications, and conclusions

10.1 Introduction

The focus of this chapter is to bring together all three phases of data collection with each stakeholder group with the aim of understanding the multi-faceted and varying experiences and considerations of what it means to implement an EPR system in a children's hospital setting. This chapter begins with a brief reminder of study aims, followed by the principal findings including integration and synthesis of the quantitative and qualitative results. The unique contribution of the study, and the implications for healthcare services beyond GOSH are highlighted. Implications for practice, recommendations for future research, and dissemination are then presented, along with strengths and limitations and conclusions.

10.2 Summary of the research

The Going Digital study sought perspectives from, and the experiences of, CYP, parents and staff before and after the implementation of EPR and its tethered patient portal MyGOSH in a children's tertiary hospital.

The aim was to understand:

1. Expectations regarding the introduction of EPR and MyGOSH patient portal, and whether these were met?
2. The benefits and challenges of transitioning to an EPR system and the use of MyGOSH?

3. Information and support needs when accessing EPR and MyGOSH?
4. The ethical dilemmas and legal implications associated with the implementation and use of EPR and MyGOSH?

A combined total of *n*=6218 participants[xvi] took part over three phases, demonstrating commitment and engagement from all stakeholder groups in what represented a significant organisational change for GOSH [198].

10.3 Key findings

The first key finding, is the validation of including CYP as stakeholders in this process. It was clearly demonstrated in the systematic review that CYP's views are rarely considered, despite care, treatment and digital health information within the EPR and patient portal being about them and for them. Consequently, paramountcy was placed on the voice of CYP throughout this thesis. The Going Digital study included CYP throughout the research process from patient and public involvement activities when designing the study, to inclusion in research activities, and dissemination, placing value on the involvement of CYP in research and their contribution to the NHS [235-237].

Secondly, appropriate access to and meaningful use of digital health records from the age of 12 years of age has be achieved. However, clinicians need to have early conversations with parents about truth-telling and sharing diagnoses and/or prognoses, support families through the process of disclosure, and prepare families for accessing health information and managing care including appointments and communications via the portal. Changes need to be made to the way records are written, with the focus being on communication addressed to the child or young person, in an accessible and cognitively relevant manner, translating the information and health data so that the child or young person can understand it. Furthermore, enabling CYP to access their health information via a patient portal can help facilitate long-term planning for the promotion of independence and transition into adult services, but this must be supported by the healthcare provider, with simultaneous access to the health record and

---

[xvi] This includes all participants reported in this thesis. Staff interview participants are not included in this figure, as the complete staff experience was outside the scope of this thesis.

commencement of the transition journey from child or adolescent services into adult health services.

Thirdly, barriers to accessing and using the EPR and/or patient portal were evident. For families, barriers were socio-technical, not just technical, due to physical, intellectual, sensory difficulty or disability, not having English as a first language, and through cultural, religious, or personal preferences [172, 173].

Lastly, but significantly, the time taken to embed an EPR system (including a patient portal) in a specialist children's hospital was at least 12-18 months. The Going Digital study's findings demonstrated that by the hospital not setting realistic expectations about the time required for all user groups to get used to the new digital system, families perceived staff members to be unprepared, leading to frustrations and confusion. Ongoing support for all users during this time is essential to ensure continual provision of targeted information, setting the expectations of all user groups, and supporting clinicians whilst they balance clinical demands during the prolonged transition period.

10.3.1 Integration

Mixed methods research is expanding, especially within healthcare [238-240]. As an approach, it is increasingly recognised as valuable [241], becoming more and more sophisticated, and utilised by multiple disciplines [242, 243]. The complexity in healthcare warrants its use. It was utilised for the Going Digital study because it enabled more comprehensive exploration of the complexities involved in EPR implementation, and what it meant for the different stakeholder groups. Mixed methods approaches were used to explore diverse perspectives and uncover relationships that existed, and this could not have been sufficiently understood using single method research [244].

Creswell et al. (2011) describe three methodological procedures or systematic integrative procedures [243]. These are merging, connecting, and embedding data, and were summarised by Johnson et al. (2017) as:

- Merging – a joint display (meta-matrix or matrix) which combines and displays both quantitative and qualitative data together
- Connecting – quantitative data set analysis, the findings of which inform subsequent qualitative data collection
- Embedding – the qualitative data set of secondary priority is embedded within a larger, primary quantitative design [242, 243, 245].

‘Merging’ was utilised for the integration of the Going Digital study’s findings, presenting both quantitative and qualitative findings in meta-matrices (Tables 10.1-10.4) to enable convergences or divergences across the datasets and stakeholder groups to be identified and explored[xvii]. Key study findings were mapped according to domain and research activity, under each of the study aims (highlighted at the beginning of this chapter). Although research activities throughout the study’s timeline informed subsequent phases of the study, for example, the World café workshop findings informed the content of the quantitative surveys and qualitative interview schedules for all stakeholders, data from each activity was considered important to include in the meta-matrices to demonstrate the depth and breadth of data captured. Similarly, equal weight has been given to both quantitative and qualitative data to also ensure the breadth and depth of each research activity and participant group’s contribution was recognised, valued and fully explored. This was particularly important given the lack of child voice in previous EPR related research. The following meta-matrices (Tables 10.1-10.4) present the study’s merged findings under four domains: expectations of EPR and MyGOSH and whether these were met; benefits and challenges of transitioning to an EPR system and the use of MyGOSH; information and support needs when accessing and using EPR and MyGOSH; ethical dilemmas and legal considerations associated with the implementation and use of EPR and MyGOSH.

[xvii] World Café workshop findings in the parent quantitative column will be indicated by (W) to differentiate these from the parent interview findings (I)

Table 10-1: Going Digital study metamatrix – Expectations

Expectations of EPR and MyGOSH patient portal and whether these were met						
Domain	**CYP Qualitative (World Café workshop)**	**CYP Quantitative (Survey)**	**Parent Quantitative (Survey)**	**Parent Qualitative (World Café workshop/interviews)**	**Staff Quantitative (Survey)**	**Committee Members Qualitative (Focus Group)**
Setting/ meeting expectations	- Expectations of what MyGOSH/EPR can do need to be set early	- Expectations of the portal not fully met	- Expectations of the portal not fully met	- Expectations high; hospital must: set realistic expectations prior to Go-Live; deliver on promises (W)	- Expectations of the portal not fully met	- Unsure of SOPs - may impact how families' expectations met/managed
Involvement in decisions	- YP want to be involved in decisions about their care	- Expectations not met regarding involvement of them/their parents in care decisions	- Expectations not met regarding involvement in care decisions	- Expectations of benefits high including helping parents make decisions about their child (W); Expectations not met: ways in which MyGOSH would change or enhance care delivery; what MyGOSH could do (I)	- High expectations of benefits EPR/MyGOSH would bring pre-Go-Live - Managing families' expectations soon after implementation was difficult	- Managing families' expectations after EPR/MyGOSH implementation was difficult
Care coordination	- Better coordination expected around the hospital	- Expectations not met	- Expectations not met	- Expectation was that the new system would aid partnerships in care (W)	X	X
Communication	- Better communication expected via MyGOSH/ InBasket messaging but YP wanted to know how quickly to expect a response from care team	- Expectations not met: communication between all involved in care	- Expectations not met: communication	- Improved communication expected (W) - In-basket messaging: expected to eliminate communication frustrations but added burden on HCPs recognised; how easy will it be to get hold of a clinician? (W)	- Improvements to communication over time, but more difficult soon after implementation to answer patient/parent questions	- Managing families' expectations regarding communication via MyGOSH time-consuming/ burdensome
Perception on ease of use	- Perception that parents may not find MyGOSH easy to use: not technology minded; lacking understanding of technology	- CYP thought MyGOSH was easier to use/ understand than expected for them/their parents	- Worries higher pre-Go-Live: using/ accessing MyGOSH - Worries post-Go-Live: MyGOSH difficult for their child to use/understand	- MyGOSH: difficult for them/their child to use if physical/ID present (I)	X	X
Potential for conflict	- Not being given access by parents/non-disclosure of diagnosis/prognosis problematic	- MyGOSH may cause conflict between them/ their parents/care team; fears unrealised	- Worries using MyGOSH may cause conflict between them/their child/care team; fears unrealised	- Worries YP aged 16 years old or above might not give their parent access – risk of YP blocking parent with risk of conflict (I)	- Worries at T_1: InBasket messaging may cause conflict between parents/ child, or parents/staff; concerns ↓over time/with MyGOSH use	X
Anxiety	- Misinterpreting information via MyGOSH when not face-to-face; being constantly reminded of diagnosis/ condition(s); information being concealed	- Anxiety levels regarding MyGOSH use unchanged pre/post-implementation	- Anxiety about using MyGOSH ↓after 18 months' use	- Parents felt a responsibility to support child's access to avoid anxiety (W) - Worries that too much information will lead to ↑anxiety for child (W)	- Difficult to manage patient/parent anxiety early post-implementation	- Communication with families prior to results release via MyGOSH advocated to ↓patient/ parent anxiety

Abbreviations (not previously defined): HCPs – healthcare professionals; (I) – Interviews; ID – intellectual disabilities; SOPs – standard operating procedures; (W) – workshop; YP – young people

10.3.1.1 Expectations of EPR and MyGOSH patient portal and whether these were met

Understanding patient expectations of healthcare can improve patient satisfaction and the delivery of patient-centred care [246]. Arguably, patient expectations within this context are rising, which may need to be sensitively and adequately managed to improve satisfaction and outcomes [247], as well as manage what is expected of staff. This is equally important in the digital health context, with the rapidly evolving digital health landscape.

Prior to implementation, hospital staff had high expectations of the clinical benefits EPR and MyGOSH would bring, but they found managing families' expectations difficult in the early phases post-implementation whilst learning to navigate the new system. Committee members with clinical roles within the hospital reported that providing support for families during this time was challenging, time-consuming and burdensome, especially related to supporting families accessing results via MyGOSH. Both young people and parents expressed during the World Café workshops that it was important to set their expectations prior to system implementation as to what the patient portal could do, and the potential benefits to care they may experience. Whilst the hospital expected 'business as usual' to return within approximately three months, the reality for parents was that it took considerably longer (12-18 months) [194]. Unmet needs were reported by CYP and parents in relation to several aspects of care which could lead to frustration and confusion. Staff also expressed anxiety in meeting clinical demands. Historically, it is well evidence in the literature on healthcare management that actively managing the expectations of healthcare users is considered important for several reasons: higher evaluations of quality is related to increased satisfaction and linked to intentions to use healthcare in the future [248-250], increased compliance with treatment and medical advice [251], and the possibility of better health outcomes [252, 253].

For healthcare providers considering digital health transformation, it is important to consider the expectations of all potential users to prevent or mitigate unmet expectations and needs which may lead to a decrease in satisfaction levels, or be met with disappointment, frustration or anger. The World Health Organisation launched guidance in 2020 on designing digital health interventions *with* and for young people [254]. Meaningful engagement with young people is advocated at every step, which means valuing young people as equal partners in programme design and delivery [6, 254], and is advocated throughout the lifecycle of EPR system implementation, not just in the pre-implementation phases. This notion of being equal partners is essential as young people still often encounter considerable resistance to having their views carry equal weight to that of adults [46, 254]. This would enable targeted system design based on user needs, and would promote prolonged user engagement, utility, user satisfaction, and digital literacy for implementation success [47, 77, 79, 86, 97, 98, 110]. Parents who had a child with a physical or intellectual disability felt that MyGOSH was difficult for them to use. The importance of collaboration and co-design with CYP with disabilities and their parents is also essential to promote usability and inclusion [255]. This will be discussed more under ethical and legal considerations below in section 10.3.1.4. This co-design element is not present in the EPR Applied Ethics Framework, and is a necessary amendment for the framework to be applicable to this patient group and setting (Figure 10-1) [40].

Evidence from this study demonstrates that the stakeholder experiences were related to the extended amount of time that was required for staff to become familiar with the system. Important learning for future digital transformations is support for all stakeholders for an extended period post-implementation, which includes the provision of easy to access practical and technical support that facilitates meeting clinical demands [71, 79, 86].

Table 10-2: Going Digital study metamatrix – Benefits and challenges

The benefits and challenges of transitioning to an EPR system and the use of MyGOSH

Domain	CYP Qualitative (World Café workshop)	CYP Quantitative (Survey)	Parent Quantitative (Survey)	Parent Qualitative (World Café workshop/interviews)	Staff Quantitative (Survey)	Committee Members Qualitative (Focus Group)
Coordination of appointments	- Expectation of functionality to change/co-ordinate appointments online with parents	- Overall improvement in coordination of appointments	- Overall improvement in: coordination of appointments; how they are booked/changed; changing appointments online was difficult	- Scepticism about whether managing appointments will be easier (W) - Frustration with repeated appointment rescheduling soon after system implementation (I)	- MyGOSH did not make it easier for parents to change appointments - Perception that MyGOSH did not ↓number of missed appointments	X
Convenience of appointments	- Perceived that parents will save time due to ↑convenience of/easier access to appointments, and less journeys to hospital	- Overall improvement in convenience of appointments	- Overall improvement in convenience of appointments	X	X	X
Staff preparedness	- ↑Efficiencies expected with HCPs more able to talk to/care for patients - Perception that loss of face-to-face contact may impact clinician/family interactions when learning new system	X	X	- Longer OPAs soon after implementation due to staff unfamiliarity with EPR; resulted in a loss of face-to-face contact, affecting clinician/parent relationship during consultations (I) - Perception that staff were unprepared, resulting in a lack of standardisation - Perception that staff required a prolonged period (12-18 months) to get used to using new system (I)	- Consistent results that it was more difficult to provide care, manage expectations and provide support for families soon after implementation - Results at T_3 higher than T_2 signifying it took up to 18 months for staff to get used to using new system	- Transition period for clinicians and families to get used to using new system may span a considerable length of time post-implementation - Members who held clinical roles were unsure of MyGOSH functionality/SOPs nine months post Go-Live
Ease of speaking to team	- Anticipation that MyGOSH will make it easier to: communicate with care team; ask questions; keep care team up to date	- Overall improvement in ease of speaking to care team member	- Overall improvement in: ease of speaking to care team member; communication *from* the care team, but parent-initiated communication *with* care team was more difficult	- Communicating via MyGOSH brought benefits: all communication in one place; everyone in care team being able to see messages; not having the difficulties associated with trying to call the hospital (I)	- Benefits of communicating with families via MyGOSH reported at T_3, but communication with families more difficult at T_2	- Inequity in access to MyGOSH may mean some families receive a less fluent means of communication with the Trust than others
Confidentiality/ security of data	- Perception of ↑confidentiality with digital patient records, but acute awareness of possible threats to data safety/integrity	X	X	- Less concerned with security than other considerations listed (W) - Confidentiality benefits (digital health records less accessible than paper notes) (I)	X	- EPR/MyGOSH provides ↑confidentiality of medical notes - YP vulnerable regarding maintaining confidentiality of health data: ease of access to

	- Great emphasis placed on privacy/security of health data - Assurances wanted: privacy/security/confidentiality of health data			- Parents of children with ID worried about data security if child was accessing MyGOSH (I)		information: level of maturity; potential for others to misuse their information - Promotion of data safety advocated
Test results	- Thoughtful release of test results desired - Accessing results on MyGOSH will be beneficial, but worries about misinterpreting information via MyGOSH when not face-to-face - Hopes for ↓need for repeated clinical tests	- Overall improvement in: time to/mode of receiving test results	X	- Worries existed about their child accessing results via MyGOSH before parent discussed these with them (W) - Difficulties existed for parents in getting their child's results consistently released onto MyGOSH (I)	- Results release onto MyGOSH enabled families to be more involved in care at T_3, but more difficult to achieve at T_2 - Perception that: results release via MyGOSH caused patient/ parent anxiety at all time-points: additional support needed by families when accessing results via MyGOSH across all time-points	- Responding to questions in a timely manner via 'InBasket' messaging important, especially if worrying information/results posted - Managing families' expectations about how quickly they get a response via MyGOSH was deemed important - Results release via MyGOSH requires time to support families, with additional burdens on staff
Informed about care	- Anticipation of feeling more informed about their care post-implementation. This was seen as a benefit	X	- Parents felt less informed about child's care post-Go-Live	- New system will aid partnerships in care (W) - Lack of preparedness revealed a lack of standardisation in departments' use of MyGOSH to manage care (I) - Lack of consistency reported (more evident if under more than one speciality) (I)	- Benefits reported related to keeping patients/parents informed of the care plan at T_3, but more challenging at T_2	X
In control	- YP anticipated feeling more in control of their care. This was seen as a benefit	X	- Parents felt less in control of child's condition post-Go-Live	- MyGOSH perceived to mean more control, more autonomy, more informed = parental empowerment (W)	X	X

Abbreviations (not previously defined): OPAs – Outpatient appointments

10.3.1.2 The benefits and challenges of transitioning to an EPR system and the use of MyGOSH

Communicating via a patient portal with the clinical team brought benefits for both parents and CYP including all communication being in one place, everyone in the care team being able to see the messages, and not having the difficulties associated with trying to call the hospital. Such improvements could be beneficial in other healthcare settings, but would require additional support, such as increased staffing levels to manage clinical demands whilst adapting to the new system, the provision of standard operating procedures (SOPs), practical support sessions to increase staff competence and confidence, and 24-hour accessible technical support [71].

The traditional clinical encounter is evolving as a result of EPR, personal health record and patient portal implementations [256]. During consultations, what matters most to patients is the emotional and human features of a consultation being met [257]. A study by Clark et al. (2008) explored families' perceptions of paediatrician communication during children's asthma appointments [258]. Characteristics that were perceived by families to positively influence the interaction were, “careful listening, inquiring about at-home management, nonverbal attention, interactive conversation, tailoring short-term goals, and long-term therapeutic plan” (p.49) [258]. Arguably, some characteristics may be more difficult to achieve if clinicians are trying to use and navigate a new EPR system. The systematic review highlighted that a loss of face-to-face interaction during consultations negatively impacted staff members' ability to provide patient care [73, 76, 79]. Potential loss of face-to-face interaction was a concern of for CYP and parents pre-implementation, and was a reality for parents post-implementation with reports of consultations taking longer due to staff unfamiliarity with the system and the amount of time it took to navigate the EPR. This was further accentuated by the COVID-19 pandemic, the impact of lack of face-to-face care being well documented [259-262].

During this study, challenges encountered by staff members resulted in parents having the perception that staff were unprepared. Parents experienced varied approaches taken by different care teams, which led to a lack of standardisation in care provision and how the portal was used, especially in relation to communication. A lack of consistency in teams' approaches to managing care was more noticeable by parents whose child was under more than one team. Furthermore, whilst staff reported benefits for parents, for example, them being more informed and more involved in care, parents themselves described feeling less informed and less in control. Effective communication is essential to providing high quality, safe patient care, and forms part of the Compassion in Practice 6C's [263]. Communication failures or miscommunications can potentially result in inadvertent harm to a patient [264], and be potentially damaging to the parent-clinician relationship and reputation of the hospital.

Lessons to be learned from this study include the provision of a standardised approach to care across the organisation which includes a communication and information release strategy via the portal. These factors would contribute to effective cultural change [264].

Table 10-3: Going Digital study metamatrix – Information and support needs

Information and support needs when accessing EPR and MyGOSH

Domain	CYP Qualitative (World Café workshop)	CYP Quantitative (Survey)	Parent Quantitative (Survey)	Parent Qualitative (World Café workshop/interviews)	Staff Quantitative (Survey)	Committee Members Qualitative (Focus Group)
Info/support needs	- Recognition that support may be needed accessing/using MyGOSH	- At T_1 CYP reported high levels of agreement about wanting to know that they would get the information/ support they needed, but at T_2 a proportion did not feel they had received this	- At T_1 parents reported high levels of agreement about wanting to know that they would get the information/ support they needed, but at T_2 a proportion did not feel they had received this	- Parent wanted to know if technical support would be available? (W) - Parents had high information needs that were not consistently met (I)	- It was more difficult for staff members to answer families' questions soon after implementation	- Staff require support for 12-18 months following implementation, then ongoing access to support thereafter
Support accessing/ using MyGOSH		- Ongoing emotional/ technical support, and information required when accessing/using MyGOSH	- Ongoing emotional/ technical support, and information required when accessing/using MyGOSH	- Parents did not receive adequate information or support (I) - Parents were proactive, often taking the initiative themselves in trying to access/learn how to use MyGOSH (I)	- It was difficult for staff to provide support to families whilst navigating the new system	- A one-size-fits-all system may not meet the needs of all families: individualised approach to care advocated - Providing support for families in the early phases post-implementation was challenging, time-consuming/burdensome
Support accessing results via MyGOSH	- YP raised the notion of seriousness, and the importance of delivering test results with serious implications face-to-face rather than online - Support when accessing results was important to YP, as was timing of results release e.g., not late on a Friday with no explanation	- Support when accessing results via MyGOSH	- Parents reported that their child needed support when accessing results	- Inconsistencies reported and difficulties in getting their child's results released onto MyGOSH (I) - Culture change required related to release of information/results onto portal (I)	- Results release via portal caused patient/parent anxiety at all time-points - Additional support was needed by families when accessing results via portal across all time-points	- Families need ongoing support whilst adapting to new ways of thinking with raw data (results) released via portal - Communication with families prior to results release advocated to ↓anxiety but burdens on staff acknowledged
Technical	- Need for 24-hour technical support identified	X	- Parents wanted technical support, and guidance on accessing/using MyGOSH and InBasket messaging	- Practical accessibility issues may be an issue e.g. accessing MyGOSH if password lost/forgotten (W) Locating MyGOSH on personal phones was difficult (MyChart) (I)	X	X

Worries	- YP worried about being constantly reminded about their diagnosis/condition(s) - Worries existed about the potential loss of face-to-face contact/interaction due to EPR/MyGOSH use	- Both pre- and post-implementation, CYP worried about being constantly reminded about their condition(s)	- Parents still reported not getting answers to their questions quickly enough at T_2	- Parents worried their child may read something they did not want them to read, and questioned whether too much information will lead to increased anxiety for child (W)	X	X
Understanding	- YP worried their parents would not have sufficient understanding of technology to use portal - Worries existed about not understanding information on portal	- Over a third of CYP read something they did not understand on MyGOSH	- Prior to implementation, parental worries were high about their child reading something they did not understand but this lessened with portal use	- Parents worried their children would read something they did not understand (I)	X	- Complexities exist around CYP understanding or misunderstanding information on MyGOSH
Informed about MyGOSH	- YP felt well informed about MyGOSH as they had been involved in its development	- CYP felt more informed about MyGOSH at T_2	- Parents felt more informed about portal at T_2	X	X	X

10.3.1.3 Information and support needs when accessing EPR and MyGOSH

Children's and young people's, and parents' information and support needs were not consistently met post-implementation. Parents had to be proactive to find out about MyGOSH and its functionality, often by trial and error, and also identified technical aspects that proved difficult. This emphasises the need for clarity of communication during preparation for implementation, which is important learning for other healthcare providers considering implementation.

The Going Digital study highlighted the importance of culture change related to the release of information via the portal, which resonates with the literature on the importance of effective communication and patient safety [264], on wider literature of change management [265, 266]. When assessing readiness for change, several factors are reported to be important to consider including clinician reaction to the proposed change, departmental reaction to proposed changes in workflow and procedures, individual perceptions on the proposed changes, and the provision of support [266]. Generational differences are reported to contribute to the digital divide amongst clinicians, with younger generations of clinicians being more fluent in technology use than older clinicians [267]. For healthcare providers planning digital health record implementation, it is crucial this includes a top-down approach to leadership including a consistent approach to information release. This is vital to successful change management [268]. In response to study participants' perceptions that results release via the portal can create anxiety for CYP and their parents, the provision of user-specific emotional and technical support is necessary. This will, in turn, encourage clinicians to adapt their ways of working, and help mitigate inconsistencies in information release experienced during this study. The additional emotion support would be provided by clinical teams, creating additional burdens, which would need to be factored in when resource planning the implementation.

Prior to implementation, parental worries were high about their child reading something they did not understand, but this lessened with portal use. However, over a third of CYP still read something on MyGOSH they did not understand, which may be problematic for those CYP with long term conditions, who are reported to have significantly worse educational outcomes than their peers [269, 270]. In a systematic review on how health professionals can enhance interpersonal communication with adolescents and young adults to improve health outcomes, themes arising included trust and emotional safety as prerequisites for open/engaging communication, and the importance of having a sense of autonomy and inclusion [271]. This is important because CYP with long term conditions often feel different from their peers, despite striving for normalcy [272-274]. Persistent worries existed from CYP about being constantly reminded of their diagnosis or condition(s), meaning that support is required to facilitate meaningful access through the understanding of portal content in a way that will not cause additional stress.

Table 10-4: Going Digital study metamatrix – Ethical and legal considerations

Ethical dilemmas and legal considerations associated with the implementation and use of EPR and MyGOSH						
Domain	**CYP Qualitative (World Café workshop)**	**CYP Quantitative (Survey)**	**Parent Quantitative (Survey)**	**Parent Qualitative (World Café workshop/interviews)**	**Staff Quantitative (Survey)**	**Committee Members Qualitative (Focus Group)**
MyGOSH access at 12 years of age	- YP felt it as their right to have access - Worried existed about whether their parents would give them access - If access not given they worried that information was being hidden	- Positive attitudes to accessing/using MyGOSH at 12 years of age	- Positive attitudes to their children accessing/using MyGOSH at 12 years of age	- Positive attitudes reported to their children accessing/using MyGOSH at 12 years of age, but will depend on child's readiness/maturity (W/I) - Some parents may not give their child access to MyGOSH (W) - Should access should be lowered to 11 years old – secondary school age? (W) - Who will assess children's competence to access MyGOSH? (W)	X	- Complexities exist in assessing competence/capacity to access MyGOSH; this may not carry the same weight as assessments for medical/surgical procedures - Staff training need identified due to inconsistencies in staff's ability to assess competency/capacity - Concerns exist that some CYP will be excluded from MyGOSH due to non-disclosure of diagnosis/ prognosis - Truth-telling/transparency of information to CYP highlighted
MyGOSH access at 16 years of age	- Awareness of Intricacies and considerations around sole access at 16	- Intention to continue to allow their parents access to MyGOSH when reached 16 years of age	- Wide ranging responses regarding their child having sole access at 16, but no change in views seen over time from pre/post	- Risk of conflict identified if YP aged ≥16 did not grant parents access – parental worries about risk of YP blocking parent (W) - Sense of responsibility existed for promoting their child's autonomy but conflicted by a reluctance to relinquish that responsibility. -- Relinquishing control at 16 was viewed as problematic (I)		- Complexities exist in patients with medical conditions that result in fluctuating capacity
Involvement in aspects of care	- Hopes of feeling more involved in care, with ↑confidence, responsibility, and independence	- CYP/their parents were not more involved in care: making decisions about care; care coordination following MyGOSH implementation	- Not more involved in care: decisions about care, care coordination following MyGOSH implementation	- A more child-focused approach advocated, with a gradual process of the child taking on ↑responsibility (I)	- It was more difficult in the early stages post-implementation to involve families in care	- CYP are not routinely involved in discussions/decisions about care so early/↑engagement with families advocated including: • Discussions directed towards CYP Preparation of both CYP/parents for when YP becomes the consenter
Health-related social media (SM) use	- Posting health information and results on SM could lead to cyberbullying/ harassment,	- CYP reported low SM use	- Parents reported low SM use by them and their children	- Parents were unhappy about the potential for child to post health results on SM (W)	- Prior to implementation, staff worried that families would post about them	- The complexity of trying to educate families about responsible SM use for posting health information was acknowledged

	peer-pressure may influence sharing			- The importance of educating CYP about sharing data online was highlighted (I)	or the hospital on SM but worries ↓over time with MyGOSH use - Overall consensus at all time-points that MyGOSH made it easier for families to share health data on SM	
Ownership of health data	- Ownership of personal/health data, and control over who accesses their data important - YP wanted to know who was accessing their data	X	X	- Parents wanted ownership of child's health data (W) - Added responsibility for parent/onus on parent: to ensure child's health data is correct; supporting child's access to avoid anxiety (W)	X	- Importance of empowering CYP to take ownership of their health data emphasised: • ↑Understanding of condition(s) • Developing autonomy • Reduced vulnerability
Transition from child/ adolescent services into adult services	- MyGOSH will help with transition into adult services	X	X	- MyGOSH may help parents prepare the child for: ↑independence; transition into adult services (W)	X	- As above. These factors may help CYP on the journey of transitioning into adult services
Barriers accessing/ using MyGOSH	- Potential barriers to accessing MyGOSH exist for those with physical/ intellectual/sensory difficulties/disabilities; if non-English speaking	- Barriers exist for CYP to access/use MyGOSH	- Barriers exist for parents to access/use MyGOSH	- Parents may not engage if shielding child from diagnosis/prognosis (W) - Access inequity identified (I) - MyGOSH was difficult to use if child had physical/ intellectual disability (I)	- Overwhelming consensus at all time-points that some patients/ families are unable to access MyGOSH	- Barriers to access exist, with complexities relating to equitable access. Inequity will depend on portal – the greater the utility, the greater the inequity
CYP translating medical information	- Worries existed about needing to translate health information for parents who don't understand English	X	X	- Concerns exist about CYP of non-English speaking parents being required to translate medical information for parents (I)	X	- CYP translating medical information for their non-English speaking parents was seen as problematic - best practice approach of translator use was advocated

Abbreviations (not previously defined: SM – social media

10.3.1.4 Ethical dilemmas and legal considerations associated with the implementation and use of EPR and MyGOSH

A consistent theme from all participant groups and throughout all phases of data collection is that some families will experience barriers to accessing and using MyGOSH. Participants reported barriers related to having a physical, intellectual, or sensory difficulty or disability, not having English as a first language, not having the technical skills or through cultural, religious, social or personal preferences. This is consistent with the wider literature on this topic related to barriers to accessing and using patient portals [37, 154, 155, 181, 182], related to functional impairment [182], income [37, 154], internet equality [37, 154, 181], and health literacy [182]. It follows that CYP (and their parents) who need to engage with health services on an ongoing basis are likely to have long-term, often more complex health conditions [199]. These CYP are then more likely to need to use a patient portal [199], which is echoed by the parent interview data in this study. Paradoxically, as the findings of this study also confirm, those who require access to healthcare and its related technology the most may face more barriers to accessing it [199], which emphasises the need for patient portals to be available across multiple platforms to aid access and reduce disparities where possible [154].

With the increasing need for digital literacy, and the concern that those with a disability or impairment are at risk of digital exclusion, especially those with multiple impairments [50], there is increasing awareness of the need to adapt technology to enable inclusivity. According to the 3rd UK Essential Digital Skills benchmark report (2021), “32% of people with an impairment do not have even the most basic digital skills” [50], and of the 11 million people who do not have essential digital skills for life, more than fifty percent of them have an impairment [50, 275, 276]. There is increasing awareness of the need to address the most common digital and disabling barriers, and enabling more people to be connected and learn digital skills [50]. This is increasingly pertinent in the digital health context. According to NHS Digital, “one in 10 people in England lack the confidence and skills to benefit from digital health technologies” [277]. Such barriers need to be considered in the procurement and planning stages prior to implementation of an EPR system, and the requirements of accessible, useable digital health platforms should be advocated at policy level. Furthermore, with the legal obligation to make reasonable adjustments for disabled people, this must be incorporated into digital health transformation [232]. This should include materials in an easy read format, large print, or other alternative formats, and provisions specified in NHS England's Accessible Information document [278]. This is crucial to improving communication, promoting health advocacy skills, and supporting equitable health outcomes [117, 199]. Such efforts are needed to reduce systematic discrimination and marginalisation of social groups who have different levels of underlying social advantage or disadvantage, in this case access to health information and the benefits of portal access [9, 230]. This will help promote social justice and fairness. The promotion of inclusion and equity are essential if CYP are to fulfil their right to 'the highest attainable standard of health' under Article 24 of the United Nations Convention on the Rights of the Child (1989) [234].

Barriers may also not be limited to those described above, and may relate to a difference in opinion as to the importance of parents viewing their child's EPR. A study in the systematic review reported that doctors had lower agreement (78%) that parents have the right to view their child's EPR, whilst 94% of parents wanted to view their child's EPR, with almost all (98%) feeling the information was important to them [47, 70]. This links to the tensions reported in this study with regard to parents wanting to access/view their child's health data via the portal [47], and may have an impact on the clinician-patient or parent relationship as a result. When considering the application of EPR and patient portals in other healthcare settings, barriers to use and access must be considered, with measures in place to support users, plus approaches planned to overcome barriers or provide equitable care for those who are unable to use the digital health record for whatever reason.

Another important limitation of the system is the inability to conceal the address of a parent if it is deemed a 'secure address', for example, if one parent was a victim of domestic abuse and the address needed to be kept secure from the other parent. This means that the parent from whom the address is being kept secure cannot not be granted MyGOSH access despite having parental PR. This is important because those with PR have the right of access to information about their child, including their medical, educational and Children’s services records [279]. A system that cannot provide this is problematic and has safety implications for our hospital and other centres wishing to implement the same system. Resolution of this issue is important to not only reduce risk but also promote equity in access.

Complexities exist when assessing and granting CYP access to digital health data via a patient portal, which were acknowledged by all stakeholder groups during the study. However, this does not mean that access should be denied. Individual assessment is required when making that decision. The findings from this study revealed that competency assessments for portal access do not carry equal weight to making a complex decision about medical treatment. The threshold for granting portal access could be lower. Every effort should be made to ensure each child or young person is as involved and as autonomous as possible, within their capabilities, with the aim of empowering them to manage their own health. These complexities and the need for an individualised approach are completely overlooked in the EPR Applied Ethics Framework, which results in limited utility in the paediatric context. This reflects a wider tendency for innovative healthcare solutions to focus on adult patients, however, with accelerated digital pathways during the pandemic [209, 210], and a resultant increase in patient portal use by CYP and adolescents [205], these issues required consideration.

The literature on transition suggests that this process should commence within the second decade of life [142], with the maximum age to transfer into adult services identified as 25 years [143]. This can present challenging changes in biological, psychological and social processes ss young people develop their autonomy [280]. The Growing up and Gaining Independence (GUGI) framework at GOSH encourages young people to gradually become as independent as they can in preparation for transition into adult services [281]. The GUGI framework encourages and supports young people talking to professionals on their own during consultations, the promotion of confidentiality, reassuring young people that what they say to a HCP is private and stays private, and preparation for the legal and financial changes after their 16th birthday, including preparation for becoming the consenter [281]. Findings from the Going Digital study emphasise the importance of preparing CYP for becoming the consenter, with early engagement deemed essential. Fostering a culture of truth-telling is advocated and is a prerequisite for trusting relationships [222]. These points are particularly pertinent if the child or young person is unaware of their diagnosis or prognosis. Workshop participants felt strongly that it was their right to have portal access and worried about what information was being hidden from them if access was not granted. In the Association for Young People's Health's consultation on the NHS Digital Strategy, a high proportion of young people (87%) thought having access to their digital health record was a good thing [282]. Similarly, parent workshop participants reported worries about parents not giving their children access, therefore open communication, collaboration between clinical teams and parents, as well as involvement of CYP in all aspects of care, is advocated [223].

This study's findings advocate that CYP-focused communication is central to CYP gradually gaining independence, namely discussions being directed towards them, using terms about their diagnosis they can understand, and letters written to them in a readable format. Within the GUGI framework, the young person is to be prepared for when they receive hospital communication addressed to them from the age of 16 [281]. However, the findings from this study suggest that this should be done much earlier, and that CYP want to be informed and involved in their care. These steps in engagement should correspond with age and cognitive abilities, reflective of an increasing understanding as they approach transition from child into adult health services, which links to their readiness, their knowledge, ability and competence to be able to comprehend what is being asked of them if providing consent (or assent) [224]. This may also be dependent on the extent of their involvement with healthcare services, for example, a child or young person who goes into hospital once may not be as ready to engage as early as someone with a long-term condition, which is also reflected in the Association for Young People's

Health’s consultation on the NHS Digital Strategy [282]. The Going Digital study findings align with the Aldiss et al.’s (2015) Benchmarks for transition which provide factors and statements of best practice for young people’s transition into adult services [225]. These include information and advice for young people on how to manage health conditions, support for gradual transition as young people progress through the transition process, emphasis on the young person’s readiness for transition and the provision of young people friendly services [225]. The importance of knowledgeable and coordinated child and adult teams who are provided with clear and effective documentation containing all relevant information about the young person’s transition is highlighted, including involvement of the GP [225]. The inclusion of parents is also important but with a gradual process to transfer responsibility to the young person [225]. The findings from this study suggest that there is a unique opportunity for HCPs to have a coordinated, synchronised approach to transitioning CYP to using a patient portal and to commencing their transition journey from child into adult services. Both of these concepts have the same goals, namely increasing understanding, educating young people about health services and future crucial changes to their care, with the aim of empowering young people to increase their independence, and involvement of CYP and their families in decisions about care [283].

A survey study by Allende-Richter et al. (2020) investigated self-management skills towards readiness to transition into adult services and their patient portal use by young people with and without special healthcare needs [284]. Out of 61 participants, it was reported that 33% did not know how to schedule an appointment, 50% did not know how to refill prescriptions, and 58% did not know how to access their personal health information [284]. Moreover, 84% were unaware of the portal and 92% never used it [284]. The authors concluded that although study participants exhibited low self-management skills and a high proportion of participants were unaware of a patient portal, most welcomed using it to manage their health [284]. Children and young people in the Going Digital study reported requiring support, especially related to emotional support, wanting to understand information on the portal, and support when accessing results, which suggests they are not adequately prepared for patient portal use, reinforcing the need for a coordinated approach to portal use and commencing the transition journey. As the study findings show, preparation of parents is also required to aid the gradual relinquishing of responsibility from the parent to the young person. Therefore, preparation of the whole family is the key to successful transition to not only a patient portal but also from child into adult services [225, 226], and for empowering young people to take increasing ownership of their health data as they increase in autonomy and decision-making [164, 227]. Support for young people to understand privacy concerns and the impact of their digital footprint on their future as they become more autonomous is also important [228].

It is important to think broadly and innovatively about how information is shared with young people and their families, and to use a variety of methods. This may include: during hospital visits; via videos and visual information on the hospital website, via the portal, or around the hospital, which includes the development of virtual reality [285]; through support groups; and including ways of preparing CYP and personalising the journey of the patient, for example, the interactive ‘My operation book’ that patients have at GOSH which is available in standard and accessible format or through social stories and comic strip conversations [286]. These are all potential avenues for sharing information in the future.

The findings from this study highlight that a one-size-fits-all system does not and, therefore, will not meet the needs of all CYP or families, requiring an individualised approach to care, the complexities of which are not adequately reflected in the EPR Applied Ethics Framework.

10.3.1.5 Summary of integration

As discussed in Chapter 1, Jacquemard and colleagues developed the EPR Applied Ethics Framework to guide the identification and assessment of EPR-related ethical opportunities and challenges. Their framework encompasses two components: context and core functions, and their intention was for the framework to be used to help positively steer EPR implementation, rather than simply as a tool to prevent ethically-related risks [40]. Within ‘context’ it was essential to clarify the purpose(s) within which the EPR exists or will exist, the interested parties and their relationships, and codes of professional conduct, organisational policy frame of reference and regulatory requirements [40].

The EPR Applied Ethics Framework is presented as an adaptable and iterative tool, that can be applied to an EPR of interest, assessed against sections, categories, and attributes in order to identify any ethical considerations, and to determine associated risks or benefits [40]. However, it could be argued that the framework fails to capture the work that is required pre-implementation to prepare all of the stakeholders who will be using, or affected by the use of the EPR (and tethered patient portal), and the ongoing support required post-implementation. Arguably, the findings of this study indicate additional components are required before and after the framework's 'Context' and 'Core functions'. These would be 'Preparation of all end-users', and 'Ongoing support of all end-users'. The term 'end-users' is specified here rather than 'all interested parties', which is the language used in the EPR Applied Ethics Framework. The framework refers to all interested parties as including patients, carers, family, healthcare personnel and healthservice (sic) managers, however, the challenges and negative experiences were described by end-users: CYP, parents and hospital staff (healthcare personnel).

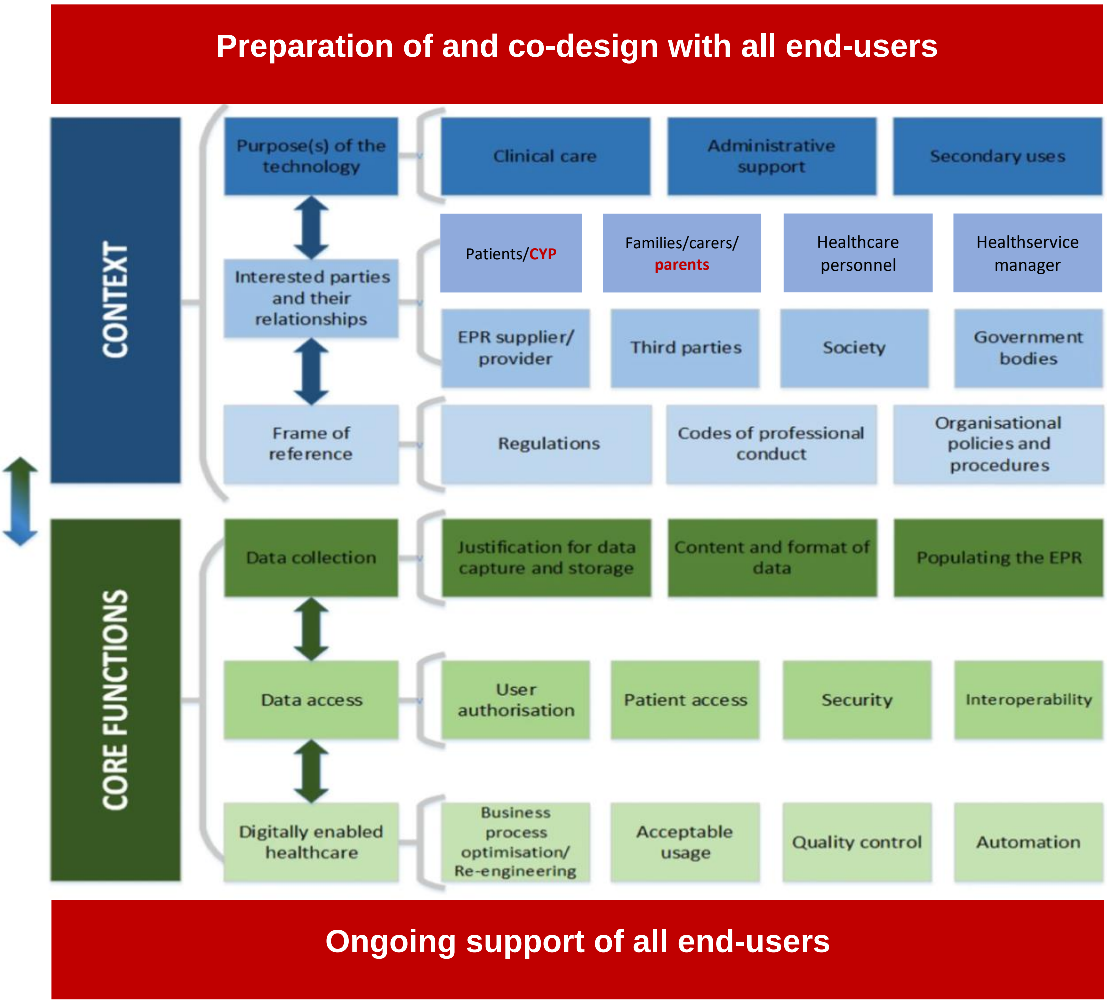
Digital inclusion factors should also be considered under the Framework's 'core functions'. Jacquemard et al. (2021) advocate understanding of how interested stakeholders relate to each other and exert influence on the design, development, implementation, and use of the EPR [40]. Yet, there is no guidance on promoting digital inclusion or literacy within the framework, and no mention of additional considerations for disabled people. A user-centred approach, with co-design would be beneficial to determine the specific needs of stakeholder groups including disabled people prior to system implementation, and on an ongoing basis post-implementation to ensure usability continues [9, 97]. The findings of the systematic review indicate that ongoing consultation with end-users, valuing their feedback and incorporating their views into system improvements will increase user satisfaction, utility, and engagement [47]. Suggestions for ongoing consultation with end-users are provided in

‘Recommendations for clinical practice when implementing an EPR system with a patient portal’ and ‘Recommendations for future research’ below. Special consideration ought to be given to the views of CYP [47], with due weight being given to what matters to them, in accordance with Article 12 of the United Nations Convention on the Rights of the Child (1989) [234], to empower them to be involved in and have ownership of their health [120, 121].

Recognition and inclusion of all of the related intricacies that need considering when CYP are cared for, and CYP and their parents access and use an electronic patient records system, are a must. These considerations are multi-faceted, as the findings of the Going Digital study demonstrate. Inclusion of these considerations in an EPR Applied Ethics Framework is required for it to be applicable to this patient group and setting, and for other healthcare providers considering digital transformation. Arguably, there is a further missing component within the ‘context’ aspect of the current framework, concerning interested parties and their relationships. The framework needs to encompass pertinent ethical/legal aspects specifically related to CYP in the digital health context and should include:

- Competency assessment for access to digital health platforms
- Early involvement of CYP, and preparation of both CYP and parents, for when the child or young person becomes the consenter
- The provision of CYP-focused communication/health information, including in easy read format
- Translation services to reduce the need for CYP to translate health information for their non-English speaking parents
- The provision of additional portal functions to promote access and use by those with physical, intellectual, or sensory difficulties or disabilities

These points cannot sufficiently be accounted for by inclusion in the patients/carers/family component of the framework alone. Consequently, an adapted EPR Applied Ethics Framework is proposed, which recognises CYP as a distinct group with their own unique needs (Figure 10-1). The adapted framework may also be applied to other clinical settings when other triads are cared for, for example, older people with carers, adults with carers such as those with learning disabilities or cognitive impairment, increasing transferability of the study’s findings.



Adapted from Jacquemard et al. (2021)[40][xviii].

Figure 10-1: Adapted EPR Applied Ethics Framework

10.4 Unique contribution of the study

This research makes a unique and significant contribution to the literature, narrative and clinical understanding of the intricacies of EPR and tethered portal implementation in the children’s hospital setting.

The Going Digital study provides a recent, modern example of how digital transformation can be achieved despite encountering numerous challenges and

---

[xviii] Amendments to the EPR Applied Ethics Framework have been applied in either red text or red boxes.

considerations that are specific to healthcare contexts in which CYP are cared for. Unique insight is reported about the benefits, the specific information and support needs of CYP and their parents related to accessing and using digital health records, and the pertinent ethical and legal issues that require consideration. This study has revealed the challenges of making such a big transition in a children’s hospital with very complex patients, often being cared for by multiple specialities, with a wide geographical reach, and a large staff group. Furthermore, pre and post implementation data collection was vital to understanding the unique experiences of all user groups.

This is the first study to present pre and post-implementation findings. This approach made it possible to examine more closely the nuances associated with implementation, within a particular context. The EPR system was launched at the same time as the tethered patient portal, and was a very different approach when compared with studies in the systematic review. The principal difference was that GOSH utilised a 'Big Bang' approach, rather than a phased approach [287]. What this means is that the EPR system and the patient portal went live at the same time, rather than implementing them at separate time-points, as Addenbrooke's hospital in Cambridge had done [24]: where the patient portal was implemented two years after EPR implementation [24]. In fact, in the systematic review (Chapter 4), none of the studies reported using the ‘Big Bang’ approach (Figure 3-3), making this the key difference between those studies, other hospitals' experiences, and the Going Digital Study.

This may be an important factor to explain why our findings might be different from other reported studies but also highlights the uniqueness of the study findings, when considered alongside the ‘Adapted Applied Ethics Framework’ (Figure 10-1), provides guidance for children’s hospitals that are planning synchronous implementation of an EPR system and a patient portal. Learning can also be gained by those who engage with CYP and their families in the wider hospital or health settings context. Understanding what is important to this patient population and their families, and what information and support they need accessing and using digital health information and platforms, highlights the transferability of the study findings. This also applies to patient groups such as adults with learning disabilities supported by carers/family members. Our intention was that other hospitals and healthcare settings would be able to learn from the experiences of the study's participants and the distinct contribution they made to this study.

10.5 Recommendations for clinical practice when implementing an EPR system with a patient portal

Following integration of the research findings which combined both quantitative and qualitative data, there are six main recommendations for clinical practice and future digital transformation:

1. Set end-user expectations as early as possible. This should include:
    - Clear, targeted user-focused information on the upcoming changes in advance of implementation using different formats to increase visibility, for example, posters in clinical/patient-facing areas, flyers, highlighted and clearly visible information in any written communication from the healthcare provider, consistent verbal communication from the care team, and reminders at different stages prior to Go-Live including details of how to access support
    - Consistent information release from the healthcare provider on an ongoing basis post-implementation about patient portal functionality. This should include changes or updates to functionality for new and existing families, as well as details of technical and emotional support
    - Support for staff whilst transitioning and adapting to digital health initiatives, especially in the first 12-18 months following implementation. This should include increased staffing levels to balance the clinical demands with increased burdens of learning to navigate and manage the new system, drop-in support sessions, clear standardised SOPs, accessible technical support, user-targeted updates when system changes occur.

2. Deliver a consistent approach across specialities and the hospital, where able, to lessen family anxiety and frustration. This should include:

- A consistent approach to communication via a patient portal, agreed across specialities, with the approach advocated and supported by the healthcare provider's Executive leads and senior leadership team
- The consistent release of information (e.g. results) via the portal (it is acknowledged that different specialities may need to release different results but to be as consistent as possible)
- Clinicians should plan information release to mitigate patient and parent anxieties. This should include the preparation of families for reading raw (uninterpreted) clinical results, and liaison with them about what are acceptable results for the child or young person, even if deemed out of range but clinically insignificant. The clinician should prepare the patient/family about what to do if the results are out of range and clinically significant, giving clear communication about the process, and setting expectations about how quickly their messages will be responded to.

3. Foster early partnerships between CYP, parents and care team(s) to: prepare CYP (where appropriate) to gradually increase their independence, to promote their autonomy, empower them to take increasing responsibility for their health, where able, and simultaneously support parents for when their child becomes the consenter. This can be achieved by:
    - Facilitating a Trust-wide or healthcare provider-wide coordinated approach to the introduction of CYP to a patient portal *and* commencing their journey transitioning from children's/adolescent's services into adult services. This should include utilisation of Transition Clinical Nurse Specialists (CNSs) or designated Transition Champions (acknowledging that Transition CNSs are not routinely employed in all health care setting that care for CYP) to coordinate and guide the dual-pronged approach. This should include preparation of the young person to access appointments, access and understand raw results, how to communicate with the clinical team(s), expected response times to messages submitted via the portal, when to seek expert help, and what to do in an emergency. This should be commenced at 10-12 years of age, taking into consideration the

  young person's cognitive and emotional readiness to commence this process.
  - Having early conversations with parents about truth-telling if their child is unaware of their diagnosis or prognosis. It will be important to inform parents of when their child will be able to access their health information without their consent (16 years of age), and plan how and when to have conversations with the child, and how to frame such conversations, with the support of the clinical team
  - Directing discussions during clinical encounters towards CYP
  - Addressing and writing communications to CYPs, including clinic letters/AVSs, writing in a language the individual will understand
  - The involvement of trained learning disability nurses where possible may be helpful for patients with learning disabilities who may lack or have fluctuating capacity.

4. Plan approaches to overcome barriers to accessing and using MyGOSH, and reducing the digital divide *but* with the provision of an equitable service for those who cannot/do not want to access the portal (religious, cultural, or personal reasons). This may include accessible instructional videos in different languages on how to use the portal, on how to seek support.

5. A best practice approach to translation must be used and advocated to minimise CYP translating medical information for their non-English speaking parents.

6. Ensure secure addresses are kept secure to eliminate the risk posed, and to facilitate appropriate portal access for both parents with parental responsibility. This will require work with the EPR system provider and local EPR/IT support teams to eliminate this design flaw.

10.6 Recommendations for future research

There are four main areas for consideration for future research that have resulted from the Going Digital study's findings.

1. Continuous consultation with CYP is required to determine ongoing portal utility that meets their diverse and varying needs. This could be in the form of regular informal consultations with CYP through specially set up groups within hospital, much like the YPF, and could include CYP in other healthcare settings such as general hospitals, to determine if their views are concordant or divergent. In addition, a more formal investigation over a longer period of time with longitudinal research to gather CYP experiences of using evolving health-related platforms.

2. There is clear evidence that it takes 12-18 months for end-users to even begin to feel confident and competent at navigating and using a ‘newly’ implemented EPR system. Therefore, an additional point of data collection would be beneficial to compare the study findings with the current perspectives of all relevant stakeholders after they have been using the system for a longer period of time.

3. National research is required to identify needs of families for whom English is not their first language, with the provision of appropriate study materials and interpreters (the complexities of this are acknowledged). This should include ongoing evaluation at regular time-points, and could be in the form of a short survey, for example,10 questions long, capturing key findings every 12-24 months, plus routine evaluation of all new users after a defined period of use (individualised depending on who, for example, CYP, parents or staff).

4. Further investigation is required into the barriers to CYP and their parents accessing and using a patient portal. Potential inequities need to be established with ways to overcome them to ensure the equal provision of care for all. This could include a larger national qualitative study and/or observational research to understand how a portal is used in practice.

10.7 Strengths of this research

The extant literature is dominated by either research in the adult setting or does not include the views and experiences of CYP. The Going Digital Study presents a unique insight into the clinical understanding of the intricacies of EPR and tethered portal implementation in the children's hospital setting, prioritising the experiences of CYP. This research spans the life-cycle of implementation from before to after transition to the new system.

Strengths of this research included an extensive and comprehensive systematic review of the literature, which informed and shaped the Going Digital study, with decisions made to:

- Focus on CYP's views and experiences
- Include all staff groups in the research
- Collect pre and post data
- Consider of the ethical/legal issues

A major strength of this research was the use of mixed methods to enable multi-faceted investigation, and deeper understanding of experiences and perceptions that would not have been achieved through single method research [55]. Within this, choosing and utilising each research activity was conducted using a considered approach, to fulfil each respective aim. Rigorous research processes were followed throughout, with robust methodology applied, strengthening the study's findings.

Inclusion of all stakeholder groups who use, or were affected by the use of, EPR/MyGOSH was also a strength of this study. Strengths related to specific research activities will now be described.

10.7.1 World Café workshops

A major strength of using World Café methodology was inclusivity. This methodology enabled the participation of everyone who wanted to attend, which was crucial to gaining a wide variety of views from all stakeholders. Young people from the YPF who participated included those with physical, intellectual disabilities, and those with sensory impairments. The Young People's Participation Officer was available during the workshop for support. The methodology was adapted to enable young people who required the use of a wheelchair to participate fully by rotating the researchers/moderators around the tables, rather than rotating the groups during the workshop with the YPF members.

World Café methodology was also a time-efficient and cost-effective way to gain the views of multiple participants in a creative, open, and non-threatening manner. Reflecting on the workshops, a particular strength was being able to conduct these face-to-face, as this research activity was pre-pandemic. Had the workshops been conducted virtually, albeit with the use of break-out rooms, the atmosphere would have been different. The energy in the physical room as participants/researchers moved around and new topics were discussed, and thoughts and concepts were built upon, was vibrant and energising. This places great value on face-to-face interpersonal interactions. The World Café workshops may not have yielded such a rich discussion or insight virtually, which highlights challenges faced by researchers during the pandemic.

10.7.2 Parent interviews

Diversity in the parent interviewees, in terms of the ages of the children, how many teams they were cared for by and ethnic background, was a strength.

Another strength is that parents were given ample time to share all of their feelings. This meant parents were not rushed, and they were able to tell their stories. Parents were reassured that the researcher was looking for honest feedback and this is demonstrated throughout, in the frankness of some of the quotes.

10.7.3 Focus group

Focus group participants worked in a diverse range of clinical and non-clinical roles within and external to the hospital, across different disciplines and specialities, all with specific expertise in the field of enquiry. This enabled open ethical, philosophical, and legal discussion. A larger group may not have yielded such deep thinking or allowed each person within the group to participate fully. It is anticipated that these findings will contribute to the understanding of ethical and legal considerations of young people and parents using patient portals, and in the wider digital health context.

10.8 Limitations of this research

Firstly, and importantly, it is pertinent to emphasise that the study team was not granted funds required or permissions to provide translation or interpreter services that would have facilitated the inclusion of non-English speakers. The study team was also not granted access to private patients, despite strongly advocating for the inclusion of both private patients and non-English speakers. This Trust directive was based on the initial roll-out of EPR being in English only. Therefore, this study was limited to those who could understand English, and limited to NHS patients only. The ethical considerations of excluding non-English speakers are acknowledged, and the importance of capturing the views of all EPR-users in future research is highlighted.

The other main limitation was that we were unable to recruit CYP for the interviews in phase 3 of the study. Invitations were sent to parents (of children of eligible ages), and to young people over 16 years of age, with information highlighting that CYP could also participate, however none volunteered. It was felt at the time that with the additional burdens of shielding, home-schooling and worries associated with the pandemic, participating in this study, understandably, was not the priority. Furthermore, following analysis of the parent interviews, it became apparent that MyGOSH was not necessarily of interest or relevance to all CYP. Another possible reason for being unable to recruit any CYP for interviews, and for the lower than expected survey response was that parents were limiting what information their child had access to. Garcia de Avila et al. (2021) described how parents shared or limited their child’s access to information, in this case about COVID-19 during the first wave of the pandemic [288]. According to the authors, “some parents reported adopting an open and honest approach to sharing information with their children” (p.1) [288] whereas other parents chose to minimise their child’s access and exposure to

COVID-19 related information, particularly related to mortality [288]. This study highlighted the importance of the parental role in imparting information to their children [288], which can also be applied to the research context regarding the importance of parents in enabling their children to participate.

The limitations related to each research activity will be outlined, recognising that not all of these factors were within the researcher's control. These are included and discussed to give an overview of the challenges encountered throughout the study, for completeness.

10.8.1 World Café workshops

A limitation was the small number of parents who attended the workshop. This may have been because the workshop was held in December (2019) in the run up to Christmas, when parents were busy. However, both parents who attended the workshop were very well informed as they had been involved in and consulted on the development of EPR and MyGOSH throughout the pre-Go-Live preparation phases.

10.8.2 Parent interviews

Two limitations were related to the parent interviews:

- Fathers and mother-father dyads were invited to participate but none volunteered.
- It is acknowledged that people who respond to invitations to participate in research may be thinking about what is wrong, with the intention of helping to make improvements. Inevitably, this may lead the reader to perceive that the findings are overly negative. This does not mean that parents' concerns are not valid, but it may give an unbalanced view. Parent participants were vocal in emphasising how much they appreciated everything and everyone at GOSH and that they wanted to help improve MyGOSH through their feedback rather than criticise. Furthermore, the views of parents who were more engaged and wanting to participate may not fully reflect those who are harder to reach, who are not coping or are not able to access MyGOSH.

10.8.3 Quantitative data collection

Several limitations were evident during this research activity:

- Baseline survey distribution for parents and CYP was initially planned for pre-Go-Live but engagement from the Trust/EPR team was predominantly with hospital staff prior to implementation, meaning that families had minimal exposure to EPR at this time. As a result, the study timeline was modified so that families would be given the survey as they were approached for MyGOSH sign-up so that they could make a meaningful contribution to the study, and out of respect for participant time.
- The complexities and difficulties surrounding providing survey measures in different languages meant that it was only provided in English, which matched the language of the EPR system, and was predetermined by the Trust. We acknowledge that this does not promote inclusion and has been raised within recommendations for further research. This may have had an impact on the number of CYP (if of an age where parental consent to participate was required) being sent the survey by their parents if their non-English speaking parents could not understand the study information or instructions.
- Some CYP may not have been able to complete the survey without the help of their parents. An example of this was a patient with visual impairment in the ophthalmology clinic. They were unable to read the font unless it was size 36, however it was not feasible to provide large font surveys due to the survey’s length. The difficulty of parents going through the whole survey with them whilst waiting for their appointment is acknowledged.
- Major disruption and inconsistencies in survey distribution by designated clinical teams was evident despite clear guidance, support, and regular update emails to Managers/Teams leaders/Division Lead. Three clinical areas disposed of or cleared away surveys and collection boxes during the study period, hindering accurate response rate calculation. As a result, the researcher needed to provide additional, extensive support in clinical areas distributing the surveys.
- Additional demographic details were not added until the follow-up surveys, limiting the comparisons between the baseline and follow-up participant population. It is acknowledged that not having demographic data at T_1 is a

limitation and that demographic data from both time-points would have been preferable.

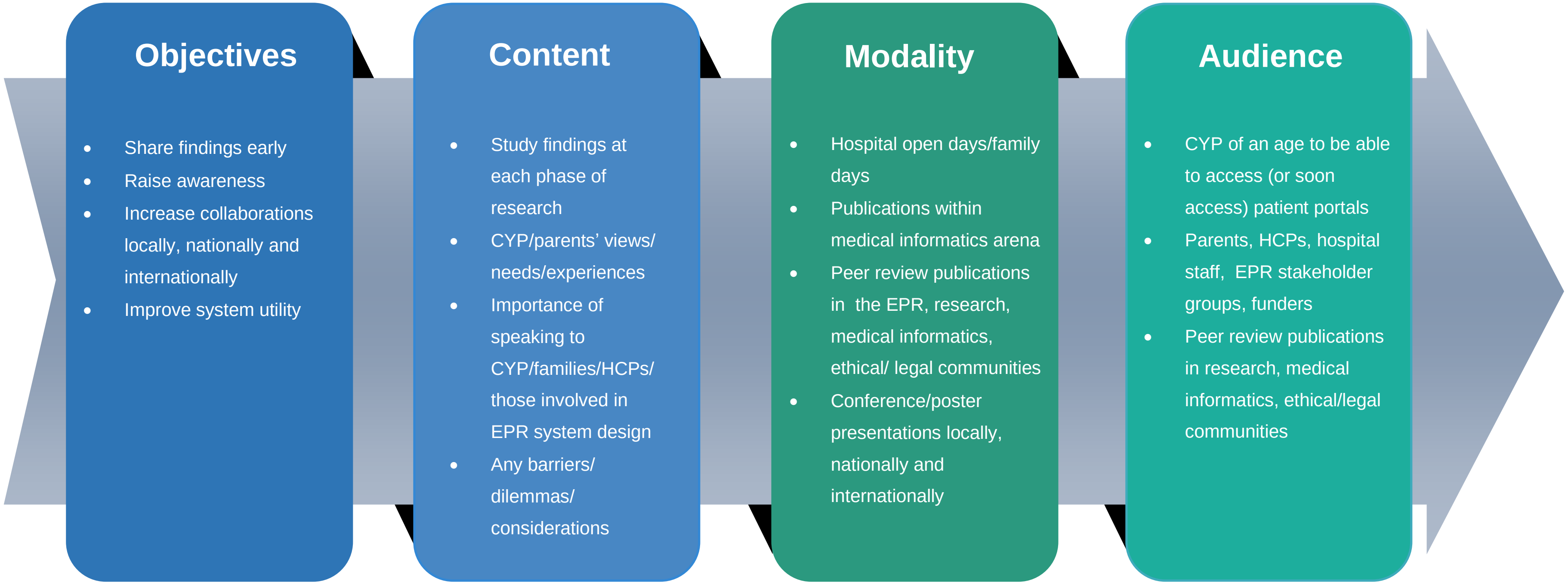
- The baseline CYP and parent surveys were paper (apart from being sent electronically to the members of the Young People's Forum) and the follow-up surveys were distributed via REDCap, meaning linkage via a unique identifier was not possible. Also, anonymity and confidentiality were maintained to promote open and honest feedback. Therefore, comparisons over time were cross-sectional rather than paired.
- Follow-up data collection was via MyGOSH due to the COVID-19 pandemic restricting access to the hospital. It was hoped that the study would capture families' reasons for not wanting to sign-up to MyGOSH but, due to conducting all data-collection via MyGOSH only during the pandemic, this was not possible.
- Low response rates were seen at all three time-points of the staff surveys. At baseline (T_1), anecdotal evidence suggests that this was due to staff members being extremely busy in preparation for EPR implementation. Similarly, staff had a high workload at the first follow-up survey (T_2), with challenges evident throughout the staff quantitative findings related to adjusting to the new system whilst managing the needs of children and families within their care. As evidence suggests from this study and other studies [71, 79, 86], support is required for an extended period after transition to an EPR system. Adding to staff's challenges was that the final follow-up survey (T_3) was between the first and second wave of the COVID-19 pandemic, with staff members facing additional associated challenges (those with caring responsibilities which may include shielding, home-schooling children [289], redeployment [289, 290], possibly coping with bereavement or loss [289, 291, 292], and other challenges). Furthermore, staff may have been dealing with the possible psychological effects of caring for patients with COVID-19 at GOSH or during redeployment [289, 293, 294]. Every effort was made to increase the number of responses including providing study information at departmental meetings, via Head of Department emails, emails from the Chief Executive and Chief Nurse, and via presentations at the Senior Leadership Team meetings. However,

despite trying to time the surveys to the least intrusive times, these factors may have affected survey response rates.

- REDCap linkage via a unique study number was used for all three staff surveys. It was unfeasible to individualise each survey, so staff were asked to add in their unique ID from their invitation email. However, staff were reluctant to use this for fear of being identified (or may not have remembered the number) despite the invitation email emphasising that responses were anonymous and confidential. These concerns were verbalised to members of the research team by a number of staff members. Further reassurances were given but analysis was limited to cross-sectional comparisons.
- Feedback from those who piloted the survey deemed the length to be appropriate as all content was important to them. However, the staff survey remained long, and may have resulted in staff members commencing but not completing the survey, especially if they worked in a busy clinical area. Furthermore, at T_1 the REDCap unique study number, job title and speciality sections were marked as mandatory fields. If the mandatory fields were left blank due to participants either not realising this (despite this being indicated as mandatory on the survey), or they felt they did not want to enter the unique study number, participants were then unable to submit the survey. This resulted in 1065 participants who clicked through, but only 650 who completed the survey. When it became apparent that the same was happening at the first follow-up survey, this was discussed between research team members and the mandatory field function was disabled to enable participation without providing these data.
- The GOSH staff population information provided by GOSH Workforce Planning did not match the number of staff surveys sent. This is believed to be because the staff list provided at the time was not 100% up to date in terms of staff members leaving or on leave for other reasons as this is accurately collated retrospectively (which is explained by the number of undeliverable emails). This meant reporting the number of baseline surveys distributed did not match the GOSH staff population figure. However, this only impacted reporting, not distribution, as the surveys went to all staff.

10.9 Dissemination

Due to the rapidly evolving digital health revolution, and with reduced access to face-to-face care and an expedited shift to virtual appointments due to the pandemic, phase by phase dissemination was crucial. Wide multi-modal dissemination was achieved to multiple stakeholder groups for maximum reach and impact locally, nationally across the NHS, and internationally for the benefit of patients and their families. This is in-line with the HRA’s Make it Public Transparency Strategy [64]. The dissemination strategy is summarised in Figure 10.2 and achieved dissemination is presented in Table 10-2.



Objectives

- Share findings early
- Raise awareness
- Increase collaborations locally, nationally and internationally
- Improve system utility

Content

- Study findings at each phase of research
- CYP/parents' views/ needs/experiences
- Importance of speaking to CYP/families/HCPs/ those involved in EPR system design
- Any barriers/ dilemmas/ considerations

Modality

- Hospital open days/family days
- Publications within medical informatics arena
- Peer review publications in the EPR, research, medical informatics, ethical/ legal communities
- Conference/poster presentations locally, nationally and internationally

Audience

- CYP of an age to be able to access (or soon access) patient portals
- Parents, HCPs, hospital staff, EPR stakeholder groups, funders
- Peer review publications in research, medical informatics, ethical/legal communities

Figure 10-2: Dissemination strategy

Table 10-5: Dissemination throughout the Going Digital study

Year/month	Name of Meeting/Title	Type of Dissemination	Target Audience	Location
September 2018	The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) PhD Day: The Going Digital Study	Lecture	Students, Members of the Clinical Academic Faculty (CAF)/Research Faculty (RF), ORCHID	London
October 2018	PPIE event with GOSH's Young People's Forum (YPF) – presenting the Going Digital Study to the YPF prior to the World Café workshops	Lecture	Members of the YPF	London
October 2018	EPR Showcase session and presentation of the Going Digital Study at GOSH Children's Charity Staff Event	Lecture	GOSH Charity Staff	London
November 2018	UCL GOS ICH Postgraduate Open Day – Going Digital – The implementation of Epic Electronic patient records in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications	Conference (poster) presentation	PhD Students, Academics, HCPs	London
November 2018	GOSH Conference – Going digital – The implementation of Epic electronic patient records in a paediatric tertiary hospital: understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications (Appendix 46)	Conference (digital poster) presentation	HCPs	London
November 2018	**Sipanoun P,** 130 Going digital – The implementation of Epic electronic patient records in a paediatric tertiary hospital: understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications. *Archives of Disease in Childhood* 2018;103:A52-A53 Available at: <http://dx.doi.org/10.1136/goshabs.130> (Appendix 47) [295]	Published abstract	HCPs	Peer-review Journal
2018	ORCHID 2018 Report – 'The Going Digital Study' - The implementation of electronic patient records in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications	Publication in Research Report	HCPs, Researchers	London

Year/month	Name of Meeting/Title	Type of Dissemination	Target Audience	Location
April 2019	Publication in 'Roundabout' the staff magazine of Great Ormond Street Hospital for Children - Going Digital Study: This research study explores the befits, challenges and practical implications of GOSH transitioning to a digital hospital (Appendix 48)	Publication in hospital magazine	CYP, parents, hospital staff	London
July 2019	Workforce change meeting: The Going Digital Study	Short presentation	Hospital staff	London
September 2019	ORCHID PhD Day: The Going Digital study	Lecture	Students, Members of the CAF/RF, ORCHID	London
September 2019	Royal College of Nursing International Nursing Research Conference – Being in the right place at the right time: Going digital – The implementation of Epic Electronic patient records and its impact on patients, parents and staff – Symposia with Oulton K, Livermore P, and Gibson F. Single site approach to developing clinical academic careers: Strategy, personal and organisation impact (Appendix 49)	Conference (oral) presentation	Nurses	Sheffield
October 2019	Upgrade presentation	Lecture	HCPs, GOSH staff	London/online
November 2019	GOSH Conference – The Going Digital Study: Ethical and legal considerations of young people accessing their digital health data - Young People's Perspectives (Appendix 50)	Conference (oral) presentation	HCPs	London/online
November 2019	**Sipanoun P,** Gibson F, Wray J, Oulton K. (2019) The Going Digital Study: Ethical and legal considerations of young people accessing their digital health data - Young People's Perspectives *Archives of Disease in Childhood* 104 (4) Available at: <http://dx.doi.org/10.1136/archdischild-2019-gosh.4> (Appendix 51) [296]	Published abstract	HCPs	Peer-review Journal
2019	ORCHID 2019 Report – 'The Going Digital Study' - The implementation of electronic patient records in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications	Publication in Research Report	HCPs, Researchers	London
February 2020	Senior Leadership Team: The Going Digital Study	Short presentation	HCPs/Managers	London/online

Year/month	Name of Meeting/Title	Type of Dissemination	Target Audience	Location
September 2020	ORCHID PhD Day: The Going Digital study	Lecture	Students, Members of the CAF/RF, ORCHID	London
October 2020	Senior Leadership Team: The Going Digital Study	Short presentation	HCPs/Managers	London/online
November 2020	Institute of Medical Ethics Postgraduate Bioethics Conference – Ethical and Legal considerations of Children and Young People's Digital Health Data: The Children and Young People's Perspective (Appendix 52)	Abstract submission	Students, HCPs, Ethicists	London/online
2020	ORCHID 2020 Report – 'The Going Digital Study' - The implementation of electronic patient records in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications	Publication in Research Report	HCPs, Researchers, public	London/online
March 2021	GOSH Charity –The Going Digital Study – The implementation of an electronic patient record system in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff, and the practical, ethical and legal implications	Presentation to Funders	Multi-disciplinary	London/online
June 2021	UCL Doctoral School Poster Competition – The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: a systematic review (Appendix 53)[xix]	Digital poster	PhD Students, Academics, HCPs	London/online
July 2021	ORCHID PhD Day: The Going Digital study	Lecture	Students, Members of the CAF/RF, ORCHID	London/online
September 2021	Royal College of Nursing International Research Conference – The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: a systematic review (Appendix 53)	Conference (digital poster) presentation	Nurses	Online
September 2021	Royal College of Nursing International Research Conference – The Going Digital Study: the ethical and legal considerations of children and young people using a patient portal (Appendix 54)	Conference (oral) presentation	Nurses	London/online

---

[xix] The same poster was submitted to both the UCL Doctoral School Poster Competition and the Royal College of Nursing International Research Conference

Year/month	Name of Meeting/Title	Type of Dissemination	Target Audience	Location
September 2021	The Going Digital Study: The PhD, The Research, The Journey	Conference (oral) presentation	Clinical Academics	London/online
October 2021	UCL Doctoral School Poster Competition – The Going Digital Study: The views and perceptions of children and young people, parents and staff before and after electronic patient record implementation – Trust-wide survey findings (Appendix 55)	Digital poster	PhD Students, Academics, HCPs	London/online
October 2021	International Conference on Digital Health – Young People and Their Parents Accessing Their Digital Health Data Via a Patient Portal: The Ethical and Legal Implications	Conference (oral) presentation	Multi-disciplinary	London/online
October 2021	**Sipanoun P**, Wray J, Oulton K, Gibson F. Young People and Their Parents Accessing Their Digital Health Data via a Patient Portal: The Ethical and Legal Implications. World Academy of Science, Engineering and Technology: International Journal of Medical and Health Sciences https://publications.waset.org/abstracts/136691/young-people-and-their-parents-accessing-their-digital-health-data-via-a-patient-portal-the-ethical-and-legal-implications (Appendix 56) [297]	Published abstract	Multi-disciplinary	Peer review journal/online
October 2021	Clinical Ethics Journal submission – **Sipanoun P,** Wray J, Oulton K, Gibson F. Going Digital: What are the ethical and legal considerations of young people and their parents using a hospital patient portal? 2021 (Appendix 57)	Peer review journal submission	HCPs, Ethicists	Peer-review Journal
November 2021	The GOSH Conference – The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: a systematic review (Appendix 58)	Conference (digital poster) presentation	HCPs	London/online
November 2021	**Sipanoun P,** Oulton K, Gibson F, Wray J. 97 The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: a systematic review *Archives of Disease in Childhood* 2021;106:A36 DOI: 10.1136/archdischild-2021-gosh.97 (Appendix 59) [163]	Published abstract	HCPs	Peer-review Journal

Year/month	Name of Meeting/Title	Type of Dissemination	Target Audience	Location
November 2021	The GOSH Conference – The Going Digital Study: The views and perceptions of children and young people, parents and staff before and after electronic patient record implementation – Trust-wide survey findings (Appendix 60)	Conference (digital poster) presentation	HCPs	London/online
November 2021	**Sipanoun P,** Oulton K, Gibson F, Wray J. 96 The going digital study: the views and perceptions of children and young people, parents, and staff before and after electronic patient record implementation – trust-wide survey findings *Archives of Disease in Childhood* 2021;106:A36 DOI: 10.1136/archdischild-2021-gosh.96 (Appendix 61) [298]	Published abstract	HCPs	Peer-review Journal
2021	ORCHID 2021 Report – 'The Going Digital Study' - The implementation of electronic patient records in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications	Publication in Research Report	HCPs, Researchers	London/online
January 2022	**P. Sipanoun**, K. Oulton, F. Gibson, J. Wray, The experiences and perceptions of users of an electronic patient record system in a pediatric hospital setting: a systematic review, International Journal of Medical Informatics (2022), 160, doi: https://doi.org/10.1016/j.ijmedinf.2022.104691 (Appendix 62) [47]	Publication	HCPs, Medical Informaticists	Peer-review Journal
February 2022	ORCHID Clinical Academic Faculty hospital screensavers showcasing research impact and raising the profile of Clinical Academic Careers (Appendix 63)	Hospital screensaver	All hospital staff	London/online within the hospital
March 2022	School of Health Sciences Maternal, Child and Family Health Cluster Seminar: World Café methodology – A creative way to explore young people's views	Lecture	University of Surrey students/staff, Members of the CAF/RF, ORCHID, HCPs, public	Surrey/online
April 2022	Planned dissemination with the members of the Young People's Forum at GOSH	Online meeting	Young people Parents will also be invited	London/online

10.9.1 Engagement in research and priorities during COVID-19

Early in the pandemic, there were huge uncertainties about the impact of COVID-19 on children, parents had additional worries about having a sick, and potentially vulnerable, child at home, and needing to shield: none of which was helped by confusing government guidance [299, 300]. In response, the study team decided to delay follow-up survey distribution until August 2020, after the first wave of the pandemic. However, it was understandable that survey completion may not have been a priority for families. Follow-up survey responses were lower in the younger age groups (12-14 years) than at baseline. It was impossible to deem whether the child was competent to participate due to the survey being sent as a bulk message to all those who had signed up to MyGOSH, with parents making the decision about whether their child could participate. There is an assumption that parents will make decisions about their child participating in research that promotes and protects their child's best interests [301], however, this raises ethical issues around inclusion, about allowing the child or young person to voice their views and how this can be realised. Arguably, there needs to be open discourse about inclusion of CYP in research. Evidence in the literature describes how CYP report better decision efficacy when researchers proactively engage with them by asking questions or their opinion [302]. Moreover, if the researcher promoted their autonomy by enabling them to be central to the decision about whether to participate, CYP perceived the decision-making process to be fairer [302]. This researcher-patient engagement was not possible due to the pandemic (despite the surveys going out via MyGOSH, engagement would have been possible to a certain extent had there been access to the hospital). The HRA advocate that, "In the absence of law relating specifically to research, it is commonly assumed that the principle of 'Gillick competence' can be applied not only to consent for treatment, but also to consent for research" [303], although this is often not practiced. On reflection, further strategies need to be investigated for future research projects, to overcome barriers to involving CYP and to enable them to decide for themselves whether they would like to participate in research, under the realm of Gillick competence.

A confounding factor in these findings is the impact of COVID-19, with the rapid shift to tele-medicine and virtual care, a reduction in face-to-face appointments, and the need for more vulnerable patients to shield [175, 299, 304]. The experience of the patient and family during the hospital's transition to EPR/MyGOSH was ordinarily likely to be very different to their experiences of this during the pandemic, resulting in the patient and family experience being seen through the lens of COVID-19, as it has impacted on every aspect of care provided to them.

10.10 Conclusion

Implementation and transition to an EPR system with a tethered patient portal is complex and takes time to embed. Setting realistic expectations and involving all stakeholders at all stages is paramount if benefits for all are to be fully realised. Managing this change process well, with prolonged engagement over time with all stakeholders, is essential if future utility is to be achieved. This requires an inclusive culture, in which the voice of all children and young people and parents is valued, and enabled through investment of appropriate resources, with equity of access a key priority.

Despite the challenges experienced by all stakeholders, including ethical and legal issues associated with CYP and parents accessing health data for the first time through the patient portal, meaningful portal access can be achieved from the age of 12 years of age. Families need support accessing health information via the portal. Clinicians need to have early conversations with parents about truth-telling and sharing diagnoses and/or prognoses, supporting families through the process of disclosure. Staff require prolonged support to balance clinical demands during implementation of and adjustment to the new clinical system, whilst continuing care provision and managing families' expectations.

The EPR Applied Ethics Framework has been amended to incorporate such complexities to enable application of the framework in the paediatric setting, which could also be applied to triads in other health and care settings. Recommendations for clinical practice and for future research have been given. The dissemination strategy and wide dissemination of the study's findings have been described. Strengths and limitations of the study and each research activity have been discussed.

The final chapter in this thesis will provide the reader with reflections from the journey throughout this study and PhD. Professional, educational, and personal growth will also be discussed, including additional activities and dissemination related to this professional growth.

11

11 Reflections and future directions

In this final chapter, I will reflect on my journey throughout this study and PhD. I have overcome anticipated and unanticipated challenges. Through hard work, determination, and persistence, I have experienced professional, educational, and personal growth, and achieved more than I ever thought I could during this PhD. These aspects will be discussed, including the impact COVID-19 had on the study, and then future directions will be proposed.

11.1 Reflecting on challenges

As with any study, challenges occurred, both anticipated and unanticipated. With each challenge and remedy, I learned problem solving skills and developed increasing resilience and perseverance.

Despite the majority of staff supporting the study, challenges existed regarding the behaviours from a minority of hospital staff members during data collection phases of the study. These included:

- Staff members openly opposed to distributing research materials
- Disposal of research materials during the study period
- Ignoring the researcher when visiting clinical areas to collect completed surveys/offer support during study period
- Unprofessional behaviours such as talking openly about personal circumstances in front of patients/families and using mobile phones openly in front of patients/families

- Failure to comply with Trust initiative to sign families up to MyGOSH (with equity implications, as discussed in Table 11.1 of this chapter), with the resultant impact on my study, and larger impact on families (described below)
- Inconsistent communication to parents about MyGOSH functionality, meaning families may not have sufficient information to make an informed decision about whether to sign up for MyGOSH
- Staff members breaching the Trust's always values: always be welcoming, helpful, expert, and one team [305].

On reflection, I found these behaviours challenging and frustrating. I had come from a team within the ICU, and within ORCHID research team who very much promote the Trust values and witnessing these behaviours was very surprising to me. I had a professional obligation to escalate my concerns to the senior nurses in each department and also escalated my equity and research concerns to my PhD supervisors, the EPR team and the MyGOSH Steering committee. Consequently, the clinical areas were retrained in MyGOSH sign-up.

COVID-19 brought additional challenges, the impact of which be discussed later in this chapter, that not only hampered the study's progress but also affected its timeline. However, through the effective use of time, other aspects of the study were worked on (systematic review), and through close liaison with the R&D department, the three substantial amendments were given approval in due course and data collection could recommence.

Additional challenges related to covid were home working. Although efficiency increased with less time spent travelling, it took six months to be set up with the correct and necessary equipment to function effectively at home. Furthermore, remote working posed difficulties when trying to problem solve or seek advice. When working in the research office, colleagues would often have been a source of support for each other in terms of sharing knowledge, skills, or advice, which was lost to a certain extent whilst working from home. The overall challenges encountered during this research are presented in Table 11.1, along with the reason, the remedy and resultant learning.

Table 11-1: Challenges encountered, reason, remedy, and resultant learning

Challenge	Reason	Remedy	Learning
Confusion re PhD student role and blurring of role – seen as an EPR team member	Blurred lines – hospital staff see EPR team member; EPR team have different expectations	Clarify role of PhD student Rationalise commitments within EPR team, prioritisation of study activities	Manage expectations early on Clarify often
Printing paper survey copies	Time-consuming printing/putting in envelopes – not an effective use of time	No remedy initially, but when new administrator in post she was able to help	Efficiency is key Commercial printing advocated in the future
Low return of paper surveys from staff baseline survey (*n*=18 from a total of *n*=650 responses)	Time-consuming for researcher visiting all wards frequently for low returns	Follow-up surveys were all electronic	It was correct to offer a paper version of the survey pre-Go-Live, but it was evident that electronic was preferred method for staff
Parent/CYP baseline survey distribution was required to commence at Go-Live rather than pre-Go-Live, as initially planned	Engagement from Trust/EPR team pre-Go-Live was predominantly with hospital staff meaning that families had minimal exposure to EPR at this time	Approach modified so that familied would be invited to complete the survey when approached for MyGOSH sign-up	Despite a very well-planned study, timelines may need to be amended emphasising the need for researcher adaptability and reflexivity
Barriers to recruitment to parent/CYP baseline survey	Inconsistencies in survey distribution by designated clinical team despite clear guidance, support and update emails to Managers/Teams leaders/Division Lead Clinical areas (x3) disposing of or clearing away surveys and collection boxes, making accurate response rate calculations impossible	Researcher spent considerable time in clinical areas supporting the staff during survey distribution phase Close liaison with senior members of the clinical team was required frequently	Some staff members were resistant to contributing towards GOSH being a research hospital, regardless of the approach taken by researcher It is important to utilise/encourage those willing to help – ‘Champion’ those individuals Increased researcher visibility required where research is ongoing

Challenge	Reason	Remedy	Learning
Observation and identification of a larger issue with inequity implications, including observation of staff members not reflecting the Trust's 'Always Values'	Inconsistencies were witnessed in how frontline staff signed up families to MyGOSH and how they described what MyGOSH could do for them	Escalated concerns to MyGOSH Steering Committee (of which I was a member). As a result, all clinical staff in area re-trained in MyGOSH sign-up Staff members not displaying 'Always Values' were reported to their manager	Although what was observed impacted on the study, the issues were a Trust issue with implications wider than simply impacting on the study. This needed to be escalated and, therefore, took precedence I would take the same action again if needed
Using REDCap for the first time	REDCap was more difficult to navigate than simpler platforms such as Survey Monkey Support for REDCap users was limited at the time	Liaising with fellow ORCHID team researchers to share experiences Reached out via UCL to ask for advice Now a member of a newly formed REDCap user support group/forum via UCL e-mail so that all REDCap users can help each other	It is essential to utilise the knowledge and support around you and, as my experience increases, help other researchers overcome their challenges using REDCap
Challenges associated with remote working	Due to the pandemic, it was necessary to work remotely. This brought challenges such as not being able to troubleshoot as quickly or as easily as if located in the research office, and not having the correct equipment for the first six months to work effectively. This was particularly challenging when trying to solve statistical/SPSS related problems, and when conducting a large systematic review on a small screen	After six months, GOSH provided appropriate remote working equipment, resulting in increased efficiency. I had also just purchased an additional monitor due to the long wait for equipment The PhD Student group set up a WhatsApp group for peer-support, and also arranged virtual support meetings and social evenings. This was invaluable during this time Also, excellent support was available from the ORCHID Senior Leadership Team	Having the correct remote working set up including equipment, technical support and infrastructure from your institution is essential to being able to work competently and efficiently The model of peer-support from the PhD group was written up as a published abstract (Appendix 64) and presented as a poster at the 2021 GOSH Conference Perseverance is an important skill to have

Challenge	Reason	Remedy	Learning
Additional pandemic related challenges	The unknowns in the early stages of the pandemic were of great concern. Challenges existed in homeschooling three children, in addition to working/studying with a strain on time, coping abilities of all household occupants, the capacity of the internet, and the ability to get family supplies We had an added burden of coping with a bereavement during the first wave of the pandemic. This was an extremely challenging time	Setting realistic, achievable goals for each day was the best approach	The last two years has resulted in the development of resilience and increased problem-solving capabilities that will serve as useful in the future

11.2 Professional, educational, and personal growth

Before embarking on this doctoral educational journey it was impossible to imagine what it would *really* take to do a PhD. Prior to a recent ORCHID study day for Clinical Academics where I presented ‘The PhD, the research, the journey’, I conducted a poll with my peer group of Clinical Academics, all at different stages of their PhD to find out what it takes to do a PhD. The results sum up perfectly what is required (Figure 11-1).

Figure 11-1: What does it take to do a PhD?

Despite the complexity of the challenge to complete a PhD, this journey of has been transformative. I have taken every opportunity available to me within UCL’s Doctoral School, the research team, external learning opportunities, teaching within the research team and the hospital, and attending and presenting at conferences and events. I have seen my knowledge, skills and abilities grow over the last three (almost four) years and I am proud of what I have achieved. My formal doctoral training and additional development activities are documented in Appendix 65. This includes formal study, which was built on the Vitae’s Researcher Development Framework incorporating the RDF domains [306], specialist academic training and development in addition to formal study, clinical training and development, additional research training, conferences attended, mentoring/advisory roles, review/peer review, grant funding and awards, and prizes/other achievements.

During the study period and my PhD I have continued to develop relevant expertise further through membership of and involvement with various committees and groups:

- Expert member of GOSH Paediatric Bioethics Service and Rapid Response Team
- Alternate Vice-Chair and Expert Member of HRA Research Ethics Committee Bloomsbury
- UCL GOS ICH/BRC Junior Faculty Representative for Applied Child Health Informatics
- Member of the Institute of Medical Ethics
- Member of the EPR Transformation and Benefits Steering Committee
- Member of the EPR MyGOSH Steering Committee
- GOSH Collaborate Network

In recognition of my many years of teaching experience I applied for, and was granted, ‘Associate Fellowship’ of the Higher Education Academy (Appendix 66). I have been also involved in projects additional to the Going Study during the PhD. These include the promotion of clinical academic careers locally and nationally (Appendix 49), and peer-support for clinical academics/PhD students (Appendix 64) [307]. Due to my extensive intensive care nursing experience and ethical/legal expertise, I also co-authored a paper on the ‘Legal implications for critical care’ during COVID-19 (Appendix 67) [308]. Furthermore, due to my ethics expertise, I was part of a team who conducted a service evaluation of paediatric services in the North Thames Network during the first wave of the pandemic (Appendix 68/69) [309]. The results and recommendations formed from the findings have been widely disseminated due to the impact of diversion of paediatric services on children and young people. Table 11.2 presents additional dissemination activities including conferences, teaching and publications conducted as part of my professional and educational development during the PhD.

From the professional and educational advancements and achievements throughout this PhD journey, I have developed immensely from a personal perspective. I have always been determined, but I have developed greater problem-solving skills, resilience, and vigorous perseverance. When coming from the top of your profession to be a novice researcher, the learning curve is steep, with ups and downs along the way. This includes overcoming imposter syndrome, and learning from rejection, for example, when your journal submission requires amendments. This was illustrated beautifully by Katie Chappell, a live illustration specialist during a presentation to Clinical Academics during an ORCHID study day (Figure 11-2). This journey has, however, brought new opportunities and learning, for which I am grateful.

Figure 11-2: Illustration of the Going Digital study journey

Table 11-2: Additional dissemination activities

Year/month	Name of Meeting/Title	Type of Dissemination	Target Audience	Location
July 2018	2nd International Conference on Nursing Science and Practice – The 'New' Eugenics: The Ethical and Legal Implications of CRISPR/Cas9 Germline Editing Therapies	Conference (poster) presentation	HCPs, Scientists	London
September 2018	16th Introduction to Congenital Heart Disease Conference – Ethics of Everyday Cardiac Practice	Conference (oral) presentation	Nurses	London
September 2018	Bioethics Conference – Aylett SE, Moore B, Brierley J, Archard D, **Sipanoun P,** Delany C, Gillam L, Rahman S. Social media in healthcare and innovative treatments – parents' views and their use of it	Conference (oral) presentation (by Dr Aylett)	HCPs	Melbourne, Australia
January 2019	Critical Care Junior Band 5 Teaching, Great Ormond Street Hospital – Ethics and Difficult Decisions	Lecture	Nurses	London
February 2019	Gastroenterology Study Day for Nurses - RCN on behalf of UCL GOS ICH – The Ethics of Long-term feeding	Lecture	Nurses	London
July 2019	Ethics in Congenital Heart Disease	Lecture	Nurses	London
September 2019	Academic Inquiring Minds – Designing questionnaires	Lecture	Students, Members of the CAF/RF, ORCHID	London
May 2020	Coghlan N, Archard D, **Sipanoun P,** Hayes T, Baharlo B. (2020) COVID-19: Legal implications for critical care. Anaesthesia. Available at: <doi:10.1111/anae.15147> (Appendix 67) [308]	Publication	Intensive Care Professionals, Ethicists, those with legal interest	Peer-review Journal
September 2020	Academic Inquiring Minds – Research Ethics	Lecture	Students, Members of the CAF/RF, ORCHID	London/online
November 2020	GOSH Conference – Livermore P, Bichard E, Brind J, Evans J, Handley S, Harniess P, Jewell T, Katchburian L, Kerr-Elliott T, Kim JS, Nightingale, R, Shkurka E, Simcock I, **Sipanoun P,** Stewart A. (2020) **"**The importance of peer-support for clinical academics at Great Ormond Street Children's Hospital"	Conference (digital poster) presentation (by Dr Livermore)	HCPs	London/online

Year/month	Name of Meeting/Title	Type of Dissemination	Target Audience	Location
November 2020	Livermore P, Bichard E, Brind J, Evans J, Handley S, Harniess P, Jewell T, Katchburian L, Kerr-Elliott T, Kim JS, Nightingale, R, Shkurka E, Simcock I, **Sipanoun P,** Stewart A. (2020) **"**The importance of peer-support for clinical academics at Great Ormond Street Children's Hospital" *Archives of Disease in Childhood* 105:A24. Available at: <http://dx.doi.org/10.1136/archdischild-2020-gosh.69> (Appendix 64) [307]	Published abstract	Peer-review Journal	Peer-review Journal
February 2021	Institute of Medical Ethics Student Conference 2021 – Kumar NS, **Sipanoun P**, Dittborn M, Doyle M, Aylett, S. Ethical review of the impact of changes in services on children during the first wave of the COVID-19 pandemic. Available at: <https://ime-uk.org/events-and-news/news/student-conference-posters/> [260]	Conference (digital poster) presentation (by Ms. Kumar)	Students, HCPs, Ethicists	London/online
May 2021	Cardiac Ethics: Ethics and difficult decisions in cardiac practice	Lecture	Nurses	London/online
November 2021	The GOSH Conference: Ethical review of the impact of changes in services on children during the first wave of the Coronavirus Disease 2019 pandemic	Conference (digital poster) presentation (by Ms. Kumar)	HCPs, Ethicists	London/online
November 2021	Kumar NS, **Sipanoun P**, Dittborn M, Doyle M, Aylett, S. 47 Ethical review of the impact of changes to healthcare services on children and young people during the first wave of the coronavirus disease 2019 (COVID-19) pandemic *Archives of Disease in Childhood* 2021;**106:**A18. (Appendix 68) [310]	Published abstract	HCPs, Ethicists	Peer-review Journal
December 2021	Sunil Kumar N, **Sipanoun P**, Dittborn M, Doyle M, Aylett S. North Thames multi-centre service evaluation: Ethical considerations during COVID-19. *Clinical Ethics*. December 2021. Available at: <doi:10.1177/14777509211063590> (Appendix 69) [309]	Publication	HCPs, Ethicists	Peer-review Journal
February 2022	Ethics at the end of Life	Lecture	Nurses	London/online
March 2022	UCL Paediatrics Conference – Sunil Kumar N, **Sipanoun P**, Dittborn M, Doyle M, Aylett S. ethical review of the impact of changes to healthcare services on children and young people during the first wave of the Coronavirus disease 2019 pandemic.	Conference (poster) presentation (by Ms. Kumar)	HCPs, Academics, Scientists, members of the Child Health Community	London/online

11.3 The impact of COVID-19 on the study

There was an inevitable COVID-related impact on the study’s timeline. Due to the necessary prioritisation of COVID-related studies, local R&D approval for two substantial amendments and one minor amendment took an extended amount of time. The amendments were to facilitate virtual data collection methods, and the addition of demographic details to follow-up surveys. Local approvals took almost five months, causing unavoidable delays to phase three data collection.

Face-to-face aspects of the study had to be amended to be undertaken virtually. This may have impacted on patient and family recruitment. COVID-19 may have impacted families’ engagement or willingness to be involved in the study.

Furthermore, it was intended that we would capture families’ reasons for not signing up to the portal, as part of recruitment, however, COVID-19 restrictions limited face-to-face conversations with families in the hospital.

The addition pressures placed on staff during the pandemic may have impacted their capacity to engage with the study.

11.4 Future directions

My work continues within the hospital as a Research Fellow in Digital methods. Pushing forward various initiatives from the digital health perspective and the promotion of Clinical Academic careers. The next year sees the formal analysis of the staff experience from the Going Digital study, with dissemination continued accordingly.

I am also progressing as an Early Careers Researcher, gaining experience by taking a role as a Research Fellow in Transition at the University of Surrey, working on a national study evaluating services for the transition of young people from children’s/adolescent’s services into adult services. I feel that these two joint roles will enable me to grow as a Researcher following my Doctoral training, taking all opportunities to advocate for children and young people, and striving to provide the best care and opportunities for them

My post-doctoral development timeline can be found here:

https://padlet.com/psipanoun/ahpm5t8s6zalw8x2

Or by following this QR code:

11.5 Final thoughts

I finish this PhD a different person to the one who started it. Despite the numerous skills I have gained and the knowledge growth, it has enabled me to progress to a higher level of thinking, which I will use to continue to advocate for children’s and young people’s rights and interests in the healthcare context.

References

1. NHS England, *Five Year Forward View*. 2014: Online.
2. Trewella, S., *Great Ormond Street Hospital Digital Roadmap* 2017, Great Ormond Street Hospital: Online.
3. National Information Board (NIB), *Personalised Health and Care 2020: Using Data and Technology to Transform Outcomes for Patients and Citizens*. November 2014.
4. Health and Social Care Information Centre (HSCIC), *Information and technology for better care: HSCIC Strategy 2015-2020*. March 2015.
5. Care Quality Commission, *Safe Data, Safe Care: Data security review*. July 2016.
6. Wachter, R.M., *Making IT Work: Harnessing the Power of Health Information Technology to Improve Care in England Report of the National Advisory Group on Health Information Technology in England*. 2016, Crown Copyright: England.
7. NIB, *Healthy Children: Transforming Child Health Information.* November 2016.
8. NHS. *The NHS Long Term Plan*. 2019; Available from: https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf.
9. The Topol Review, *Preparing the healthcare workforce to deliver the digital future. An inpedendent report on behalf of the Secretary of State for Health and Social Care*. 2019, Health Education England: England.
10. Department of Health and Social Care, *Data saves lives: reshaping health and social care with data*. 2022, Department of Health and Social Care: Online.
11. Raut, S., *Digital transformation – The Age of Instant Gratification*, in *The Innovation Enterprise Ltd.* . 2016.
12. Topol, E., *The Patient Will See You Now*. 2015, Philadelphia: Basic Books.
13. *General Data Protection Regulation* 2016.
14. NHS England, *Acute Global Digital Exemplars.*
15. Great Ormond Street Hospital, *Great Ormond Street Hospital Charity Impact Report 2017/18 Then, now, always: our mission never changes*.
16. Hoeksma J, *GOSH becomes first UK hospital to achieve HIMSS Stage 7*, in *Digital Health*. 2020: Online.
17. McGinn, C.A., Grenier, S. and Duplantie, J., *Comparison of user groups' perspectives of barriers and facilitators to implementing electronic health records: a systematic review.* BMC Medicine, 2011. **9**(1): p. 46.
18. Wilson E.V., L., N.K., *Modeling patients' acceptance of provider delivered e-health.* Journal of the American Medical Informatics Association 2004. **11**(4): p. 241-248.
19. Staroselsky, M., Volk, L.A., Tsurikova, R., Pizziferri, L., Lippincott, M., Wald, J. and Bates, D.W., *Improving electronic health record (EHR) accuracy and increasing compliance with health maintenance clinical guidelines through patient access and input.* International Journal of Medical Informatics 2006. **75**(10-11): p. 693-700.

20. *Beyond Good Intentions: Accelerating the Electronic Health Record in Canada (PDF Version)*
21. Delpierre, C., Cuzin, L., Fillaux, J., Alvarez, M., Massip, P., Lang, T., *A systematic review of computer-based patient record systems and quality of care: more randomized clinical trials or a broader approach?* International Journal for Quality in Health Care, 2004. **16**(5): p. 407-416
22. Ueckert, F., Goerz, M., Ataian, M., Tessmann, S., Prokosch, H.U., *Empowerment of patients and communication with health care professionals through an electronic health record.* International Journal of Medical Informatics, 2003. **70**(2-3): p. 99-108.
23. Digital Health, *Alder Hey hospital upgrades its system*. 2015.
24. NHSX. *Empowering Cambridge patients through digital access to their health information*. 24 April 2021]; Available from: https://www.nhsx.nhs.uk/key-tools-and-info/digital-playbooks/respiratory-digital-playbook/empowering-cambridge-patients-through-digital-access-to-their-health-information/.
25. Copley, L.A., et al., *Electronic Medical Record Use and Satisfaction Among Pediatric Orthopaedic Surgeons.* Journal of Pediatric Orthopedics, 2019. **39**(9): p. e722-e728.
26. Al-Rayes, S.A., Alumaran, A., AlFayez, W., *The Adoption of the Electronic Health Record by Physicians.* Methods of Information Medicine, 2019. **58**(2-3): p. 63-70.
27. Malycha, J., Redfern, O.C., Ludbrook, G., Young, D., Watkinson, P.J., *Testing a digital system that ranks the risk of unplanned intensive care unit admission in all ward patients: protocol for a prospective observational cohort study.* BMJ Open, 2019. **9**(9).
28. Muhlenkamp, R., Ash, N., Ziegenbusch, K., Rampe, N., Bishop, B., Adane, E., *Effect of modifying dose alerts in an electronic health record on frequency of alerts.* American Journal of Health-System Pharmacy, 2019. **76**: p. S1-S8.
29. Apter, A.J., Localio, A.R., Morales, K.H., Han, X., Perez, L., Mullen, A.N., Rogers, M., Klusaritz, H., Howell, J.T., Canales, M.N., Bryant-Stephens, T., *Home visits for uncontrolled asthma among low-income adults with patient portal access Journal of Allergy and Clinical Immunology.* Journal of Allergy and Clinical Immunology, 2019. **114**(3): p. 846-853e.
30. Bush, R.A., Vemulakonda, V.M, Richardson, A.C., Deakyne Davies, S.J., Chiang, G.J., *Providing Access: Differences in Pediatric Portal Activation Begin at Patient Check-in* Applied Clinical Informatics, 2019. **10**(4): p. 670-678.
31. *Mental Capacity Act 2005, [online]*.
32. Gillick v West Norfolk and Wisbech AHA [1985] UKHL 7.
33. NATIONAL INSTITUTE FOR HEALTH AND CARE EXCELLENCE, *Decision-making and mental capacity*, in *NICE GUIDELINE NG108*. 2018, NICE: Online. p. 444.
34. Ancker, J.S., et al., *Should parents see their teen's medical record? Asking about the effect on adolescent–doctor communication changes attitudes.* Journal of the American Medical Informatics Association, 2018. **25**(12): p. 1593-1599.
35. Chang, B.L., et al., *Bridging the Digital Divide: Reaching Vulnerable Populations.* Journal of the American Medical Informatics Association, 2004. **11**(6): p. 448-457.

36. Schloman, B.F., *Information Resources Column: "The Digital Divide: How Wide and How Deep".* Online Journal of issues in Nursing, 2004. **9**(2).
37. Yamin, C.K., et al., *The Digital Divide in Adoption and Use of a Personal Health Record.* Archives of Internal Medicine, 2011. **171**(6): p. 568-574.
38. Rogerson, N.B.F.S., *A moral approach to electronic patient records.* Medical Informatics and the Internet in Medicine, 2001. **26**(3): p. 219-234.
39. Layman, E.J., *Ethical issues and the electronic health record.* Health Care Manag (Frederick), 2008. **27**(2): p. 165-76.
40. Jacquemard, T., C.P. Doherty, and M.B. Fitzsimons, *The anatomy of electronic patient record ethics: a framework to guide design, development, implementation, and use.* BMC Medical Ethics, 2021. **22**(1): p. 9.
41. Jacquemard, T., C.P. Doherty, and M.B. Fitzsimons, *Examination and diagnosis of electronic patient records and their associated ethics: a scoping literature review.* BMC Medical Ethics, 2020. **21**(1): p. 76.
42. Chan, O., *Do parents really know best? Ethical issues concerning medical consent for minors*. 2018, DIALOGUES @ RU: Online. p. 12.
43. Page, B.F., et al., *The challenges of caring for children who require complex medical care at home: 'The go between for everyone is the parent and as the parent that's an awful lot of responsibility'.* Health Expectations, 2020. **23**(5): p. 1144-1154.
44. Callery, P., *Maternal knowledge and professional knowledge: co-operation and conflict in the care of sick children.* International Journal of Nursing Studies, 1997. **34**(1): p. 27-34.
45. Aarthun, A., K.A. Øymar, and K. Akerjordet, *Parental involvement in decision-making about their child's health care at the hospital.* Nursing Open, 2019. **6**(1): p. 50-58.
46. Mohr Lone, J., *Philosophical thinking in childhood*, in *The Routledge Handbook of the Philosophy of Childhood and Children (Routledge Handbooks in Philosophy)*, A. Gheaus, G. Calder, and J. De Wispelaere, Editors. 2019, Routledge Taylor and Francis Group: London. p. 424.
47. Sipanoun, P., et al., *The experiences and perceptions of users of an electronic patient record system in a pediatric hospital setting: a systematic review.* International Journal of Medical Informatics, 2022. **160**: p. 104691.
48. Valdez, R.S., et al., *Ensuring full participation of people with disabilities in an era of telehealth.* Journal of the American Medical Informatics Association, 2020. **28**(2): p. 389-392.
49. Seeability (The Royal School for the Blind). *Digital inclusion: making every connection count*. 2021 [cited 2022 9 March]; Available from: https://donate.thebiggive.org.uk/campaign/a056900001wZbCTAA0.
50. The Good Things Foundation. *Disability, equality and digital exclusion*. 2021 [cited 2022 9 March]; Available from: https://www.goodthingsfoundation.org/what-we-do/news/disability-equality-and-digital-inclusion/.
51. Department of Health, *Liberating the NHS: No decision about me, without me. Government response*. 2012, DH: Online. p. 42.
52. Zelmer, J., *Nothing About Me Without Me.* Healthc Policy, 2019. **14**(4): p. 6-9.

53. Thiese, M.S., *Observational and interventional study design types; an overview.* Biochemia Medica, 2014. **24**(2): p. 199-210.
54. Creswell, J.W., Plano Clark, V.L., *Designing and Conducting Mixed Methods Research*. 3rd ed. 2018, London: Sage.
55. Tashakkori, A. and J.W. Creswell, *Editorial: The New Era of Mixed Methods.* Journal of Mixed Methods Research, 2007. **1**(1): p. 3-7.
56. Barbour, R., *Doing Focus Groups (Qualitative Research Kit)*. 2nd ed. 2018, London: Sage.
57. @NIHRevidence. *'Research is of no use unless it gets to the people who need to use it' - Chris Whitty on dissemination* Twitter 2016 18 November [cited 17 February]; Available from: https://twitter.com/nihrevidence/status/799617200525033472?lang=en-GB.
58. National Institute of Health Research. *How to disseminate your research*. 2019 [cited 2022 17 February]; Available from: https://www.nihr.ac.uk/documents/how-to-disseminate-your-research/19951.
59. Guyatt, G., et al., *Users' guides to the medical literature. IX. A method for grading health care recommendations.* JAMA, 1995(274): p. 1800–4.
60. Greenhalgh, T., *How to read a paper: getting your bearings (deciding what the paper is about).* BMJ, 1997. **315**(7102): p. 243.
61. Mazurek-Melnyk, B. and E. Fineout-Overholt, editors, *Evidence-based practice in nursing and health-care: a guide to best practice*. 4th ed. 2019, Philadelphia: Wolters Khuwer Health.
62. Green, S., *Systematic reviews and meta-analysis.* Singapore medical journal, 2005. **46**(6): p. 270-3; quiz 274.
63. Sipanoun, P., Oulton, K., Gibson, F., Wray, J. *A systematic review of the experiences of users of an electronic patient record system in a paediatric hospital setting.* PROSPERO 2020.
64. Health Research Authority. *Planning and approving research, Research summaries*. 2020 [cited 2020 7 November 2020]; Available from: https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/.
65. Moher, D., et al., *Preferred Reporting Items for Systematic Reviews and Meta-Analyses: The PRISMA Statement.* PLOS Medicine, 2009. **6**(7): p. e1000097.
66. Hong QN, P.P., Fàbregues S, Bartlett G, Boardman F, Cargo M, Dagenais P, Gagnon M-P, Griffiths F, Nicolau B, O'Cathain A, Rousseau M-C, Vedel I, *Mixed Methods Appriasal Tool (MMAT), version 2018*. Registration of Copyright (#1148552), Canadian Intellectual Property Office, Industry Canada. .
67. Ahlers-Schmidt, C.R. and M. Nguyen, *Parent intention to use a patient portal as related to their children following a facilitated demonstration.* 2013.
68. Alsohime, F., et al., *Satisfaction and perceived usefulness with newly-implemented Electronic Health Records System among pediatricians at a university hospital.* Computer Methods and Programs in Biomedicine, 2019. **169**: p. 51-57.
69. Cavuoto, K.M., P. Monsalve, and T.C. Chang, *The impact of the transition to an electronic medical record on patient perceptions in a*

pediatric ophthalmology practice. Journal of Pediatric Ophthalmology and Strabismus, 2016. **53**(3): p. 173-178.

70. Chung, R.K., U.O. Kim, and M.A. Basir, *Differing perspectives on parent access to their child's electronic medical record during neonatal intensive care hospitalization: a pilot study.* Journal of Maternal-Fetal and Neonatal Medicine, 2018. **31**(8): p. 1078-1084.
71. Colligan, L., et al., *Cognitive workload changes for nurses transitioning from a legacy system with paper documentation to a commercial electronic health record.* International Journal of Medical Informatics, 2015. **84**(7): p. 469-476.
72. Ghazi Al-Shammari, M.A., A.A. Yasir, and N.M. Al-Doori, *Application of electronic medical record at Intensive Care Unit in Maternity and Children Hospital.* Journal of Global Pharma Technology, 2018. **10**(3): p. 35-41.
73. Hollenbeck, S.M., et al., *Electronic Medical Record Adoption: The Effect on Efficiency, Completeness, and Accuracy in an Academic Orthopaedic Practice.* Journal of Pediatric Orthopedics, 2017. **37**(6): p. 424-428.
74. Johansen, M.A., et al., *Health Professionals' Experience with Patients Accessing Their Electronic Health Records: Results from an Online Survey.* Studies in health technology and informatics, 2019. **264**: p. 504-508.
75. Kelly, M.M., P.L. Hoonakker, and S.M. Dean, *Using an inpatient portal to engage families in pediatric hospital care.* Journal of the American Medical Informatics Association, 2017. **24**(1): p. 153-161.
76. Kelly, M.M., et al., *Healthcare Team Perceptions of a Portal for Parents of Hospitalized Children Before and After Implementation.* Applied clinical informatics, 2017. **8**(1): p. 265-278.
77. Kirkendall, E.S., et al., *Transitioning from a computerized provider order entry and paper documentation system to an electronic health record: Expectations and experiences of hospital staff.* International Journal of Medical Informatics, 2013. **82**(11): p. 1037-1045.
78. Lee, G., et al., *Which Users Should Be the Focus of Mobile Personal Health Records? Analysis of User Characteristics Influencing Usage of a Tethered Mobile Personal Health Record.* Telemedicine Journal & E-Health, 2016. **22**(5): p. 419-28.
79. Matton, M.P., et al., *Electronic Medical Record in Pediatric Intensive Care: Implementation Process Assessment.* Journal of Pediatric Intensive Care, 2016. **5**(3): p. 129-138.
80. Palma, J.P., P.J. Sharek, and C.A. Longhurst, *Impact of electronic medical record integration of a handoff tool on sign-out in a newborn intensive care unit.* Journal of Perinatology, 2011. **31**(5): p. 311-317.
81. Raval, M.V., et al., *Development and Implementation of an Electronic Health Record Generated Surgical Handoff and Rounding Tool.* Journal of Medical Systems, 2015. **39**(2).
82. Rosen, P., et al., *Parent satisfaction with the electronic medical record in an academic pediatric rheumatology practice.* Journal of medical Internet research, 2011. **13**(2): p. e40.
83. Shenson, J.A., et al., *Rapid growth in surgeons' use of secure messaging in a patient portal*. 2016: Surgical Endoscopy and Other Interventional Techniques. 30 (4) (pp 1432-1440), 2016. Date of Publication: 01 Apr 2016.

84. Singh, A., et al., *Who's my doctor? Using an electronic tool to improve team member identification on an inpatient pediatrics team.* Hospital pediatrics, 2016. **6**(3): p. 157-165.
85. Wieck, M.M., et al., *Utilizing technology to improve intraoperative family communication.* American Journal of Surgery, 2017. **213**(5): p. 895-900.
86. Cillessen, F., P.F. de Vries Robbe, and M.C.J. Biermans, *A hospital-wide transition from paper to digital problem-oriented clinical notes. A descriptive history and cross-sectional survey of use, usability, and satisfaction.* Applied Clinical Informatics, 2017. **8**(2): p. 502-514.
87. Selvadurai, H., et al., *An online patient portal to enhance clinical communications for patients with chronic asthma.* Respirology, 2019. **24**.
88. Williams, D.C., et al., *Physician Use of Electronic Health Records: Survey Study Assessing Factors Associated With Provider Reported Satisfaction and Perceived Patient Impact.* JMIR Medical Informatics, 2019. **7**(2): p. e10949.
89. Cross, M.S., G.W. Aylward, and J.S. Rahi, *The experiences and perceptions of paediatric ophthalmic clinicians using electronic medical records in the United Kingdom.* Investigative Ophthalmology & Visual Science, 2016. **57**(12): p. 5546-5546.
90. Zhou, Y.Y., et al., *Personal health record use for children and health care utilization: Propensity score-matched cohort analysis.* Journal of the American Medical Informatics Association, 2015. **22**(4): p. 748-754.
91. Lee, J., et al., *Beneficial Effects of Two Types of Personal Health Record Services Connected With Electronic Medical Records Within the Hospital Setting.* Computers, informatics, nursing : CIN, 2017. **35**(11): p. 574-581.
92. Aylor, M., et al., *Resident Notes in an Electronic Health Record.* Clinical Pediatrics, 2017. **56**(3): p. 257-262.
93. Byczkowski, T.L., J.K. Munafo, and M.T. Britto, *Family perceptions of the usability and value of chronic disease web-based patient portals.* Health informatics journal, 2014. **20**(2): p. 151-162.
94. Byrd, A.S., et al., *Integration of mobile devices to facilitate patient care and teaching during family-centered rounds.* Hospital Pediatrics, 2018. **8**(1): p. 44-48.
95. Hanauer, D.A., et al., *Two-year longitudinal assessment of physicians' perceptions after replacement of a longstanding homegrown electronic health record: does a J-curve of satisfaction really exist?* Journal of the American Medical Informatics Association, 2017. **24**(e1): p. e157-e165.
96. Hong, M.K., et al., *Adolescent and Caregiver use of a Tethered Personal Health Record System.* Amia .. 2016. **Annual Symposium proceedings. AMIA Symposium. 2016**: p. 628-637.
97. King, G., et al., *Connecting Families to Their Health Record and Care Team: The Use, Utility, and Impact of a Client/Family Health Portal at a Children's Rehabilitation Hospital.* Journal of medical Internet research, 2017. **19**(4): p. e97.
98. Kelly, M.M., et al., *Parent perceptions of real-time access to their hospitalized child's medical records using an inpatient portal: a qualitative study.* Hospital Pediatrics, 2019. **9**(4): p. 273-280.
99. Tubaishat, A., *Evaluation of Electronic Health Record Implementation in Hospitals.* Computers, informatics, nursing : CIN, 2017. **35**(7): p. 364-372.

100. Varpio, L., et al., *The impact of adopting EHRs: how losing connectivity affects clinical reasoning.* Medical education, 2015. **49**(5): p. 476-486.
101. Varpio, L., et al., *The EHR and building the patient's story: A qualitative investigation of how EHR use obstructs a vital clinical activity.* International Journal of Medical Informatics, 2015. **84**(12): p. 1019-1028.
102. British Medical Association, *Access to health records. Updated to reflect the General Data Protection Regulation and the Data Protection Act 2018. Guidance for health professionals in the United Kingdom*. 2019, British Medical Association: Online. p. 1-11.
103. *Data Protection Act, 2018 [online]*.
104. Nursing and Midwifery Council, *The Code: Professional standards of practice and behaviours for nurses, midwives and nursng associates* 2015. p. 1-23.
105. Professional Record Standards Body, *Standards for the structure and content of health and records*. 2018. p. 1-128.
106. Griffiths, P., et al., *Implementing an interprofessional patient record.* Clinical medicine (London, England), 2011. **11**(2): p. 128-131.
107. Thompson D, W.K., *Developing a unified patient record. A practical guide*. 2003, Oxford: Radcliffe. 137.
108. Otte-Trojel, T., et al., *Characteristics of patient portals developed in the context of health information exchanges: early policy effects of incentives in the meaningful use program in the United States.* J Med Internet Res, 2014. **16**(11): p. e258.
109. Berg, M., et al., *Considerations for sociotechnical design: experiences with an electronic patient record in a clinical context.* International Journal of Medical Informatics, 1998. **52**(1): p. 243-251.
110. Alanazi, A. and Y.A. Anazi, *The Challenges in Personal Health Record Adoption.* Journal of Healthcare Management, 2019. **64**(2).
111. Mumford, E., *The story of socio-technical design: reflections on its successes, failures and potential.* Information Systems Journal, 2006. **16**(4): p. 317-342.
112. Walker, G.H., et al., *A review of sociotechnical systems theory: a classic concept for new command and control paradigms.* Theoretical Issues in Ergonomics Science, 2008. **9**(6): p. 479-499.
113. Entzeridou, E., E. Markopoulou, and V. Mollaki, *Public and physician's expectations and ethical concerns about electronic health record: Benefits outweigh risks except for information security.* Int J Med Inform, 2018. **110**: p. 98-107.
114. Esch, T., et al., *Engaging patients through open notes: an evaluation using mixed methods.* BMJ Open, 2016. **6**(1): p. e010034.
115. Bell, S.K., et al., *Frequency and Types of Patient-Reported Errors in Electronic Health Record Ambulatory Care Notes.* JAMA Network Open, 2020. **3**(6): p. e205867-e205867.
116. Thomas, J., *Medical records and issues in negligence.* Indian journal of urology : IJU : journal of the Urological Society of India, 2009. **25**(3): p. 384-388.
117. Collins, S.A., et al., *Acute care patient portals: a qualitative study of stakeholder perspectives on current practices.* Journal of the American Medical Informatics Association, 2017. **24**(e1): p. e9-e17.

118. Antonio, M.G., O. Petrovskaya, and F. Lau, *Is research on patient portals attuned to health equity? A scoping review.* Journal of the American Medical Informatics Association, 2019. **26**(8-9): p. 871-883.
119. Mlinarić, A., M. Horvat, and V. Šupak Smolčić, *Dealing with the positive publication bias: Why you should really publish your negative results.* Biochemia medica, 2017. **27**(3): p. 030201-030201.
120. NHS. *NHS Long term plan: Digitally enabled care will go mainstream across the NHS: Empowering people*. 2019 1st November 2021]; Available from: https://www.longtermplan.nhs.uk/online-version/chapter-5-digitally-enabled-care-will-go-mainstream-across-the-nhs/1-empowering-people/.
121. Sharko, M., et al., *Variability in adolescent portal privacy features: how the unique privacy needs of the adolescent patient create a complex decision-making process.* Journal of the American Medical Informatics Association, 2018. **25**(8): p. 1008-1017.
122. Braun, V. and V. Clarke, *Using thematic analysis in psychology.* Qualitative Research in Psychology, 2006. **3**(2): p. 77-101.
123. Fereday, J., Muir-Cochrane, Eimear., *Demonstrating rigor using thematic analysis: A hybrid approach of inductive and deductive coding and theme development.* Journal of Qualitative Methods, 2008. **5**(1): p. 80-92.
124. Ritchie, J., Lewis, J. , *Qualitative Research Practice - a Guide for Social Science Students and Researchers*. 2003, London: Sage.
125. Gale, N.K., et al., *Using the framework method for the analysis of qualitative data in multi-disciplinary health research.* BMC Medical Research Methodology, 2013. **13**(1): p. 117.
126. Brown, J., Isaacs, D., The World Café Community, *The World Café: Living knowledge through conversations that matter.* Systems Thinker, 2001. **12**(5): p. 1-5.
127. Hurley, T.J., Brown, J. , *Conversational Leadership: Thinking together for change.* Systems Thinker, 2009. **20**(9): p. 2-7.
128. Burke, C. and K. Sheldon, *Encouraging workplace innovation using 'World Cafe' model.* Nurs Manag (Harrow), 2010. **17**(7): p. 14-9.
129. Brown, J., Isaacs, D., The World Café Community *The World Café: Shaping Our Futures Through Conversations that Matter*. 2005, San Francisco: Berrett-Koehler Publishers, Inc.
130. Oulton, K., et al., *Pay More Attention: a national mixed methods study to identify the barriers and facilitators to ensuring equal access to high-quality hospital care and services for children and young people with and without learning disabilities and their families.* BMJ Open, 2016. **6**(12): p. e012333.
131. Ritchie, J., Spenser, L., Connor, W. , *Carrying out qualitative analysis*, in *Qualitative Research Practice: A Guide for Social Science Students and Researchers*, J. Ritchie, Lewis, J. , Editor. 2003, Sage: London. p. 219-262.
132. Gibbs, G.R., *Analyzing Qualitative Data (Qualitative Research Kit)*. 2nd ed. 2018, London: Sage.
133. Toor, M., *How to design rating scale questions*. 2021, Qualtrics XM: Online.
134. Moors, G., *Exploring the effect of a middle response category on response style in attitude measurement.* Quality & quantity, 2008. **42**(6): p. 779-794.

135. Floyd J. Fowler, J., *Survey Research Methods*. 5th ed. 2014, London: Sage. 1-168.
136. Harris, P.A., et al., *Research electronic data capture (REDCap) - A metadata-driven methodology and workflow process for providing translational research informatics support.* J Biomed Inform, 2009. **April 42**(2): p. 377-81.
137. Lindermann, N., *What's the average survey response [2019 Benchmark]*. 2019: Online.
138. Al-Abri, R. and A. Al-Balushi, *Patient satisfaction survey as a tool towards quality improvement.* Oman medical journal, 2014. **29**(1): p. 3-7.
139. Mák, G., et al., *The Effects of Web-Based Patient Access to Laboratory Results in British Columbia: A Patient Survey on Comprehension and Anxiety.* J Med Internet Res, 2015. **17**(8): p. e191.
140. General Medical Council, *Ethical guidance: 0–18 years: Guidance for all doctors; Accessing medical records by children young people parents*. 2021: Online.
141. Blum, R.W., et al., *Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine.* J Adolesc Health, 1993. **14**(7): p. 570-6.
142. Viner, R.M., *Transition of care from paediatric to adult services: one part of improved health services for adolescents.* Arch Dis Child, 2008. **93**(2): p. 160-3.
143. Palmer, A., *"I don't want to grow up." Transitioning HIV-infected adolescents to adult care.* HIV Clin, 2007. **19**(4): p. 1-3.
144. Wilcox, L., et al., *The need for guidance and consistency in adolescent privacy policies: a survey of CMIOs.* AMIA ... Annual Symposium proceedings. AMIA Symposium, 2018. **2018**: p. 1084-1092.
145. Carlisle, J., et al., *Concerns over confidentiality may deter adolescents from consulting their doctors. A qualitative exploration.* J Med Ethics, 2006. **32**(3): p. 133-7.
146. Jones, R.K., et al., *Adolescents' Reports of Parental Knowledge of Adolescents' Use of Sexual Health Services and Their Reactions to Mandated Parental Notification for Prescription Contraception.* JAMA, 2005. **293**(3): p. 340-348.
147. Ford, C.A., et al., *Influence of physician confidentiality assurances on adolescents' willingness to disclose information and seek future health care. A randomized controlled trial.* Jama, 1997. **278**(12): p. 1029-34.
148. Goodyear, V.A., K.M. Armour, and H. Wood, *Young people and their engagement with health-related social media: new perspectives.* Sport, Education and Society, 2019. **24**(7): p. 673-688.
149. De Nardi, L., et al., *Adolescents with chronic disease and social media: a cross-sectional study.* Archives of Disease in Childhood, 2020. **105**(8): p. 744.
150. Kelleher, E.F., P.F. Giampietro, and M.A. Moreno, *Social Media Use Among Young Adults With Connective Tissue Disorders: Cross-Sectional Pilot Study.* JMIR Pediatr Parent, 2020. **3**(2): p. e16367.
151. Wilson, C. and J. Stock, *'Social media comes with good and bad sides, doesn't it?' A balancing act of the benefits and risks of social media use by young adults with long-term conditions.* Health (London), 2021. **25**(5): p. 515-534.

152. van der Velden, M. and K. El Emam, *“Not all my friends need to know”: a qualitative study of teenage patients, privacy, and social media.* Journal of the American Medical Informatics Association, 2013. **20**(1): p. 16-24.
153. Chan A, Kow R, and Cheng J.K, *Adolescents’ Perceptions on Smartphone Applications (Apps) for Health Management.* Journal of Mobile Technology in Medicine, 2017. **6**(2).
154. Graetz, I., et al., *The Digital Divide and Patient Portals: Internet Access Explained Differences in Patient Portal Use for Secure Messaging by Age, Race, and Income.* Med Care, 2016. **54**(8): p. 772-9.
155. Walker, D.M., et al., *Exploring the Digital Divide: Age and Race Disparities in Use of an Inpatient Portal.* Telemedicine and e-Health, 2019. **26**(5): p. 603-613.
156. Ancker, J.S., et al., *Access policy and the digital divide in patient access to medical records.* Health Policy and Technology, 2017. **6**(1): p. 3-11.
157. Emani, S., et al., *Perceptions of adopters versus non-adopters of a patient portal: an application of diffusion of innovation theory.* BMJ Health; Care Informatics, 2018. **25**(3): p. 149.
158. Goel, M.S., et al., *Disparities in Enrollment and Use of an Electronic Patient Portal.* Journal of General Internal Medicine, 2011. **26**(10): p. 1112-1116.
159. Sarkar, U., et al., *Social disparities in internet patient portal use in diabetes: evidence that the digital divide extends beyond access.* Journal of the American Medical Informatics Association, 2011. **18**(3): p. 318-321.
160. Ramsetty, A. and C. Adams, *Impact of the digital divide in the age of COVID-19.* Journal of the American Medical Informatics Association, 2020. **27**(7): p. 1147-1148.
161. Watts, G., *COVID-19 and the digital divide in the UK.* The Lancet Digital Health, 2020. **2**(8): p. E395-E396.
162. Baker, C.H., Georgina; Christie, Lorna; Wright, Susie, *COVID-19 and the digital divide*. 2020, UK Parliament: Online.
163. Sipanoun, P., et al., *97 The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: a systematic review.* Archives of Disease in Childhood, 2021. **106**(Suppl 3): p. A36.
164. Acuña Mora, M., et al., *Empowering Young Persons During the Transition to Adulthood*, in *Transition from Pediatric to Adult Healthcare Services for Adolescents and Young Adults with Long-term Conditions: An International Perspective on Nurses' Roles and Interventions*, C.L. Betz and I.T. Coyne, Editors. 2020, Springer: Switzerland. p. 19-46.
165. Akre, C. and J.C. Suris, *From controlling to letting go: what are the psychosocial needs of parents of adolescents with a chronic illness?* Health Educ Res, 2014. **29**(5): p. 764-72.
166. Office for National Statistics. *Exploring the UK’s digital divide*. 2019 [cited 2021 4th December]; Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/householdcharacteristics/homeinternetandsocialmediausage/articles/exploringtheuksdigitaldivide/2019-03-04.
167. Holmes, H. and G. Burgess. *"Pay the wi-fi or feed the children": Coronavirus has intensified the UK’s digital divide*. 2021 [cited 2021 4th December]; Available from: https://www.cam.ac.uk/stories/digitaldivide.

168. Kumar S and Stewart R, *Barriers that Affect the Use of Patient Portals.* Journal of Hospital and Healthcare Administration JHHA-117, 2018. **1**: p. 1-23.
169. Khan, A., et al., *Association Between Parent Comfort With English and Adverse Events Among Hospitalized Children.* JAMA Pediatrics, 2020. **174**(12): p. e203215-e203215.
170. Flores, G., *Language Barriers and Hospitalized Children: Are We Overlooking the Most Important Risk Factor for Adverse Events?* JAMA Pediatrics, 2020. **174**(12): p. e203238-e203238.
171. NSPCC, *Learning from case reviews briefing: People whose first language is not English*. 2014, NSPCC: Online. p. 1-4.
172. Fitzgerald, G., L. Piris, and A. Serrano. *Identification of benefits and barriers for the adoption of e-health information systems using a socio-technical approach*. in *ITI 2008 - 30th International Conference on Information Technology Interfaces*. 2008.
173. Robertson, A., et al., *Implementation and adoption of nationwide electronic health records in secondary care in England: qualitative analysis of interim results from a prospective national evaluation.* BMJ, 2010. **341**: p. c4564.
174. Graham, T.A.D., et al., *Effects of a Web-Based Patient Portal on Patient Satisfaction and Missed Appointment Rates: Survey Study.* Journal of medical Internet research, 2020. **22**(5): p. e17955-e17955.
175. Cheng, D.R., A. Coote, and M. South, *A digital approach in the rapid response to COVID-19 – Experience of a paediatric institution.* International Journal of Medical Informatics, 2021. **149**: p. 104407.
176. Vos, J.F.J., et al., *The influence of electronic health record use on collaboration among medical specialties.* BMC Health Services Research, 2020. **20**(1): p. 676.
177. Das, R., *Populist discourse on a British social media patient-support community: The case of the Charlie Gard support campaign on Facebook.* Discourse, Context & Media, 2018. **24**: p. 76-84.
178. *Alder Hey Children's NHS Foundation Trust v Evans & Anor [2018] EWHC 308 (Fam)*.
179. Boseley, S., *Charlie Gard: Key questions answered*, in *The Guardian*. 2017: Online.
180. *Great Ormond Street Hospital v Yates [2017] EWHC 1909 (Fam) [11]*.
181. Perzynski, A.T., et al., *Patient portals and broadband internet inequality.* Journal of the American Medical Informatics Association : JAMIA, 2017. **24**(5): p. 927-932.
182. Igoe, A., *Barriers to Patient Portal Use: Functional Impairment, Health Literacy, and the Digital Divide.* Journal of Informatics Nursing, 2018. **3**(3): p. 18-20.
183. Vasileiou, K., et al., *Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period.* BMC medical research methodology, 2018. **18**(1): p. 148-148.
184. Sandelowski, M., *Sample size in qualitative research.* Research in Nursing & Health, 1995. **18**(2): p. 179-183.
185. Fugard, A.J.B. and H.W.W. Potts, *Supporting thinking on sample sizes for thematic analyses: a quantitative tool.* International Journal of Social Research Methodology, 2015. **18**(6): p. 669-684.

186. Terry, G., Hayfield, N., Clarke, V. & Braun, V.Terry, G., Hayfield, N., Clarke, V. and Braun, V., *Thematic Analysis*, in *The Sage Handbook of qualitative research in psychology*, C.W.a.W. Stainton-Rogers, Editor. 2017, Sage Publications Ltd. p. 17-36.
187. Lincoln, Y.S. and E.G. Guba, *Naturalistic inquiry*. 1985, Newbury Park, CA: Sage Publications.
188. Whittemore, R., S.K. Chase, and C.L. Mandle, *Validity in Qualitative Research.* Qualitative Health Research, 2001. **11**(4): p. 522-537.
189. Mills, A.J., G. Durepos, and E. Wiebe, eds. *Encyclopedia of Case Study Research*. Vol. I and II. 2010, Sage: Thousand Oaks, CA.
190. Twycross, A. and L. Shields, *Validity and reliability - what's it all about? Part 3: Issues relating to qualitative studies.* Paediatric Nursing, 2005. **17**(1).
191. Lewis, J. and J. Ritchie, *Generalising from qualitative research*, in *Qualitative research practice: a guide for social science students and researchers*, J. Ritchie and J. Lewis, Editors. 2003, Sage Publications: London. p. 263-286.
192. Chiovitti, R.F. and N. Piran, *Rigour and grounded theory research.* Journal of Advanced Nursing, 2003. **44**(4): p. 427-435.
193. Thomas, E. and J.K. Magilvy, *Qualitative Rigor or Research Validity in Qualitative Research.* Journal for Specialists in Pediatric Nursing, 2011. **16**(2): p. 151-155.
194. Great Ormond Street Hospital for Children NHS Foundation Trust, *Full Business Case for an Electronic Patient Record System (EPR) and Research and Innovation Platform*. 2017, Great Ormond Street Hospital for Children NHS Foundation Trust. p. 105.
195. Muhammad, I. and N. Wickramasinghe, *User Perceptions and Expectations of the MyHealth Record: A Case Study of Australia’s e-health Solution*, in *Proceedings of the 50th Hawaii International Conference on System Sciences*. 2017: Hawaii. p. 3441-3450.
196. Joukes, E., et al., *End-user expectations during an electronic health record implementation: a case study in two academic hospitals.* Stud Health Technol Inform, 2015. **210**: p. 501-5.
197. McGinn, C.A., et al., *Users' perspectives of key factors to implementing electronic health records in Canada: a Delphi study.* BMC Med Inform Decis Mak, 2012. **12**: p. 105.
198. Priestman, W., et al., *What to expect from electronic patient record system implementation: lessons learned from published evidence.* BMJ Health; Care Informatics, 2018. **25**(2): p. 92.
199. Diffin, J., et al., *The usefulness and acceptability of a personal health record to children and young people living with a complex health condition: A realist review of the literature.* Child: care, health and development, 2019. **45**(3): p. 313-332.
200. Wong, D. and S. Morgan-Lynch, *Patient portals and young people: addressing the privacy dilemma of providing access to health information.* J Prim Health Care, 2017. **9**(4): p. 240-243.
201. Royal College of Paediatrics and Child Health. *Digital by default or digital divide? Virtual healthcare consultations with young people 10 – 25 years*. 2020 [cited 2022 20 March]; Available from: https://www.rcpch.ac.uk/resources/digital-default-or-digital-divide-virtual-healthcare-consultations.

202. The Royal New Zealand College of General Practitioners, *Child and Adolescent Health: Patient Portals, Health Information and Disclosure*. 2017, The Royal New Zealand College of General Practitioners: Online.
203. Heath, S. *Balancing Patient Portal Privacy and Access for Pediatric Care*. 2017 [cited 2022 20 March]; Available from: https://patientengagementhit.com/features/balancing-patient-portal-privacy-and-access-for-pediatric-care.
204. Osborn, C.Y., et al., *MyHealthAtVanderbilt: policies and procedures governing patient portal functionality.* Journal of the American Medical Informatics Association, 2011. **18**(Supplement_1): p. i18-i23.
205. Lee, J.A. and C. Holland-Hall, *Patient portals for the adolescent and young adult population: Benefits, risks and guidance for use.* Current Problems in Pediatric and Adolescent Health Care, 2021. **51**(11): p. 101101.
206. Huffman, T.P., S.J. Tracy, and R.S. Bisel, *Beautiful particularity: using phronetic, iterative, and heuristic approaches to a positively deviant case.* Communication Research and Practice, 2019. **5**(4): p. 327-341.
207. Fiks, A.G., et al., *A Shared e-Decision Support Portal for Pediatric Asthma.* The Journal of Ambulatory Care Management, 2014. **37**(2).
208. Mehta, S., T. Jamieson, and A.D. Ackery, *Helping clinicians and patients navigate electronic patient portals: ethical and legal principles.* Canadian Medical Association Journal, 2019. **191**(40): p. E1100.
209. Budd, J., et al., *Digital technologies in the public-health response to COVID-19.* Nature Medicine, 2020. **26**(8): p. 1183-1192.
210. Development Pathways. *Digital Transformation in the age of COVID-19*. 2020 [cited 2022 12 March]; Available from: https://www.developmentpathways.co.uk/news/digital-transformation-in-the-age-of-covid-19/.
211. O.Nyumba, T., et al., *The use of focus group discussion methodology: Insights from two decades of application in conservation.* Methods in Ecology and Evolution, 2018. **9**(1): p. 20-32.
212. Herrman, A.R., *The SAGE Encyclopedia of Communication Research Methods*, M. Allen, Editor. 2017: California
213. Krueger RA and M.A. Casey, *Focus Groups A Practical Guide for Applied Research*. 5th ed. 2014, London: Sage Publications, Inc. 280.
214. Parker, A. and J. Tritter, *Focus group method and methodology: current practice and recent debate.* International Journal of Research & Method in Education, 2006. **29**(1): p. 23-37.
215. Barbour, R.S., *Are focus groups an appropriate tool for studying organisational change?* , in *Developing Focus Group Research*, R.S. Barbour and J. Kitzinger, Editors. 2011, SAGE Publications Ltd: Online/London. p. 114-126.
216. Morgan, D.L. and R.A. Krueger, *When to use focus groups and why*, in *Successful Focus Groups: Advancing the State of the Art*, D.L. Morgan, Editor. 1993, SAGE Publications, Inc.: Thousand Oaks, California. p. 3-19.
217. Krueger, R.A., & Casey, M. A., *Focus groups: A practical guide for applied research*. 4th ed. 2009, California: Sage Publishing, Inc.,.
218. Krueger, R.A. *Designing and Conducting Focus Groups Interviews*. 2002.

219. Great Ormond Street Hospital for Children NHS Foundation Trust. *About the Clinical Ethics Service*. Available from: https://www.gosh.nhs.uk/wards-and-departments/departments/clinical-specialties/clinical-ethics-service-information-health-professionals/about-clinical-ethics-service/.
220. Byrne, D., *A worked example of Braun and Clarke's approach to reflexive thematic analysis.* Quality & Quantity, 2021.
221. Braun, V. and V. Clarke, *Reflecting on reflexive thematic analysis.* Qualitative Research in Sport, Exercise and Health, 2019. **11**(4): p. 589-597.
222. Pergert, P. and K. Lützén, *Balancing truth-telling in the preservation of hope: a relational ethics approach.* Nurs Ethics, 2012. **19**(1): p. 21-9.
223. Hudson, N., M. Spriggs, and L. Gillam, *Telling the truth to young children: Ethical reasons for information disclosure in paediatrics.* J Paediatr Child Health, 2019. **55**(1): p. 13-17.
224. Brady LM and B. Graham, *Social research with children and young people: A Practical Guide (Social Research Association Shorts)*. 2019, Bristol: Policy Press. 164.
225. Aldiss, S., et al., *Transition From Child to Adult Care – 'It's Not a One-Off Event': Development of Benchmarks to Improve the Experience.* Journal of Pediatric Nursing, 2015. **30**(5): p. 638-647.
226. Campbell, F., et al., *Transition of care for adolescents from paediatric services to adult health services.* Cochrane Database of Systematic Reviews, 2016(4).
227. Aldiss, S., et al., *Gathering expert opinion to inform benchmarks to support transitional care.* J Child Health Care, 2019. **23**(1): p. 131-146.
228. O'Keeffe, G.S., et al., *The Impact of Social Media on Children, Adolescents, and Families.* Pediatrics, 2011. **127**(4): p. 800-804.
229. Krasowski, M.D., et al., *Variation in Results Release and Patient Portal Access to Diagnostic Test Results at an Academic Medical Center.* Journal of pathology informatics, 2017. **8**: p. 45-45.
230. Wiles, J. and A. Kobayashi, *Equity*, in *International Encyclopedia of Human Geography*, R. Kitchin and N. Thrift, Editors. 2009, Elsevier: Oxford. p. 580-585.
231. Rawls, J., *A Theory of Justice: Revised Edition*. 1999: Harvard University Press.
232. *The Equality Act 2010 [Online]*, in *2010 c.15*, U.P.G. Acts, Editor. 2010, The National Archives: Online.
233. Hughes, O. *Reasonable adjustment flags to be integrated with patient record systems*. 2019 30th July 2021]; Available from: https://www.digitalhealth.net/2019/08/reasonable-adjustment-flags-to-be-integrated-with-patient-record-systems/.
234. United Nations, *Convention on the Rights of the Child*. 1989.
235. Preston, J., et al., *How to involve children and young people in what is, after all, their research.* Archives of Disease in Childhood, 2019. **104**(5): p. 494.
236. Department of Health and Social Care, *Report of the children and young people's health outcomes forum* 2012.
237. Johnson, V., *Moving beyond voice in children and young people's participation.* Action Research, 2017. **15**(1): p. 104-124.

238. Tariq, S. and J. Woodman, *Using mixed methods in health research.* JRSM short reports, 2013. **4**(6): p. 2042533313479197-2042533313479197.
239. Plano Clark, V.L., *The Adoption and Practice of Mixed Methods: U.S. Trends in Federally Funded Health-Related Research.* Qualitative Inquiry, 2010. **16**(6): p. 428-440.
240. Ivankova, N. and Y. Kawamura, *Emerging Trends in the Utilization of Integrated Designs in the Social, Behavioral, and Health Sciences*, in *SAGE Handbook of Mixed Methods in Social and Behavioral Research*, C.T. Abbas Tashakkori, Editor. 2010, SAGE Publications, Inc.: Thousand Oaks, California. p. 581-612.
241. O'Cathain, A., E. Murphy, and J. Nicholl, *Why, and how, mixed methods research is undertaken in health services research in England: a mixed methods study.* BMC Health Services Research, 2007. **7**(1): p. 85.
242. Johnson, R.E., A.L. Grove, and A. Clarke, *Pillar Integration Process: A Joint Display Technique to Integrate Data in Mixed Methods Research.* Journal of Mixed Methods Research, 2017. **13**(3): p. 301-320.
243. Creswell, J.W., et al., *Best Practices for Mixed Methods Research in the Health Sciences.* 2011: p. 1-39.
244. Stern, C., et al., *Methodological guidance for the conduct of mixed methods systematic reviews.* JBI Evid Synth, 2020. **18**(10): p. 2108-2118.
245. Creswell, J.W., *Research design: Qualitative, quantitative and mixed methods approaches*. 2nd ed. 2003, Thousand Oaks, CA: Sage.
246. El-Haddad, C., I. Hegazi, and W. Hu, *Understanding Patient Expectations of Health Care: A Qualitative Study.* Journal of Patient Experience, 2020. **7**(6): p. 1724-1731.
247. Lateef, F., *Patient expectations and the paradigm shift of care in emergency medicine.* Journal of emergencies, trauma, and shock, 2011. **4**(2): p. 163-167.
248. Bowers, M.R., J.E. Swan, and W.F. Koehler, *What attributes determine quality and satisfaction with health care delivery?* Health Care Manage Rev, 1994. **19**(4): p. 49-55.
249. O'Connor, S.J., R.M. Shewchuk, and M.R. Bowers, *A Model of Service Quality Perceptions and Health Care Consumer Behavior.* Journal of Hospital Marketing, 1992. **6**(1): p. 69-92.
250. Woodside, A.G., L.L. Frey, and R.T. Daly, *Linking service quality, customer satisfaction, and behavioral intention.* J Health Care Mark, 1989. **9**(4): p. 5-17.
251. Hulka, B.S., et al., *Communication, compliance, and concordance between physicians and patients with prescribed medications.* Am J Public Health, 1976. **66**(9): p. 847-53.
252. O'Connor, S.J., H.Q. Trinh, and R.M. Shewchuk, *Perceptual Gaps in Understanding Patient Expectations for Health Care Service Quality.* Health Care Management Review, 2000. **25**(2): p. 7-23.
253. Elbeck, M., *An approach to client satisfaction measurement as an attribute of health service quality.* Health Care Manage Rev, 1987. **12**(3): p. 47-52.
254. World Health Organization. *Young people and digital health interventions: working together to design better*. 2020 [cited 2022 19 March]; Available from: https://www.who.int/news/item/29-10-2020-

young-people-and-digital-health-interventions-working-together-to-design-better.

255. NHS Improvement, *The learning disability improvement standards for NHS trusts*. 2018: Online.

256. Goodman, K.W., *Ethics, Information Technology, and Public Health: New Challenges for the Clinician-Patient Relationship.* Journal of Law, Medicine & Ethics, 2010. **38**(1): p. 58-63.

257. Bowling, A., G. Rowe, and M. McKee, *Patients' experiences of their healthcare in relation to their expectations and satisfaction: a population survey.* Journal of the Royal Society of Medicine, 2013. **106**(4): p. 143-149.

258. Clark, N.M., et al., *The Clinician-Patient Partnership Paradigm: Outcomes Associated With Physician Communication Behavior.* Clinical Pediatrics, 2007. **47**(1): p. 49-57.

259. Cadwgan, J., et al., *Care in COVID: A qualitative analysis of the impact of COVID-19 on the health and care of children and young people with severe physical neurodisability and their families.* Child: Care, Health and Development. **n/a**(n/a).

260. Kumar, N., et al. *Ethical review of the impact of changes in services on children during the first wave of the COVID-19 pandemic*. in *Institute of Medical Ethics Student Conference* 2021. Online (poster presentation): Institute of Medical Ethics.

261. Crawley, E., et al., *Wider collateral damage to children in the UK because of the social distancing measures designed to reduce the impact of COVID-19 in adults.* BMJ paediatrics open, 2020. **4**(1): p. e000701-e000701.

262. Garstang, J., et al., *Effect of COVID-19 lockdown on child protection medical assessments: a retrospective observational study in Birmingham, UK.* BMJ Open, 2020. **10**(9): p. e042867.

263. Department of Health, *Compassion in Practice.* 2012.

264. Leonard, M., S. Graham, and D. Bonacum, *The human factor: the critical importance of effective teamwork and communication in providing safe care.* Quality and Safety in Health Care, 2004. **13**(suppl 1): p. i85.

265. André, B. and E. Sjøvold, *What characterizes the work culture at a hospital unit that successfully implements change – a correlation study.* BMC Health Services Research, 2017. **17**(1): p. 486.

266. O'Connell, C., *A Culture of Change or a Change of Culture?* Nursing Administration Quarterly, 1999. **23**(2).

267. Nakagawa, K. and P. Yellowlees, *Inter-generational Effects of Technology: Why Millennial Physicians May Be Less at Risk for Burnout Than Baby Boomers.* Current Psychiatry Reports, 2020. **22**(9): p. 45.

268. Ryan, N., et al., *Top‐down organizational change in an Australian Government agency.* International Journal of Public Sector Management, 2008. **21**(1): p. 26-44.

269. Layte, R. and C. McCrory, *Paediatric chronic illness and educational failure: the role of emotional and behavioural problems.* Social Psychiatry and Psychiatric Epidemiology, 2013. **48**(8): p. 1307-1316.

270. Hopkins, L., et al., *Staying engaged: the role of teachers and schools in keeping young people with health conditions engaged in education.* The Australian Educational Researcher, 2014. **41**(1): p. 25-41.

271. Kim, B. and K. White, *How can health professionals enhance interpersonal communication with adolescents and young adults to improve health care outcomes?: systematic literature review.* International Journal of Adolescence and Youth, 2018. **23**(2): p. 198-218.
272. Taylor, R.M., F. Gibson, and L.S. Franck, *The experience of living with a chronic illness during adolescence: a critical review of the literature.* Journal of Clinical Nursing, 2008. **17**(23): p. 3083-3091.
273. Spencer, J.E., H.C. Cooper, and B. Milton, *The lived experiences of young people (13–16 years) with Type 1 diabetes mellitus and their parents – a qualitative phenomenological study.* Diabetic Medicine, 2013. **30**(1): p. e17-e24.
274. Lambert, V. and D. Keogh, *Striving to Live a Normal Life: A Review of Children and Young People's Experience of Feeling Different when Living with a Long Term Condition.* Journal of Pediatric Nursing, 2015. **30**(1): p. 63-77.
275. Lloyds Banking Group, *Essential Digital Skills Report 2021: Benchmarking the Essential Digital Skills of the UK*. 2021: Online. p. 79.
276. Department for Education, *Essential digital skills framework*. 2019, DoE: Online.
277. NHS Digital. *NHS Digital extends programme to widen participation in digital health*. 2017 [cited 2022 12 March]; Available from: https://digital.nhs.uk/news/news-archive/2017-news-archive/nhs-digital-extends-programme-to-widen-participation-in-digital-health.
278. Marsay, S., *DCB1605 Accessible Information: Specification v1.1*. 2017, NHS England: Online.
279. Child Law Advice. *Access to information*. n.d.; Available from: https://childlawadvice.org.uk/information-pages/access-to-information/.
280. Kerr, H., *Best practice in the transition to adult services for young adults who had childhood cancer.* Cancer Nursing Practice, 2021.
281. Great Ormond Street Hospital. *Growing up, gaining independence*. n.d.; Available from: https://www.gosh.nhs.uk/your-hospital-visit/growing-gaining-independence/.
282. Association for Young People's Health, *NHS Digital Strategy Consultation*. 2016, Association for Young People's Health: Online.
283. Royal College of Paediatrics and Child Health. *Health transition resources*. n.d.; Available from: https://www.rcpch.ac.uk/resources/health-transition-resources.
284. Allende-Richter, S., et al., *Assessment of: self-management skills towards transition readiness and patient portal use among Hispanic adolescent and young adult patients.* BMJ Paediatrics Open, 2020. **4**(1): p. e000658.
285. Great Ormond Street Hospital Children's Charity. *Experience Great Ormond Street Hospital with virtual reality*. n.d.; Available from: https://www.gosh.org/what-we-do/rebuilding-and-refurbishment/experience-great-ormond-street-hospital-virtual-reality/.
286. National Autistic Society. *Social stories and comic strip conversations*. 2022; Available from: https://www.autism.org.uk/advice-and-guidance/topics/communication/communication-tools/social-stories-and-comic-strip-coversations.
287. Owens, K., *EMR Implementation: Big Bang or Phased Approach?* The Journal of Medical Practice Management, 2008. **23**(5): p. 279-81.

288. Garcia de Avila, M.A., et al., *How parents share and limit their child's access to information about COVID-19: A mixed methods online survey study.* Journal of Child Health Care, 2021: p. 13674935211046724.

289. Tomlin, J., B. Dalgleish-Warburton, and G. Lamph, *Psychosocial Support for Healthcare Workers During the COVID-19 Pandemic.* Frontiers in Psychology, 2020. **11**(1960).

290. Royal College of Nursing. *RCN Guidance On Redeployment - COVID-19*. 2020 7th November 2021]; Available from: https://www.rcn.org.uk/clinical-topics/infection-prevention-and-control/novel-coronavirus/rcn-guidance-on-redeployment-covid-19.

291. Selman, L.E., et al., *Bereavement Support on the Frontline of COVID-19: Recommendations for Hospital Clinicians.* Journal of Pain and Symptom Management, 2020. **60**(2): p. e81-e86.

292. Wallace, C.L., et al., *Grief During the COVID-19 Pandemic: Considerations for Palliative Care Providers.* Journal of Pain and Symptom Management, 2020. **60**(1): p. e70-e76.

293. Froessl, L.J. and Y. Abdeen, *The Silent Pandemic: The Psychological Burden on Frontline Healthcare Workers during COVID-19.* Psychiatry Journal, 2021. **2021**: p. 2906785.

294. Koontalay A, et al., *Healthcare Workers' Burdens During the COVID-19 Pandemic: A Qualitative Systematic Review.* J Multidiscip Healthc., 2021. **14**: p. 3015-3025.

295. Sipanoun, P., *130 Going digital – the implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications.* Archives of Disease in Childhood, 2018. **103**(Suppl 2): p. A52.

296. Sipanoun, P., et al., *4 The going digital study: ethical and legal considerations of young people accessing their digital health data – young people's perspectives.* Archives of Disease in Childhood, 2019. **104**(Suppl 4): p. A2.

297. Sipanoun, P., et al. *Young People and Their Parents Accessing Their Digital Health Data via a Patient Portal: The Ethical and Legal Implications*. in *ICDH 2021: International Conference on Digital Healthcare*. 2021. Online: World Academy of Science, Engineering and Technology: International Journal of Medical and Health Sciences.

298. Sipanoun, P., et al., *96 The going digital study: the views and perceptions of children and young people, parents, and staff before and after electronic patient record implementation – trust-wide survey findings.* Archives of Disease in Childhood, 2021. **106**(Suppl 3): p. A36.

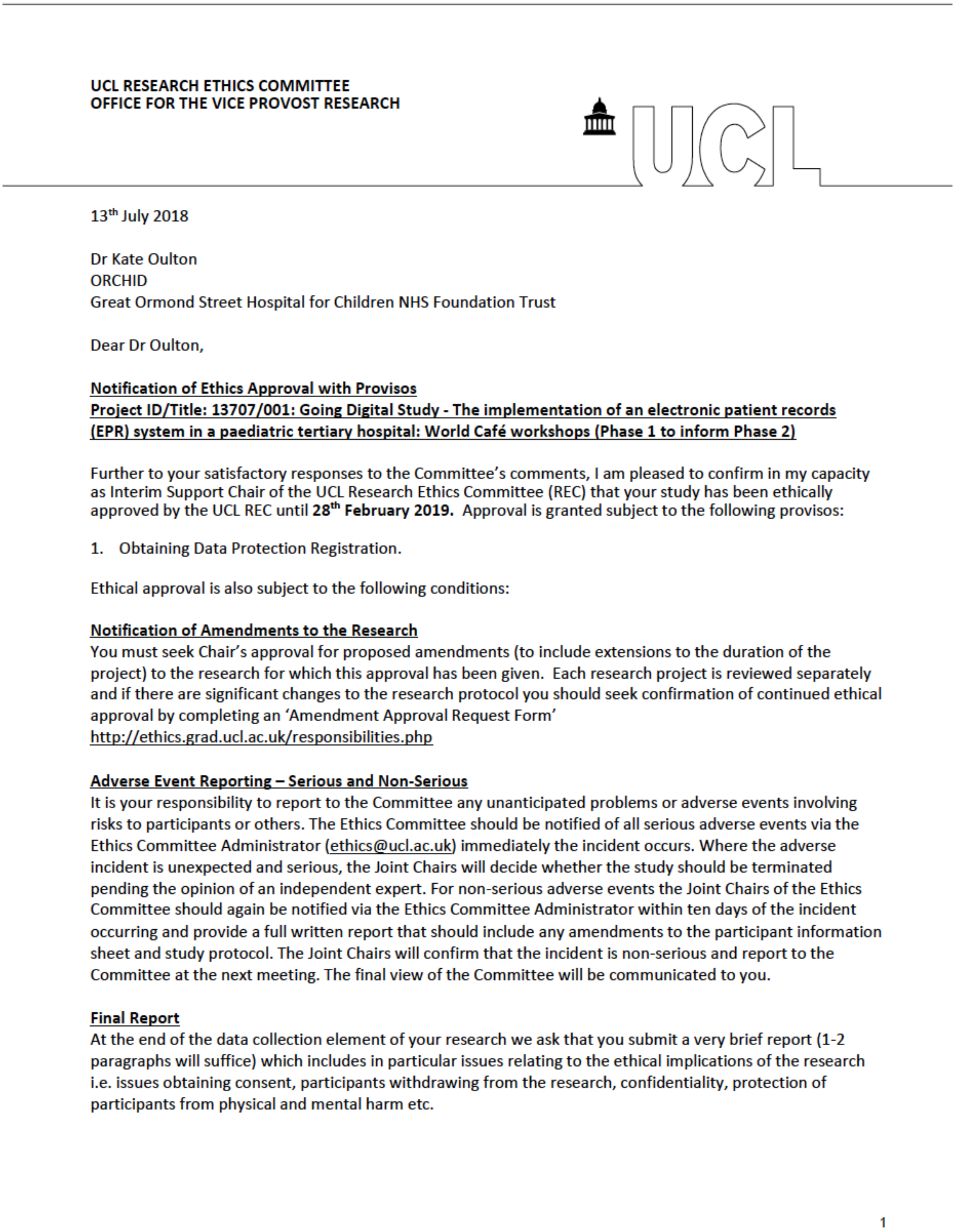
299. Carroll, W.D., et al., *European and United Kingdom COVID-19 pandemic experience: The same but different.* Paediatric Respiratory Reviews, 2020. **35**: p. 50-56.

300. Holt, L. and L. Murray, *Children and Covid 19 in the UK.* Children's Geographies, 2021: p. 1-8.

301. Field MJ, Behrman RE, and Institute of Medicine (US) Committee on Clinical Research Involving Children, *Understanding and Agreeing to Children's Participation in Clinical Research*, in *Ethical Conduct of Clinical Research Involving Children*, F. MJ and B. RE, Editors. 2004, National Academies Press (US): Washington (DC).

302. Miller, V.A., C. Feudtner, and A.F. Jawad, *Children's Decision-Making Involvement About Research Participation: Associations With Perceived Fairness and Self-Efficacy.* Journal of empirical research on human research ethics : JERHRE, 2017. **12**(2): p. 87-96.
303. Authority, H.R. *Research Involving Children*. 2018 1 June 2021]; Available from: https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/research-involving-children/.
304. Mann, D.M., et al., *COVID-19 transforms health care through telemedicine: Evidence from the field.* Journal of the American Medical Informatics Association, 2020. **27**(7): p. 1132-1135.
305. Great Ormond Street Hospital for Children NHS Foundation Trust, *Our Always Values*, Great Ormond Street Hospital for Children NHS Foundation Trust, Editor.
306. Vitae. *The Vitae Researcher Development Framework*. 2010; Available from: https://www.vitae.ac.uk/researchers-professional-development/about-the-vitae-researcher-development-framework/developing-the-vitae-researcher-development-framework.
307. Livermore, P., et al., *69 'The importance of peer-support for clinical academics at great ormond street children's hospital'.* Archives of Disease in Childhood, 2020. **105**(Suppl 2): p. A24.
308. Coghlan, N., et al., *COVID-19: legal implications for critical care.* Anaesthesia, 2020. **75**(11): p. 1517-1528.
309. Sunil Kumar, N., et al., *North Thames multi-centre service evaluation: Ethical considerations during COVID-19.* Clinical Ethics, 2021: p. 14777509211063590.
310. Kumar, N.S., et al., *47 Ethical review of the impact of changes to healthcare services on children and young people during the first wave of the coronavirus disease 2019 (COVID-19) pandemic.* Archives of Disease in Childhood, 2021. **106**(Suppl 3): p. A18.

Appendix 1 – Ethical approval for phase one (staff)



UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

13th July 2018

Dr Kate Oulton
ORCHID
Great Ormond Street Hospital for Children NHS Foundation Trust

Dear Dr Oulton,

Notification of Ethics Approval with Provisos
Project ID/Title: 13707/001: Going Digital Study - The implementation of an electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshops (Phase 1 to inform Phase 2)

Further to your satisfactory responses to the Committee's comments, I am pleased to confirm in my capacity as Interim Support Chair of the UCL Research Ethics Committee (REC) that your study has been ethically approved by the UCL REC until **28th February 2019.** Approval is granted subject to the following provisos:

1. Obtaining Data Protection Registration.

Ethical approval is also subject to the following conditions:

Notification of Amendments to the Research
You must seek Chair's approval for proposed amendments (to include extensions to the duration of the project) to the research for which this approval has been given. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing an 'Amendment Approval Request Form'
http://ethics.grad.ucl.ac.uk/responsibilities.php

Adverse Event Reporting – Serious and Non-Serious
It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Joint Chairs will decide whether the study should be terminated pending the opinion of an independent expert. For non-serious adverse events the Joint Chairs of the Ethics Committee should again be notified via the Ethics Committee Administrator within ten days of the incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Joint Chairs will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Final Report
At the end of the data collection element of your research we ask that you submit a very brief report (1-2 paragraphs will suffice) which includes in particular issues relating to the ethical implications of the research i.e. issues obtaining consent, participants withdrawing from the research, confidentiality, protection of participants from physical and mental harm etc.

In addition, please:

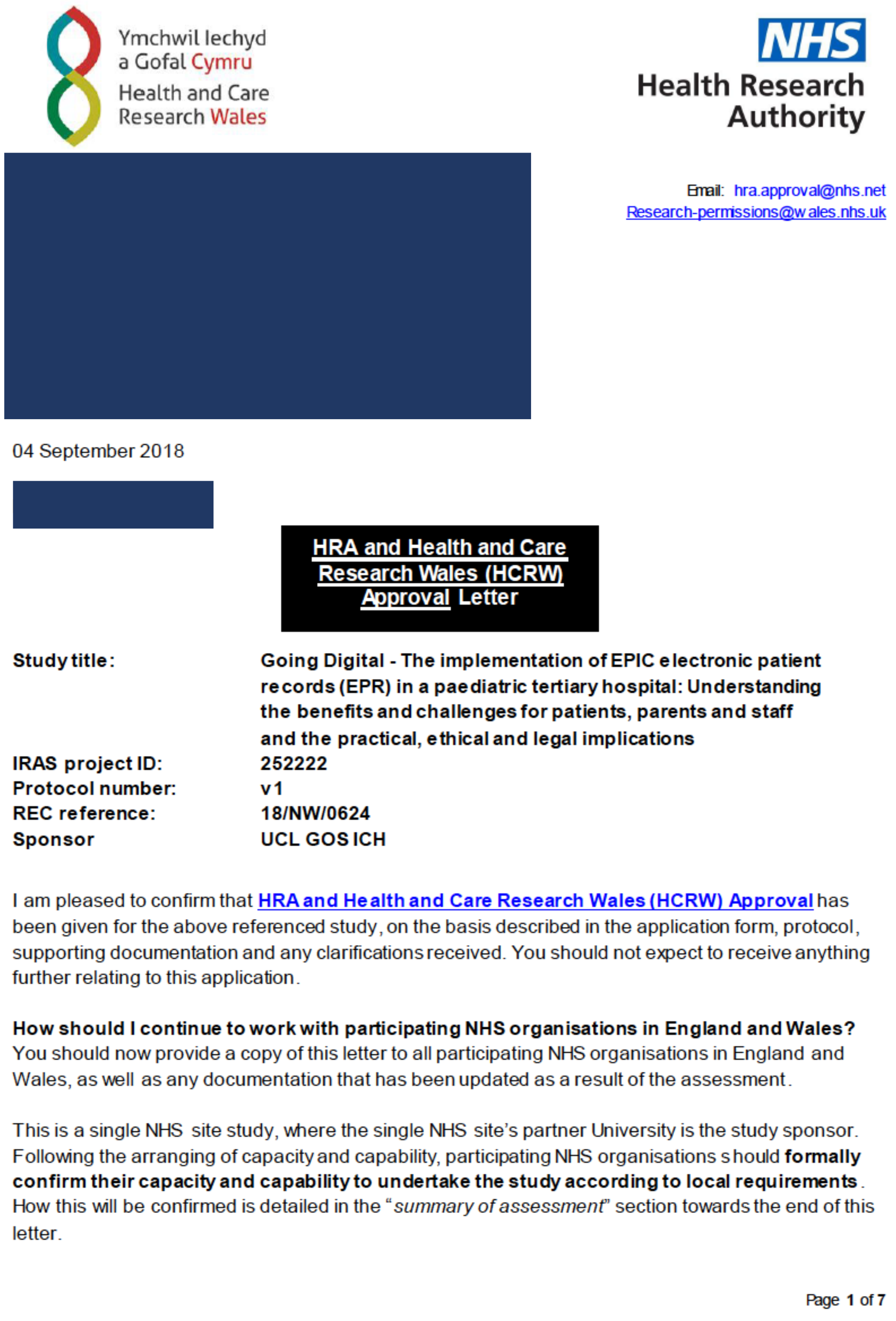
- ensure that you follow all relevant guidance as laid out in UCL's Code of Conduct for Research: http://www.ucl.ac.uk/srs/governance-and-committees/resgov/code-of-conduct-research
- note that you are required to adhere to all research data/records management and storage procedures agreed as part of your application. This will be expected even after completion of the study.

With best wishes for the research.

Yours sincerely,

[redacted]

Appendix 2 – Ethical approval for phase one (young people/parents)



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

[redacted]

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

04 September 2018

[redacted]

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Going Digital - The implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications**
IRAS project ID:	**252222**
Protocol number:	**v1**
REC reference:	**18/NW/0624**
Sponsor	**UCL GOS ICH**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

This is a single NHS site study, where the single NHS site's partner University is the study sponsor. Following the arranging of capacity and capability, participating NHS organisations should **formally confirm their capacity and capability to undertake the study according to local requirements**. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

[redacted]

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of advertisement materials for research participants [World Cafe guidelines poster]	1	27 July 2018
Copies of advertisement materials for research participants [World Cafe Poster]	1	27 July 2018
Covering letter on headed paper [Cover Letter]		08 August 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of UCL Indemnity Insurance]		25 July 2018
Interview schedules or topic guides for participants [World Cafe Topic Guide]	1	27 July 2018
IRAS Application Form [IRAS_Form_10082018]		10 August 2018
Letter from funder [Confirmation of Funds]	1	07 August 2018
Letters of invitation to participant [EPR Parent Draft e-mail]	1	27 July 2018
Letters of invitation to participant [Parent draft e-mail]	1	27 July 2018
Letters of invitation to participant [Parent draft e-mail YPF]	1	27 July 2018
Letters of invitation to participant [YPF Member draft e-mail]	1	27 July 2018
Letters of invitation to participant [Letter to parent of YPF member (to go in pack]	1	27 July 2018
Participant consent form [Parent/Carer Consent form]	1	27 July 2018
Participant consent form [Parent/Carer Consent form for child]	1	27 July 2018
Participant consent form [CYP Assent word and pictures age 10-15]	1	27 July 2018
Participant consent form [YP Consent form 16 years and above]	1	27 July 2018
Participant information sheet (PIS) [1) EPR Parent Carer Information Sheet WCW IRAS 252222 v1]	1	27 July 2018
Participant information sheet (PIS) [2) EPR Parent Carer Information Sheet re Child WCW IRAS 252222 v1]	1	27 June 2018
Participant information sheet (PIS) [4) EPR YP Information Sheet 16 years and above WCW IRAS 252222 v1]	1	27 July 2018
Participant information sheet (PIS) [CYP PIS age 10-15]	1	27 July 2018
Research protocol or project proposal [Protocol]	1	10 August 2018
Summary CV for Chief Investigator (CI) [CI CV]	1	27 July 2018
Summary CV for supervisor (student research) [Supervisor CV]		

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	No study agreements are needed as this is a single NHS site study where the single NHS site's partner University is the study sponsor.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	Funding has been secured by Great Ormond Street Hospital for Children NHS Foundation Trust
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion	Yes	No comments

IRAS project ID	**252222**

Section	Assessment Criteria	Compliant with Standards	Comments
	received for applicable studies		
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.
There is one site type. This is a single site study where the single site's partner University is the study sponsor. The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence. If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

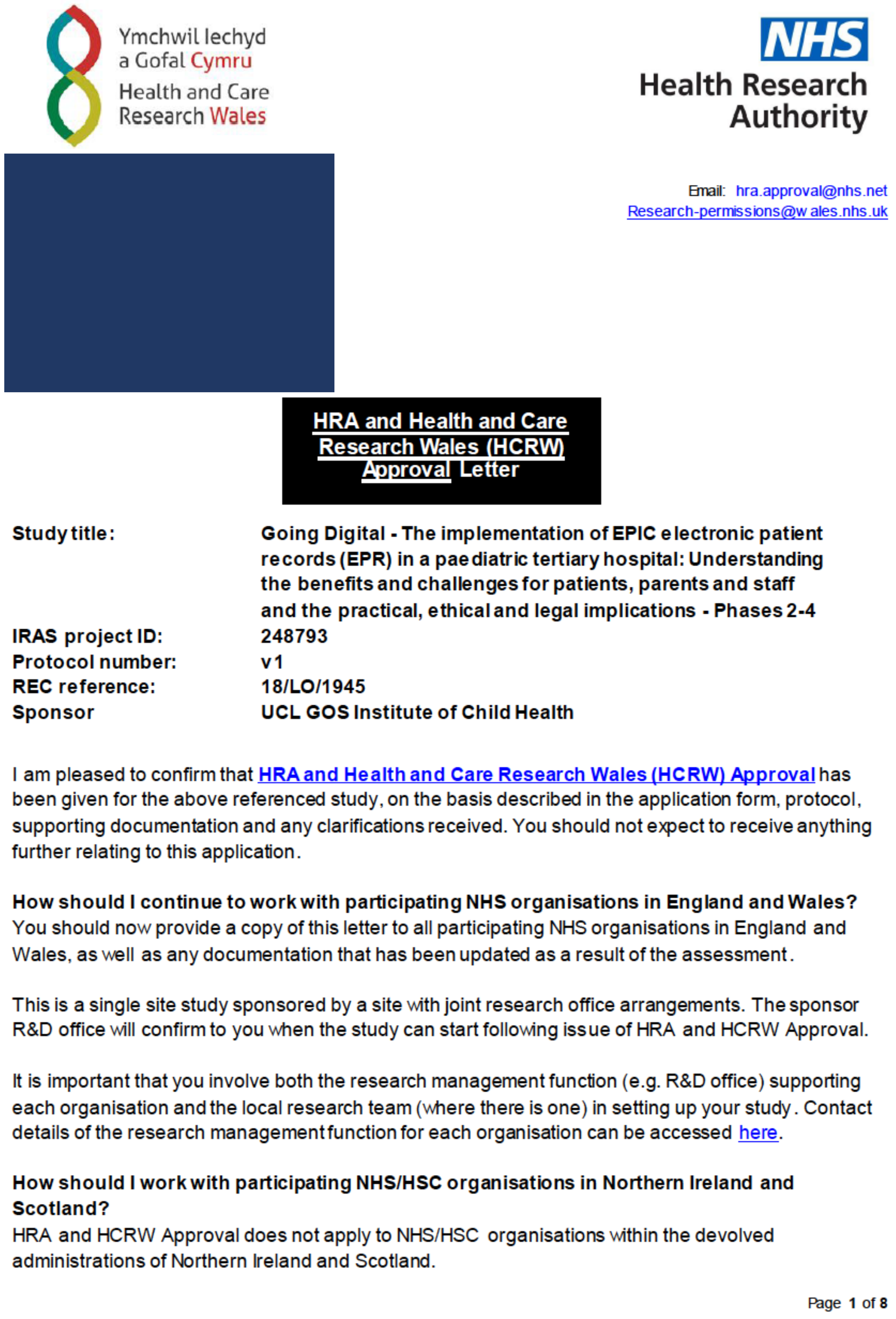
Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).
A Principal Investigator should be identified at the site. GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks

Appendix 3 – Ethical approval for phases two to four



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

[redacted]

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Going Digital - The implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications - Phases 2-4**
IRAS project ID:	**248793**
Protocol number:	**v1**
REC reference:	**18/LO/1945**
Sponsor	**UCL GOS Institute of Child Health**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

This is a single site study sponsored by a site with joint research office arrangements. The sponsor R&D office will confirm to you when the study can start following issue of HRA and HCRW Approval.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed here.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

Page **1** of **8**

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?
The document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?
You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

[redacted]

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **248793**. Please quote this on all correspondence.

[redacted]

Email: hra.approval@nhs.net

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [HRA Ethical Approval Letter for IRAS ID 252222]	1	04 September 2018
Confirmation of any other Regulatory Approvals (e.g. CAG) and all correspondence [Phase 1 UCL REC Approval]	1	13 July 2018
Contract/Study Agreement template [Signed Information Sharing Protocol with Take-Note Typing]	1	
Copies of advertisement materials for research participants [Phase 2 Staff Newsletter Excerpt]	1	03 October 2018
Copies of advertisement materials for research participants [Phase 2 Staff Poster v1 248793]	1	09 October 2018
Copies of advertisement materials for research participants [Phase 3 Newsletter Excerpts]	1	26 September 2018
Copies of advertisement materials for research participants [Phase 3 Staff Poster v1 248793]	1	09 October 2018
Covering letter on headed paper [Cover Letter]	1	03 October 2018
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Evidence of Sponsor Indemnity Insurance]	1	25 July 2018
IRAS Application Form [IRAS_Form_12102018]		12 October 2018
Letter from funder [Letter from funder]	1	07 August 2018
Letters of invitation to participant [Going Digital parent sample e-mail invitiation A]	1	10 October 2018
Letters of invitation to participant [Going Digital study parent sample e-mail B]	1	10 October 2018
Letters of invitation to participant [Going Digital study sample parent letter of invitation for interviews A]	1	10 October 2018
Letters of invitation to participant [Going Digital Study Parent letter of invitation for interview B]	1	10 October 2018
Letters of invitation to participant [Going Digital study staff sample e-mail invitation A]	1	10 October 2018
Letters of invitation to participant [Going Digital study staff e-mail invitation B]	1	10 October 2018
Non-validated questionnaire [Going Digital Study Phase 2 Staff Survey]	1	11 January 2019
Non-validated questionnaire [Going Digital Study Phase 2 CYP Survey]	1	11 January 2019
Non-validated questionnaire [Going Digital Study Phase 2 Parent Survey]	1	11 January 2019
Other [Research Assessment Panel Peer Review]	1	17 September 2018
Other [Validation Clarifications]		19 October 2018
Participant consent form [Phase 3 CYP Assent Form]	1	26 September 2018
Participant consent form [Phase 3 YP 16 years and above Consent Form]	1	26 September 2018
Participant consent form [Phase 2 Staff Consent Form]	1	26 September 2018
Participant consent form [Phase 2 Parent/Carer Consent Form]	1	26 September 2018
Participant consent form [Phase 2 Parent/Carer re Child Consent Form]	1	26 September 2018
Participant consent form [Phase 2 CYP Assent Form]	1	26 September 2018

Participant consent form [Phase 2 YP Consent Form 16 years and above]	1	26 September 2018
Participant consent form [Phase 3 Staff Consent Form]	1	26 September 2018
Participant consent form [Phase 3 Parent/Carer Consent Form]	1	26 September 2018
Participant information sheet (PIS) [Phase 2 Staff PIS]	2	20 December 2018
Participant information sheet (PIS) [Phase 2 Parent/Carer PIS]	2	20 December 2018
Participant information sheet (PIS) [Phase 2 Parent/|Carer re Child PIS]	2	20 December 2018
Participant information sheet (PIS) [Phase 2 CYP PIS 12-15 years]	2	20 December 2018
Participant information sheet (PIS) [Phase 2 YP PIS 16 years and above]	2	20 December 2018
Participant information sheet (PIS) [Phase 3 Staff PIS]	2	20 December 2018
Participant information sheet (PIS) [Phase 3 Parent/Carer PIS]	2	20 December 2018
Participant information sheet (PIS) [Phase 3 CYP 12-15 PIS]	2	20 December 2018
Participant information sheet (PIS) [Phase 3 YP 16 and above PIS]	2	20 December 2018
Research protocol or project proposal	2	20 December 2018
Summary CV for Chief Investigator (CI) [CV Philippa Sipanoun]	1	03 October 2018
Summary CV for supervisor (student research) [Primary Academic Supervisor CV]	1	03 October 2018
Summary CV for supervisor (student research) [Academic Supervisor CV]	1	30 August 2018
Summary CV for supervisor (student research) [Academic Supervisor CV]	1	04 October 2018
Summary, synopsis or diagram (flowchart) of protocol in non technical language [Going Digital Mixed Methods Plan]	1	08 October 2018

IRAS project ID	248793

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	Joint research office arrangements in place, no additional agreements expected.
4.2	Insurance/indemnity arrangements assessed	Yes	No comments
4.3	Financial arrangements assessed	Yes	Funding has been secured from Great Ormond Street Hospital for Children NHS Foundation Trust as part of an educational award.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments

Section	Assessment Criteria	Compliant with Standards	Comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

Participating NHS organisations will conduct all study activities as per protocol.

If this study is subsequently extended to other NHS organisation(s) in England or Wales, an amendment should be submitted, with a Statement of Activities and Schedule of Events for the newly participating NHS organisation(s) in England or Wales.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

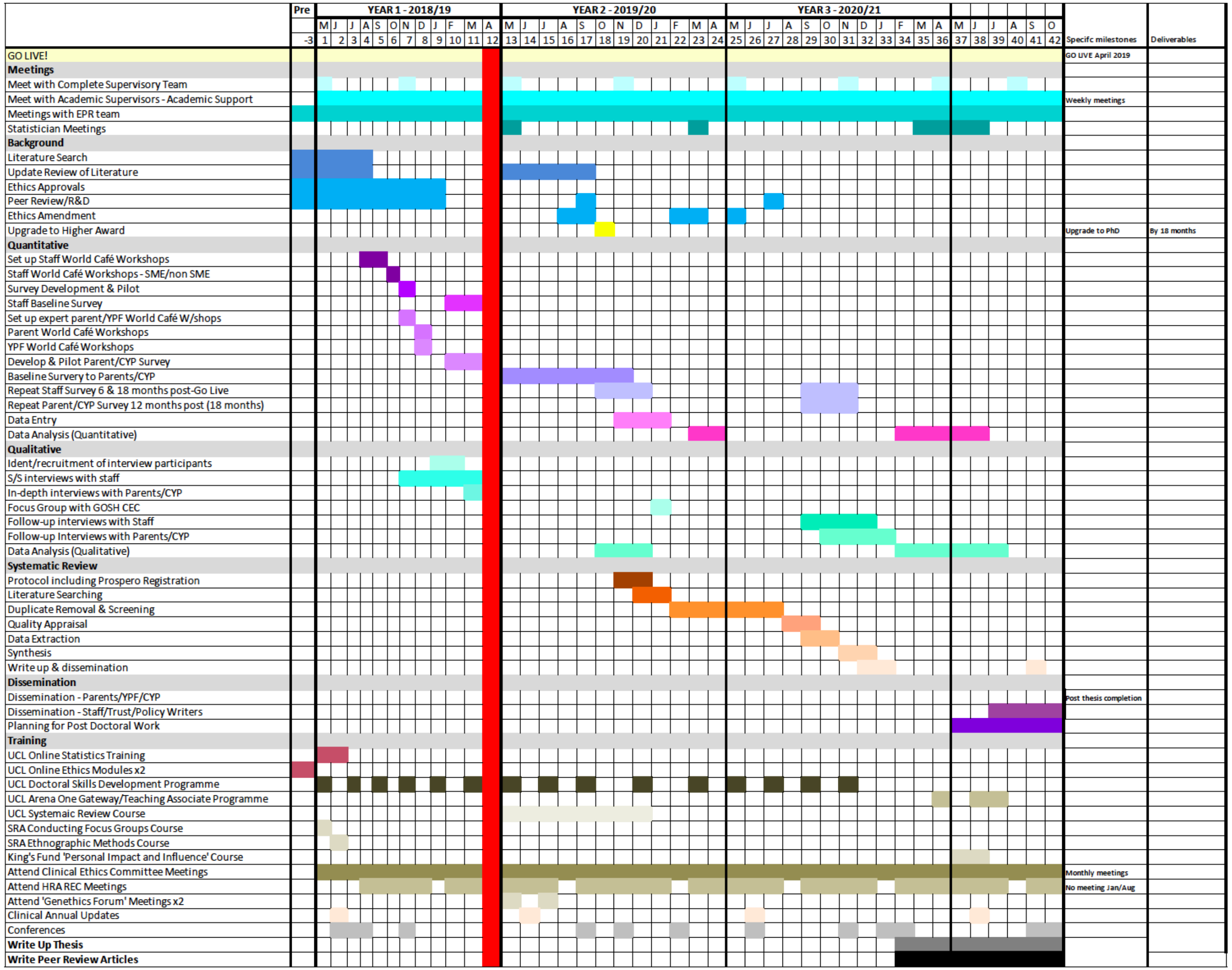
Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).

A PI is expected at participating NHS organisations.

GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

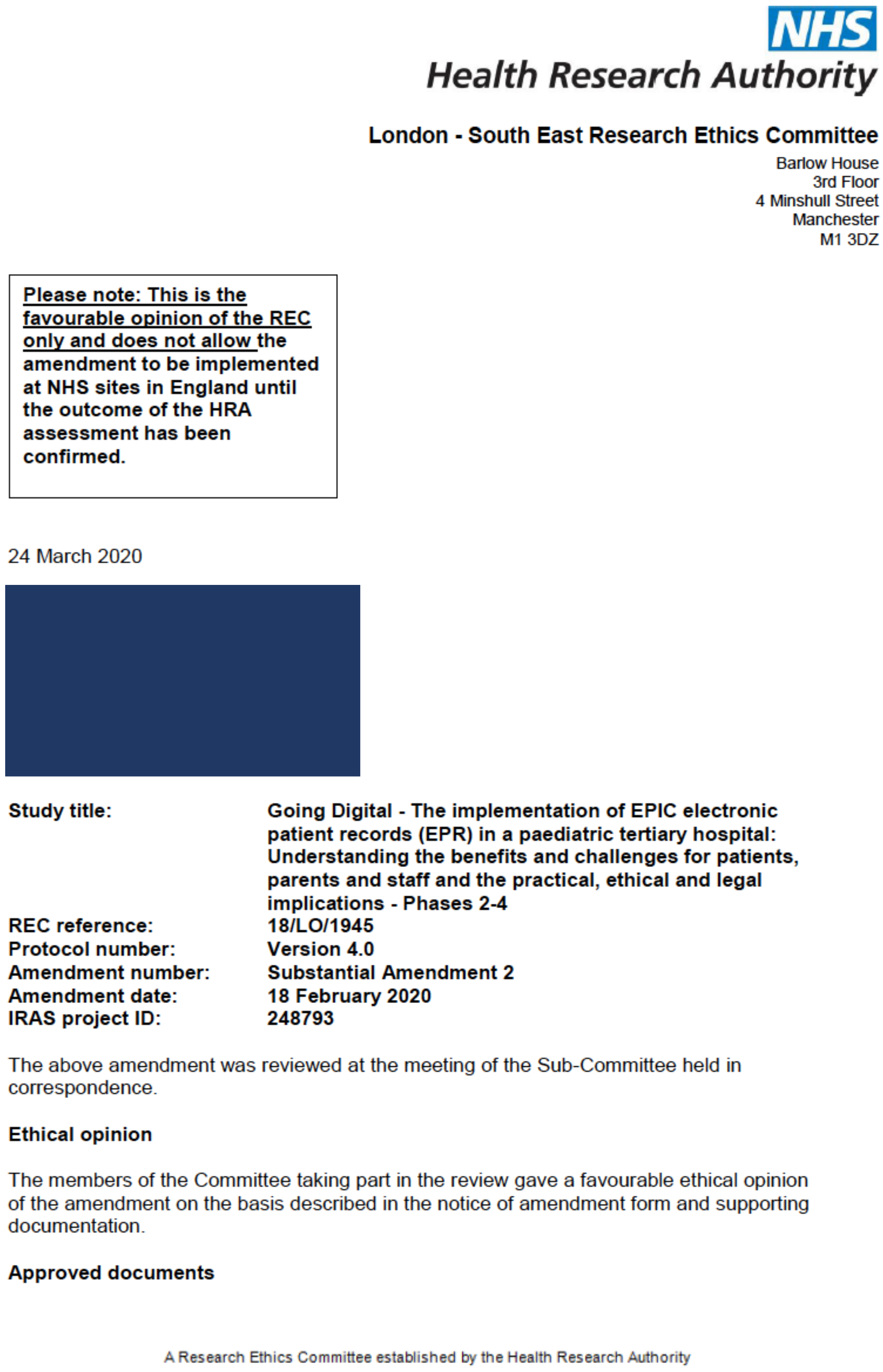
Appendix 4 – Study Gantt chart



Pre | YEAR 1 - 2018/19 | YEAR 2 - 2019/20 | YEAR 3 - 2020/21

	Specifc milestones	Deliverables
GO LIVE!	GO LIVE April 2019	
Meetings		
Meet with Complete Supervisory Team		
Meet with Academic Supervisors - Academic Support	Weekly meetings	
Meetings with EPR team		
Statistician Meetings		
Background		
Literature Search		
Update Review of Literature		
Ethics Approvals		
Peer Review/R&D		
Ethics Amendment		
Upgrade to Higher Award	Upgrade to PhD	By 18 months
Quantitative		
Set up Staff World Café Workshops		
Staff World Café Workshops - SME/non SME		
Survey Development & Pilot		
Staff Baseline Survey		
Set up expert parent/YPF World Café W/shops		
Parent World Café Workshops		
YPF World Café Workshops		
Develop & Pilot Parent/CYP Survey		
Baseline Survery to Parents/CYP		
Repeat Staff Survey 6 & 18 months post-Go Live		
Repeat Parent/CYP Survey 12 months post (18 months)		
Data Entry		
Data Analysis (Quantitative)		
Qualitative		
Ident/recruitment of interview participants		
S/S interviews with staff		
In-depth interviews with Parents/CYP		
Focus Group with GOSH CEC		
Follow-up interviews with Staff		
Follow-up Interviews with Parents/CYP		
Data Analysis (Qualitative)		
Systematic Review		
Protocol including Prospero Registration		
Literature Searching		
Duplicate Removal & Screening		
Quality Appraisal		
Data Extraction		
Synthesis		
Write up & dissemination		
Dissemination		
Dissemination - Parents/YPF/CYP	Post thesis completion	
Dissemination - Staff/Trust/Policy Writers		
Planning for Post Doctoral Work		
Training		
UCL Online Statistics Training		
UCL Online Ethics Modules x2		
UCL Doctoral Skills Development Programme		
UCL Arena One Gateway/Teaching Associate Programme		
UCL Systemaic Review Course		
SRA Conducting Focus Groups Course		
SRA Ethnographic Methods Course		
King's Fund 'Personal Impact and Influence' Course		
Attend Clinical Ethics Committee Meetings	Monthly meetings	
Attend HRA REC Meetings	No meeting Jan/Aug	
Attend 'Genethics Forum' Meetings x2		
Clinical Annual Updates		
Conferences		
Write Up Thesis		
Write Peer Review Articles		

Appendix 5 – Substantial amendment – virtual data collection



NHS
Health Research Authority

London - South East Research Ethics Committee

Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

24 March 2020

[redacted]

Study title:	**Going Digital - The implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications - Phases 2-4**
REC reference:	**18/LO/1945**
Protocol number:	**Version 4.0**
Amendment number:	**Substantial Amendment 2**
Amendment date:	**18 February 2020**
IRAS project ID:	**248793**

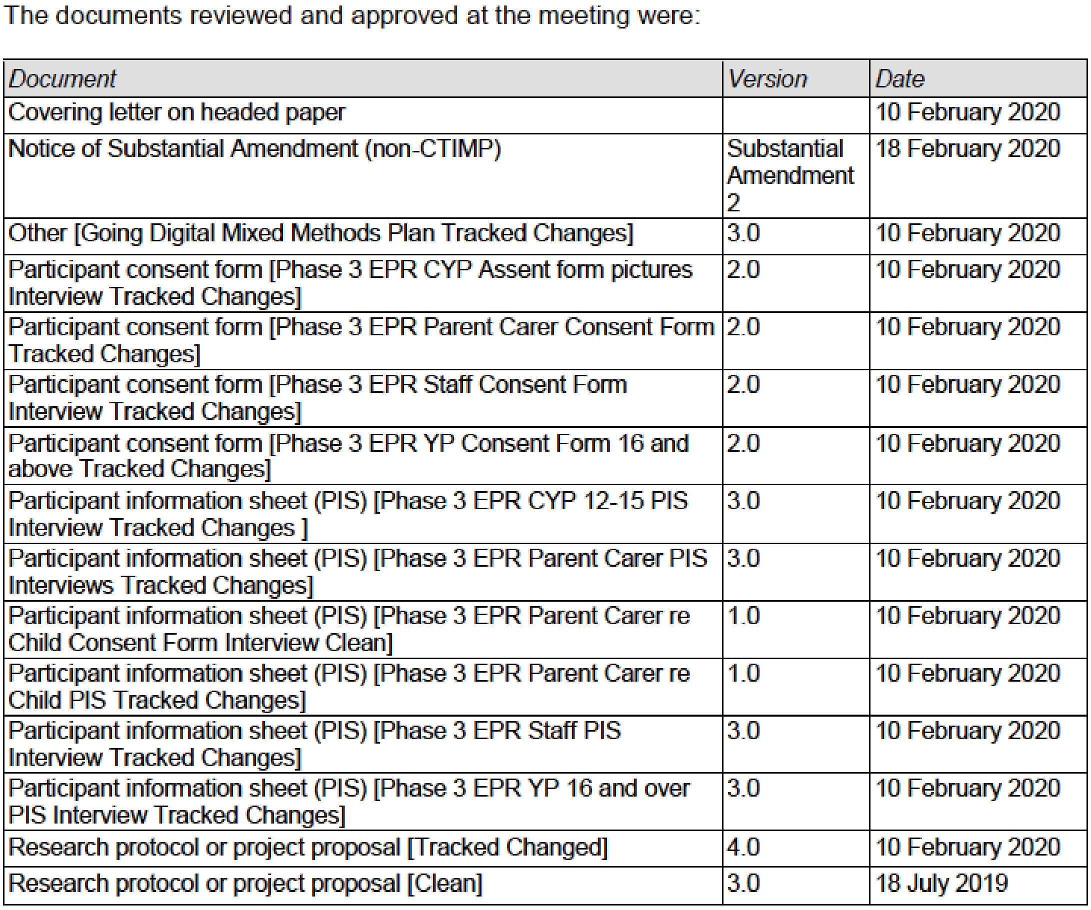
The above amendment was reviewed at the meeting of the Sub-Committee held in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

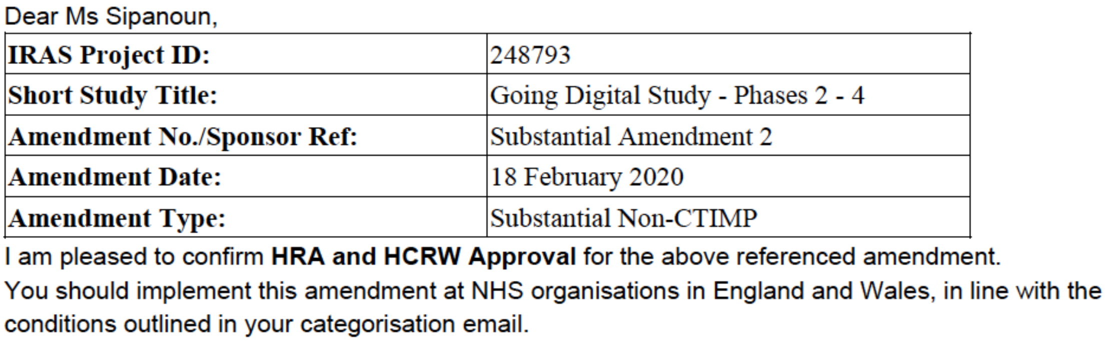
Approved documents

A Research Ethics Committee established by the Health Research Authority



The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering letter on headed paper		10 February 2020
Notice of Substantial Amendment (non-CTIMP)	Substantial Amendment 2	18 February 2020
Other [Going Digital Mixed Methods Plan Tracked Changes]	3.0	10 February 2020
Participant consent form [Phase 3 EPR CYP Assent form pictures Interview Tracked Changes]	2.0	10 February 2020
Participant consent form [Phase 3 EPR Parent Carer Consent Form Tracked Changes]	2.0	10 February 2020
Participant consent form [Phase 3 EPR Staff Consent Form Interview Tracked Changes]	2.0	10 February 2020
Participant consent form [Phase 3 EPR YP Consent Form 16 and above Tracked Changes]	2.0	10 February 2020
Participant information sheet (PIS) [Phase 3 EPR CYP 12-15 PIS Interview Tracked Changes]	3.0	10 February 2020
Participant information sheet (PIS) [Phase 3 EPR Parent Carer PIS Interviews Tracked Changes]	3.0	10 February 2020
Participant information sheet (PIS) [Phase 3 EPR Parent Carer re Child Consent Form Interview Clean]	1.0	10 February 2020
Participant information sheet (PIS) [Phase 3 EPR Parent Carer re Child PIS Tracked Changes]	1.0	10 February 2020
Participant information sheet (PIS) [Phase 3 EPR Staff PIS Interview Tracked Changes]	3.0	10 February 2020
Participant information sheet (PIS) [Phase 3 EPR YP 16 and over PIS Interview Tracked Changes]	3.0	10 February 2020
Research protocol or project proposal [Tracked Changed]	4.0	10 February 2020
Research protocol or project proposal [Clean]	3.0	18 July 2019



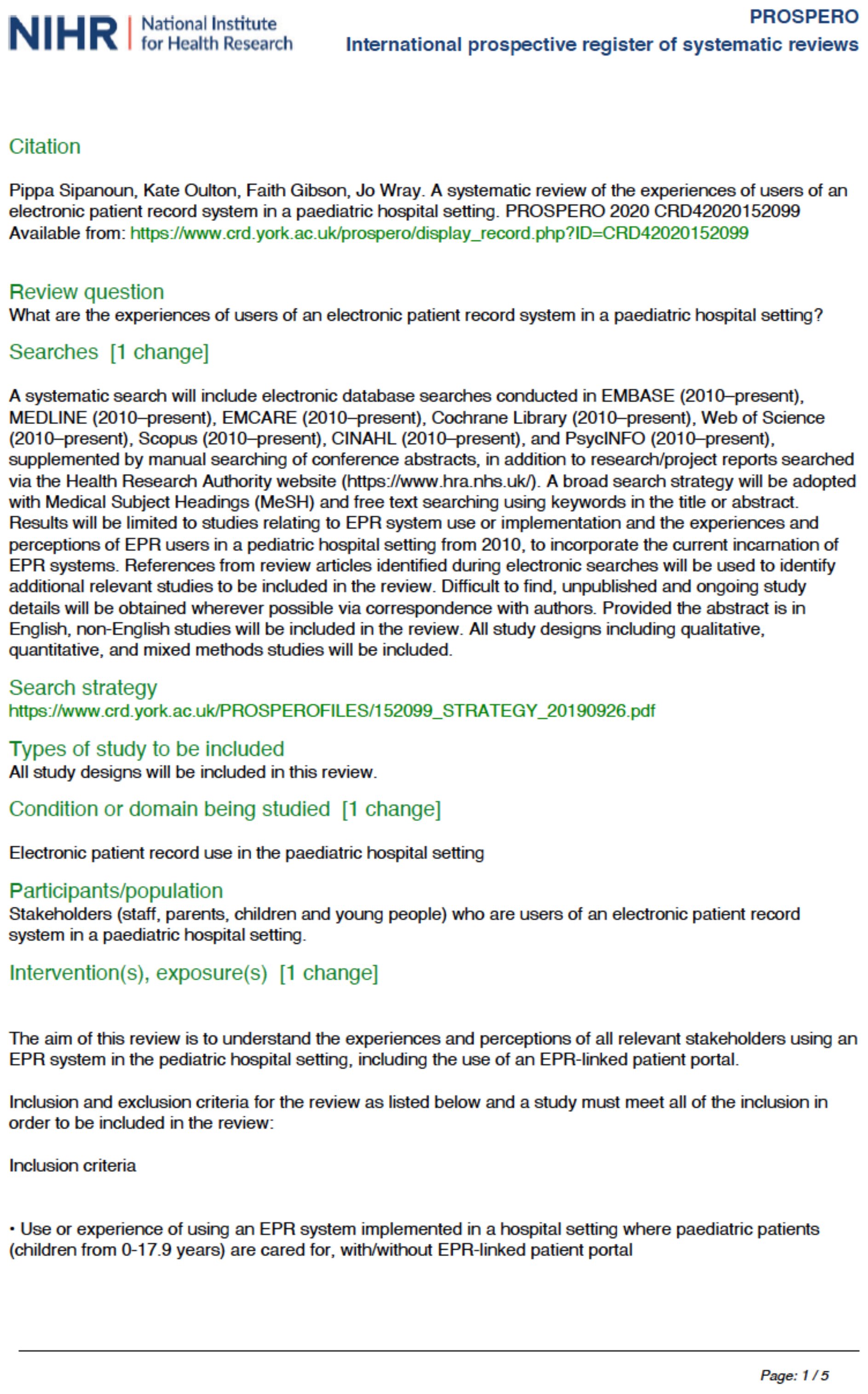
Dear Ms Sipanoun,

IRAS Project ID:	248793
Short Study Title:	Going Digital Study - Phases 2 - 4
Amendment No./Sponsor Ref:	Substantial Amendment 2
Amendment Date:	18 February 2020
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

Appendix 6 – PROSPERO registration of systematic review protocol



NIHR | National Institute for Health Research

PROSPERO
International prospective register of systematic reviews

Citation

Pippa Sipanoun, Kate Oulton, Faith Gibson, Jo Wray. A systematic review of the experiences of users of an electronic patient record system in a paediatric hospital setting. PROSPERO 2020 CRD42020152099 Available from: https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42020152099

Review question

What are the experiences of users of an electronic patient record system in a paediatric hospital setting?

Searches [1 change]

A systematic search will include electronic database searches conducted in EMBASE (2010–present), MEDLINE (2010–present), EMCARE (2010–present), Cochrane Library (2010–present), Web of Science (2010–present), Scopus (2010–present), CINAHL (2010–present), and PsycINFO (2010–present), supplemented by manual searching of conference abstracts, in addition to research/project reports searched via the Health Research Authority website (https://www.hra.nhs.uk/). A broad search strategy will be adopted with Medical Subject Headings (MeSH) and free text searching using keywords in the title or abstract. Results will be limited to studies relating to EPR system use or implementation and the experiences and perceptions of EPR users in a pediatric hospital setting from 2010, to incorporate the current incarnation of EPR systems. References from review articles identified during electronic searches will be used to identify additional relevant studies to be included in the review. Difficult to find, unpublished and ongoing study details will be obtained wherever possible via correspondence with authors. Provided the abstract is in English, non-English studies will be included in the review. All study designs including qualitative, quantitative, and mixed methods studies will be included.

Search strategy

https://www.crd.york.ac.uk/PROSPEROFILES/152099_STRATEGY_20190926.pdf

Types of study to be included

All study designs will be included in this review.

Condition or domain being studied [1 change]

Electronic patient record use in the paediatric hospital setting

Participants/population

Stakeholders (staff, parents, children and young people) who are users of an electronic patient record system in a paediatric hospital setting.

Intervention(s), exposure(s) [1 change]

The aim of this review is to understand the experiences and perceptions of all relevant stakeholders using an EPR system in the pediatric hospital setting, including the use of an EPR-linked patient portal.

Inclusion and exclusion criteria for the review as listed below and a study must meet all of the inclusion in order to be included in the review:

Inclusion criteria

• Use or experience of using an EPR system implemented in a hospital setting where paediatric patients (children from 0-17.9 years) are cared for, with/without EPR-linked patient portal

- Qualitative, quantitative, and mixed methods studies

Exclusion criteria

- Patient populations other than paediatrics e.g., exclusively adults

- Paediatric data could not be determined/not clearly specified

- Primary care setting

- Other out of hospital care e.g., community or hospice care

- No abstract

- Title or abstract not in English

- CPOE, CDS or medication management system only studies, EPR linkage/use not mentioned

(EPR – Electronic patient records; CDS – Clinical decision support; CPOE – Computerized physician order entry)

Comparator(s)/control

As the intervention is usually throughout the institution in which it is introduced, there is unlikely to be a comparison or control group. However, studies in which data have been collected before and after implementation of an electronic patient record system will be included.

Context [1 change]

All study designs conducted in the paediatric hospital setting or hospitals where paediatric patients are cared for. All regions included. Primary care settings and other out of hospital care e.g., community or hospice care will not be included.

Main outcome(s) [1 change]

Experiences and perceptions of all relevant stakeholders using an electronic patient record system in the paediatric hospital setting.

Measures of effect

Not applicable

Additional outcome(s) [1 change]

Any identified benefits and challenges of using an electronic patient record system; information and support needs of stakeholders prior to, during and after implementation; any identified ethical or legal considerations that may affect users' ability to use or access their health-related information and may impact their health-related outcomes.

Measures of effect

Not applicable

Data extraction (selection and coding) [1 change]

After the removal of duplicates, the title and abstract of records will be independently screened by two researchers (PS/JW). Full-text papers will be reviewed independently for inclusion by three researchers (PS/KO/FG), ensuring each full-text paper is reviewed by two researchers. Uncertainty regarding the inclusion of a paper will be resolved through discussion with the research team (PS/JW/KO/FG). Studies excluded from the review at this stage will be categorised by ‘reason for exclusion’ and results tabulated.

If several articles exist for the same study, for example, the publication of protocols, preliminary results, and publishing of the complete study, only the article pertaining to the complete study will be included. Nevertheless, information from the other articles may be used to provide additional information about the study necessary for the review. The review will be conducted according to Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

A data extraction form will be developed and piloted, the final version agreed between PS and JW. Extracted data will be entered into Microsoft Excel for Mac 2020 (version 16.41) by PS, verified by JW, using a standard proforma including information on: study design, population, diagnosis, and outcomes. Topic-specific information on whether the study is: pre/post system implementation, an EPR system/patient portal/both, and outcomes specifically related to answering the research question (user experiences/perceptions, benefits or challenges, user information/support needs, and ethical or legal issues encountered) will be included.

Risk of bias (quality) assessment [1 change]

Critical appraisal of the included studies was performed using the Mixed Methods Appraisal Tool (MMAT): version 2018, and was chosen because it permits methodological quality appraisal of five study categories: qualitative research; randomized controlled trials; non-randomized; quantitative descriptive; and mixed methods studies.

Strategy for data synthesis [1 change]

The aim is to understand the experiences and perceptions of all relevant stakeholders using an EPR system in the pediatric hospital setting. A systematic review and synthesis of findings from the set of included studies will be presented, drawing conclusions based on the body of evidence, using thematic synthesis. This will include a narrative presentation and tabulated summaries, structured around a) study characteristics: title, the aim of the study, methods, participants, sample selection, year of study, region, setting; and b) study outcomes: study design, pre/post-implementation, EPR system used, the focus of measures, range of outcomes, and conclusions. A narrative synthesis is the data synthesis of choice as, due to the anticipated heterogeneity of the studies with the focus on experience and/or use of EPR and due to the variability in the target population (stakeholders: staff, parents and children and young people), outcomes and study design (including qualitative, quantitative studies and mixed methods studies), it is thought that a meta-analysis will not be feasible.

Analysis of subgroups or subsets [1 change]

If there are appropriate data available, subgroup analyses will be undertaken for different groups of health professionals separately. Similarly, subgroup analyses will be undertaken for children with different diagnoses and/or parents of children with different diagnoses if the necessary data are available. Other subgroup analyses may be undertaken if different groups are identified from the synthesis of data

Contact details for further information

Pippa Sipanoun
pippa.sipanoun@gosh.nhs.uk

Organisational affiliation of the review

Great Ormond Street Hospital for Children NHS Foundation Trust / UCL GOS Institute of Child Health
https://www.gosh.org/; https://www.ucl.ac.uk/child-health/

Review team members and their organisational affiliations [1 change]

Ms Pippa Sipanoun. Great Ormond Street Hospital for Children NHS Foundation Trust / UCL GOS Institute of Child Health
Dr Kate Oulton. Great Ormond Street Hospital for Children NHS Foundation Trust
Professor Faith Gibson. Great Ormond Street Hospital for Children NHS Foundation Trust / University of Surrey
Assistant/Associate Professor Jo Wray. Great Ormond Street Hospital for Children NHS Foundation Trust / Institute of Cardiovascular Science, University College London

Type and method of review
Systematic review

Anticipated or actual start date [1 change]

06 January 2020

Anticipated completion date [1 change]

06 January 2021

Funding sources/sponsors
This review is funded by Great Ormond Street Hospital for Children NHS Foundation Trust as part of the 'Going Digital Study' - UCL Great Ormond Street Institute of Child Health Joint R&D Office - Protocol numbers: 18WA27 / 18WA46. Health Research Authority Research Ethics Approval gained for IRAS IDs: 252222 / 248793.

Conflicts of interest

Language
English

Country
England

Stage of review [2 changes]

Review Completed published

Details of final report/publication(s) or preprints if available [1 change]

P. Sipanoun, K. Oulton, F. Gibson, J. Wray, The experiences and perceptions of users of an electronic patient record system in a pediatric hospital setting: a systematic review, International Journal of Medical Informatics 2022, 160, doi: https://doi.org/10.1016/j.ijmedinf.2022.104691
https://doi.org/10.1016/j.ijmedinf.2022.104691

Subject index terms status
Subject indexing assigned by CRD

Subject index terms
Attitude of Health Personnel; Child; Electronic Health Records; Hospitals, Pediatric; Humans

Date of registration in PROSPERO
23 December 2020

Date of first submission
26 September 2019

Stage of review at time of this submission [2 changes]

Stage	**Started**	**Completed**
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	Yes
Data analysis	Yes	Yes

Revision note

No further changes. Completed and published

The record owner confirms that the information they have supplied for this submission is accurate and complete and they understand that deliberate provision of inaccurate information or omission of data may be construed as scientific misconduct.
The record owner confirms that they will update the status of the review when it is completed and will add publication details in due course.

Versions

23 December 2020
05 March 2021
07 March 2021
04 February 2022
12 February 2022
12 February 2022

Appendix 7 – Example search terms (EMCARE)

1. pediatrics/
2. adolescent/
3. child/ or exp infant/ or preschool child/
4. parent/ or father/ or mother/ or single parent/
5. health care personnel/ or advanced practice provider / or exp anesthetist/ or clinician/ or educator/
6. paramedical personnel/ or audiologist/ or clinical laboratory personnel/ or nurse/ or nursing staff/ or occupational therapist/ or pharmacist/ or physiotherapist/
7. caregiver/
8. case manager/
9. infection control practitioner/
10. dietician/
11. physician/
12. optometrist/
13. medical school/
14. nursing education/
15. health care facility/
16. family/
17. exp patient/
18. (p?ediatric* or child* or young people or young person or patient* or healthcare professional* or family or families* or parent* or mother* or father* or carer*).ti,ab.
19. stakeholder*.ti,ab.
20. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19
21. hospital/ or isolation hospital/ or mental hospital/ or pediatric hospital/ or private hospital/ or public hospital/ or exp teaching hospital/
22. heart center/
23. rehabilitation center/
24. secondary care center/

25. tertiary care center/
26. national health service/
27. (hospital* or NHS or national health service or secondary care or tertiary care).ti,ab.
28. 21 or 22 or 23 or 24 or 25 or 26 or 27
29. electronic medical record/
30. medical information system/
31. smart card/
32. medical record/
33. ((electronic or online or on-line) adj2 record*).ti,ab.
34. (EPR or EHR or EMR).ti,ab.
35. (patient portal* or (digital adj2 record*) or health information system* or clinical information system* or electronic personal child health record*).ti,ab.
36. 29 or 30 or 31 or 32 or 33 or 34 or 35
37. ethics/ or bioethics/ or ethical theory/ or institutional ethics/ or medical ethics/ or research ethics/
38. “philosophy of medicine”/
39. law/
40. medicolegal aspect/
41. (experience* or benefit* or challenge* or “information needs” or “support needs” or barrier* or facilitator* or ethic* or legal or law or legislation or perception* or attitude* or expectation* or opinion* or satisfaction* or view*).ti,ab.
42. 37 or 38 or 39 or 40 or 41
43. 20 and 28 and 36 and 42
44. limit 43 to yr=”2010 -Current”

Appendix 8 – Systematic review data extraction tool

Study ID
Author/Year/Title/Country
Citation
Aim (Primary objective)
Secondary objective
Article/study focus
Study design/methodology
Details about measures
Focus of measures
Other data collected
Distribution of measures/data collection procedure
Study setting
Participants seen as inpatient or outpatient
When did study take place?
Pre/during/post-implementation?
Support over implementation phase
Inclusion criteria
Exclusion criteria
Participant group
Sampling strategy/participant recruitment
Participants consented/assented?
Number of Participants approached
Number of Participants recruited
% participated/response rate
Age of participant (staff/parent)
Gender of participant (staff/parent)
Staff/parent ethnicity
Number of children in family
>1 child in family with chronic condition?
If CYP ?age
If CYP - gender
If CYP - ethnicity
If CYP - disease/diagnosis
If staff, prof group/job

Intervention being studied
EPR (Y/N) & system used
Patient portal
EPR & portal & type (tethered/online)
Functions on portal
Awareness of portal before approach
Use of portal before approach
Reasons for not using portal
Training provided
Format of training (EPR implementation)
% of participants attended training
Previous EPR training/use?
Follow-up intervention
Primary outcomes
Secondary outcomes
Quant analysis
Quant results
Qual analysis
Qual results
Benefits
Challenges
Info/support needs
Ethical/legal implications
Concerns
Dislikes
Desirable functionality
Safety
Intended use of portal
Intended future use of portal
Tech savvy?
Access
Transition
Other
Conclusions/recommendations
Limitations of study
Ethical approval
My notes

Appendix 9 – Mixed Methods Appraisal Tool (version 2018)

Category of study designs	**Methodological quality criteria**	**Responses**			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	S1. Are there clear research questions?				
	S2. Do the collected data allow to address the research questions?				
	Further appraisal may not be feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.				
1. Qualitative	1.1. Is the qualitative approach appropriate to answer the research question?				
	1.2. Are the qualitative data collection methods adequate to address the research question?				
	1.3. Are the findings adequately derived from the data?				
	1.4. In the interpretation of results sufficiently substantiated by data?				
	1.5. Is there coherence between qualitative data sources, collection, analysis and interpretation?				
2. Quantitative randomized controlled trials	2.1. Is randomization appropriately performed?				
	2.2. Are the groups comparable at baseline?				
	2.3. Are there complete outcome data?				
	2.4. Are outcome assessors blinded to the intervention provided?				
	2.5. Did the participants adhere to the assigned intervention?				
3. Quantitative non-randomized	3.1. Are the participants representative of the target population?				
	3.2. Are measurements appropriate regarding both outcomes and intervention (or exposure)?				
	3.3. Are there complete outcome data?				
	3.4. Are the confounders accounted for in the design and analysis?				
	3.5. During the study period, is the intervention administered (or exposure occurred) as intended?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the research question?				
	4.2. Is the sample representative of the target population?				
	4.3. Are the measurements appropriate?				
	4.4. Is the risk of nonresponse bias low?				
	4.5. Is the statistical analysis appropriate to answer the research question?				
5. Mixed methods	5.1. Is there an adequate rationale for using a mixed methods design to address the research question?				
	5.2. Are the different components of the study effectively integrated to answer the research question?				
	5.3. Are the outputs of the integration of qualitative and quantitative components adequately interpreted?				
	5.4. Are the divergences and inconsistencies between quantitative and qualitative results adequately addressed?				
	5.5. Do the different components of the study adhere to the quality criteria of each tradition of the methods involved?				

Appendix 10 – Invitation letter to YPF members

FUTURE PROOF
ELECTRONIC PATIENT RECORDS

Great Ormond Street Hospital for Children
NHS Foundation Trust

Great Ormond Street Hospital
Great Ormond Street
London
WC1N 3JH

21st October 2018

Dear YPF member,

As you are a member of the Young Person's Forum (YPF), which has been involved with helping the electronic patient record (EPR) team develop MyGOSH patient portal, I wanted to warmly invite you to take part in a research project called the **Going Digital Study** that is being run through EPR and the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at Great Ormond Street Hospital.

The aims of the study are to understand what the benefits and challenges of introducing EPR and MyGOSH patient portal are for patients, parents, and staff as well as any practical, ethical and legal implications. We will collect data before and after implementation of the EPR system to see what Going Digital means to all stakeholders involved.

Phase 1 of this study, pre EPR being introduced, involves a workshop with children and young people, parents, and staff to understand their views, with the results informing a survey for each participant group that will then be sent hospital wide. We value your input as an active member of the YPF.

The research is being undertaken by Pippa Sipanoun, a nurse who has worked in the hospital for many years, but is now studying her PhD. The workshop will be held at on Saturday 15th December at your regular YPF meeting. Refreshments will be provided. If you agree to take part, please advise if you have any food allergies.

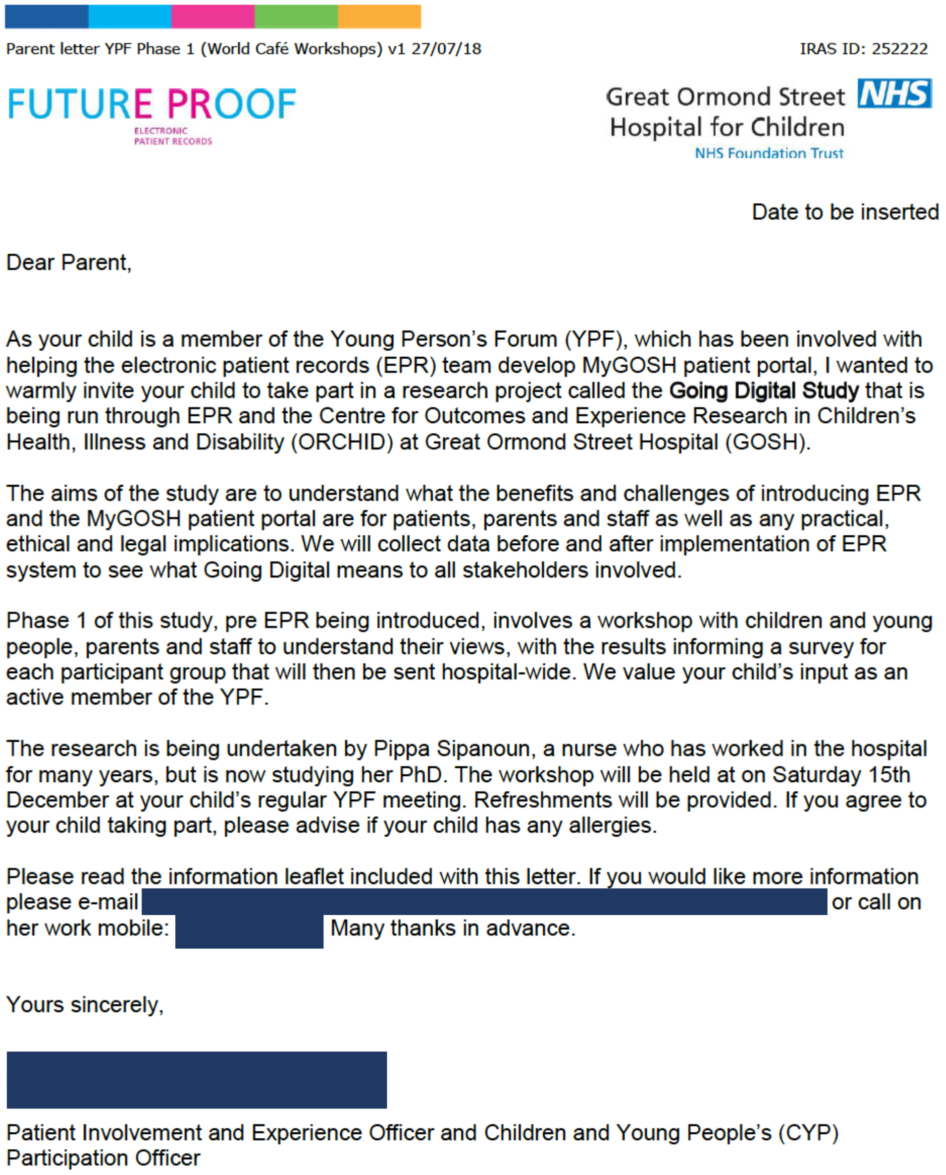
Please read the information leaflet included with this letter. If you would like more information please [redacted] or call on her work mobile: [redacted] Many thanks in advance.

Yours sincerely,

[redacted]

Patient Involvement and Experience Officer and Children and Young People's Participation Officer

Appendix 11 – Invitation letter to parents of YPF members



Parent letter YPF Phase 1 (World Café Workshops) v1 27/07/18 IRAS ID: 252222

FUTURE PROOF
ELECTRONIC PATIENT RECORDS

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Date to be inserted

Dear Parent,

As your child is a member of the Young Person's Forum (YPF), which has been involved with helping the electronic patient records (EPR) team develop MyGOSH patient portal, I wanted to warmly invite your child to take part in a research project called the **Going Digital Study** that is being run through EPR and the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at Great Ormond Street Hospital (GOSH).

The aims of the study are to understand what the benefits and challenges of introducing EPR and the MyGOSH patient portal are for patients, parents and staff as well as any practical, ethical and legal implications. We will collect data before and after implementation of EPR system to see what Going Digital means to all stakeholders involved.

Phase 1 of this study, pre EPR being introduced, involves a workshop with children and young people, parents and staff to understand their views, with the results informing a survey for each participant group that will then be sent hospital-wide. We value your child's input as an active member of the YPF.

The research is being undertaken by Pippa Sipanoun, a nurse who has worked in the hospital for many years, but is now studying her PhD. The workshop will be held at on Saturday 15th December at your child's regular YPF meeting. Refreshments will be provided. If you agree to your child taking part, please advise if your child has any allergies.

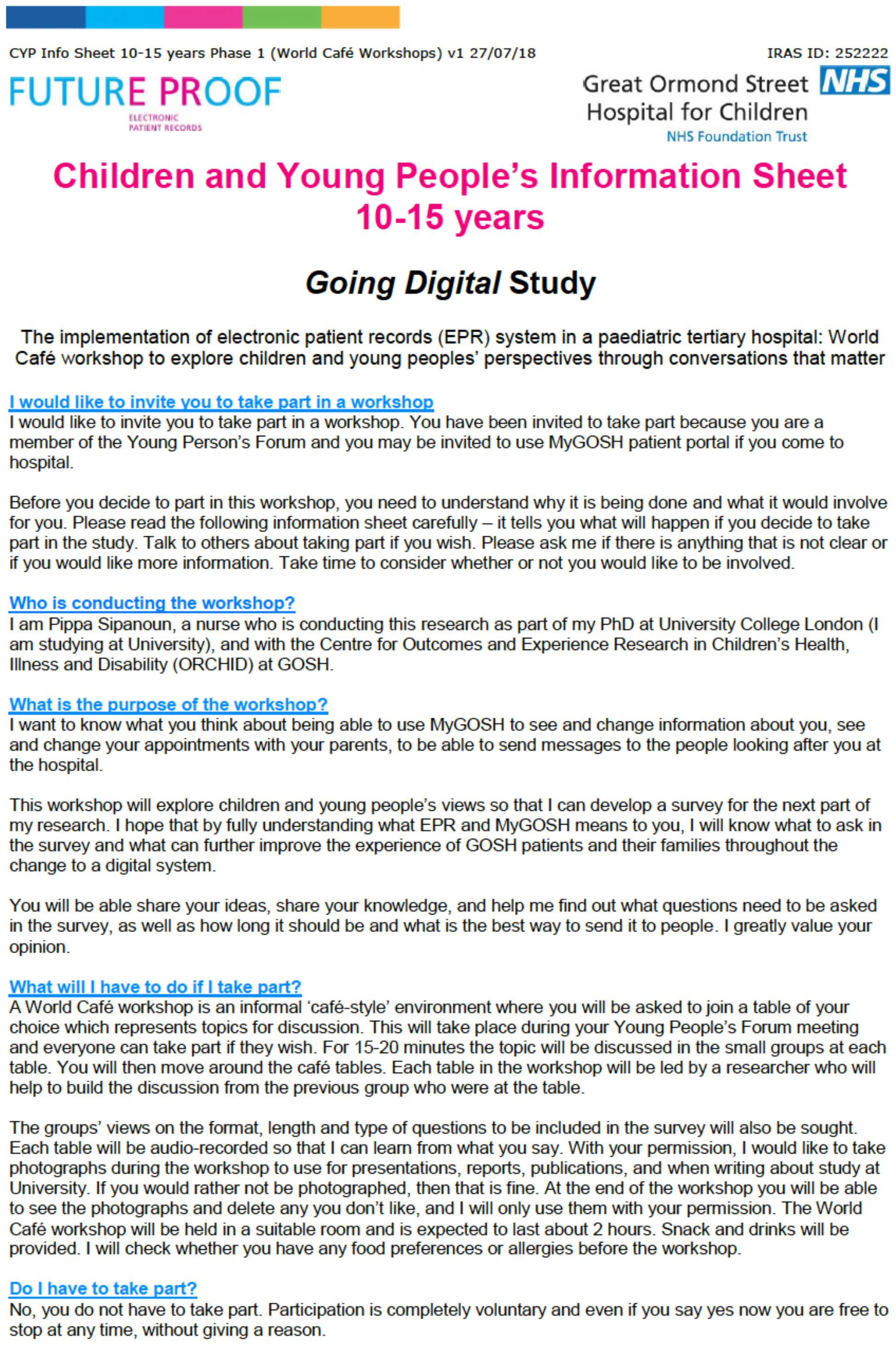
Please read the information leaflet included with this letter. If you would like more information please e-mail [redacted] or call on her work mobile: [redacted] Many thanks in advance.

Yours sincerely,

[redacted]

Patient Involvement and Experience Officer and Children and Young People's (CYP) Participation Officer

Appendix 12 – Phase 1 participant information sheet 10-15 years



CYP Info Sheet 10-15 years Phase 1 (World Café Workshops) v1 27/07/18

IRAS ID: 252222

FUTURE PROOF
ELECTRONIC PATIENT RECORDS

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Children and Young People's Information Sheet
10-15 years

Going Digital Study

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshop to explore children and young peoples' perspectives through conversations that matter

I would like to invite you to take part in a workshop

I would like to invite you to take part in a workshop. You have been invited to take part because you are a member of the Young Person's Forum and you may be invited to use MyGOSH patient portal if you come to hospital.

Before you decide to part in this workshop, you need to understand why it is being done and what it would involve for you. Please read the following information sheet carefully – it tells you what will happen if you decide to take part in the study. Talk to others about taking part if you wish. Please ask me if there is anything that is not clear or if you would like more information. Take time to consider whether or not you would like to be involved.

Who is conducting the workshop?

I am Pippa Sipanoun, a nurse who is conducting this research as part of my PhD at University College London (I am studying at University), and with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at GOSH.

What is the purpose of the workshop?

I want to know what you think about being able to use MyGOSH to see and change information about you, see and change your appointments with your parents, to be able to send messages to the people looking after you at the hospital.

This workshop will explore children and young people's views so that I can develop a survey for the next part of my research. I hope that by fully understanding what EPR and MyGOSH means to you, I will know what to ask in the survey and what can further improve the experience of GOSH patients and their families throughout the change to a digital system.

You will be able share your ideas, share your knowledge, and help me find out what questions need to be asked in the survey, as well as how long it should be and what is the best way to send it to people. I greatly value your opinion.

What will I have to do if I take part?

A World Café workshop is an informal 'café-style' environment where you will be asked to join a table of your choice which represents topics for discussion. This will take place during your Young People's Forum meeting and everyone can take part if they wish. For 15-20 minutes the topic will be discussed in the small groups at each table. You will then move around the café tables. Each table in the workshop will be led by a researcher who will help to build the discussion from the previous group who were at the table.

The groups' views on the format, length and type of questions to be included in the survey will also be sought. Each table will be audio-recorded so that I can learn from what you say. With your permission, I would like to take photographs during the workshop to use for presentations, reports, publications, and when writing about study at University. If you would rather not be photographed, then that is fine. At the end of the workshop you will be able to see the photographs and delete any you don't like, and I will only use them with your permission. The World Café workshop will be held in a suitable room and is expected to last about 2 hours. Snack and drinks will be provided. I will check whether you have any food preferences or allergies before the workshop.

Do I have to take part?

No, you do not have to take part. Participation is completely voluntary and even if you say yes now you are free to stop at any time, without giving a reason.

What are the disadvantages of taking part?

Taking part in this workshop will require some of your time but this will be during one of your Young People's Forum meetings so will not take up additional time.

What are the advantages of taking part?

I cannot promise that taking part in this study will benefit you personally, although you may value the opportunity to share your views in the knowledge that your contribution will help shape EPR and MyGOSH for the future. Your views are an important contribution to this study.

Will my data be kept confidential?

Yes. All information collected during this study will be kept confidential, which means only the research team will be able to see it. If I share any results, these will be kept anonymous, which means that you will not be able to be identified. The only reason I would break confidentiality and share any information is if I felt concerned about your safety.

What if I don't want to carry on with the study?

If you agree to take part in the study you have the right to stop at any time, without giving a reason. If you choose to withdraw, your care will not be affected in any way. However, with your permission I would still like to use the data collected up to that point.

How will the data be kept secure and what happens to the data at the end of the study?

All paper data will be stored in a locked filing cabinet, which is located in a research office at GOSH only accessible by a swipe card. Personal identifiable data and consent forms will be stored separately to research data. Electronic data is stored on password protected servers accessed by Trust computers and encrypted laptops. Photographs taken during the workshops will be stored using password-protected software. At the end of the study personal data will only be stored and accessed for up to 6 months, unless a report of study findings is requested, then until end of study (3 years). Research data will be stored in accordance with GOSH Trust and UCL policies.

What will happen to the results of the study?

You will be invited to receive a copy of the survey once developed to pilot it. A report of the study findings will be available upon request. The results will be published and presented so they can be shared with other healthcare professionals and researchers. All data that is shared will be anonymised so that children and young people, parents and staff members cannot be identified, meaning that no-one will be able to recognise you.

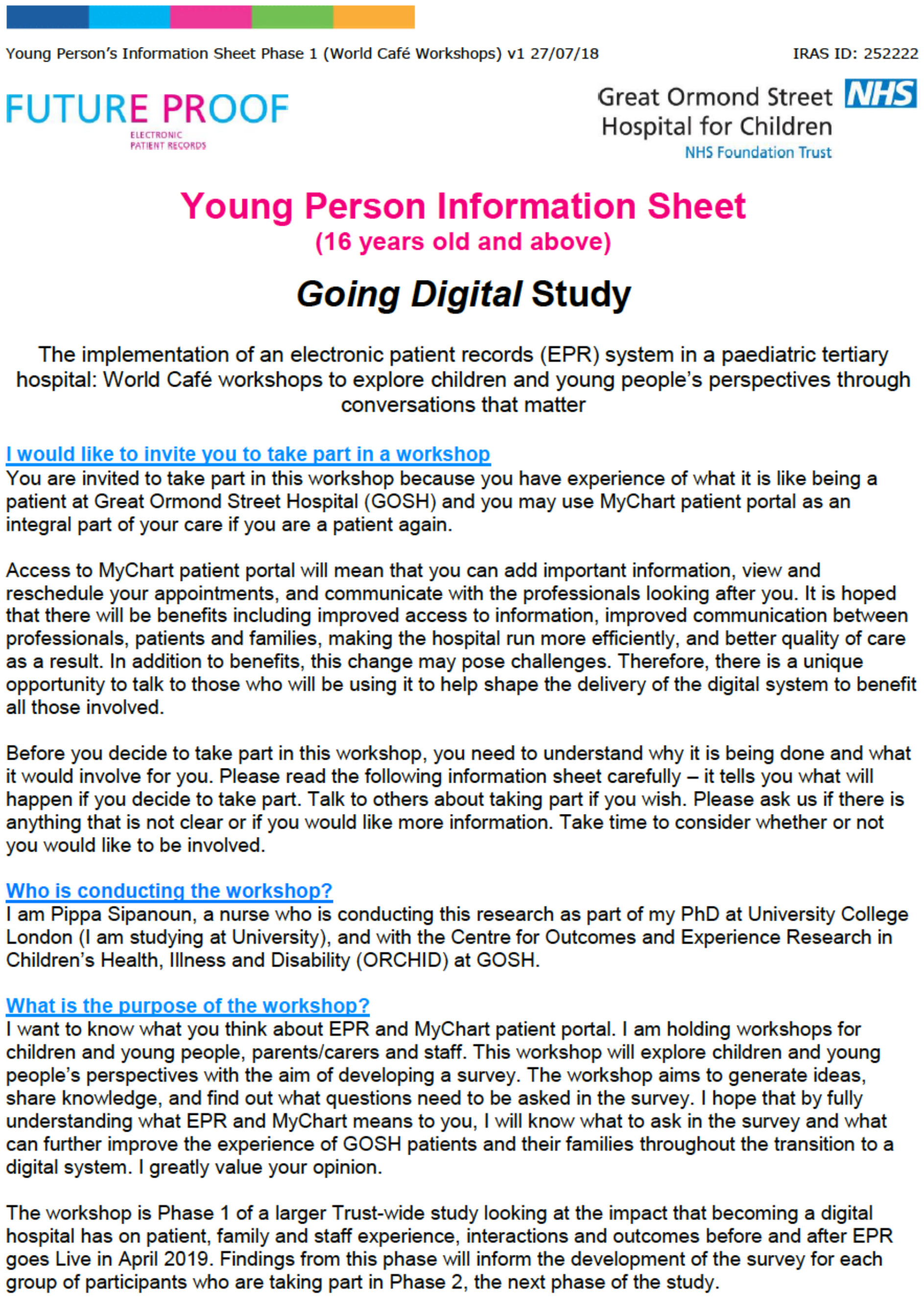
Who should I contact if I have any questions?

[redacted]

Thank you for taking the time to read this leaflet

This study is being funded by Great Ormond Street Hospital for Children

Appendix 13: Phase 1 participant information sheet ≥16 years



Young Person's Information Sheet Phase 1 (World Café Workshops) v1 27/07/18 IRAS ID: 252222

FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Young Person Information Sheet
(16 years old and above)

Going Digital Study

The implementation of an electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshops to explore children and young people's perspectives through conversations that matter

I would like to invite you to take part in a workshop

You are invited to take part in this workshop because you have experience of what it is like being a patient at Great Ormond Street Hospital (GOSH) and you may use MyChart patient portal as an integral part of your care if you are a patient again.

Access to MyChart patient portal will mean that you can add important information, view and reschedule your appointments, and communicate with the professionals looking after you. It is hoped that there will be benefits including improved access to information, improved communication between professionals, patients and families, making the hospital run more efficiently, and better quality of care as a result. In addition to benefits, this change may pose challenges. Therefore, there is a unique opportunity to talk to those who will be using it to help shape the delivery of the digital system to benefit all those involved.

Before you decide to take part in this workshop, you need to understand why it is being done and what it would involve for you. Please read the following information sheet carefully – it tells you what will happen if you decide to take part. Talk to others about taking part if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to consider whether or not you would like to be involved.

Who is conducting the workshop?

I am Pippa Sipanoun, a nurse who is conducting this research as part of my PhD at University College London (I am studying at University), and with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at GOSH.

What is the purpose of the workshop?

I want to know what you think about EPR and MyChart patient portal. I am holding workshops for children and young people, parents/carers and staff. This workshop will explore children and young people's perspectives with the aim of developing a survey. The workshop aims to generate ideas, share knowledge, and find out what questions need to be asked in the survey. I hope that by fully understanding what EPR and MyChart means to you, I will know what to ask in the survey and what can further improve the experience of GOSH patients and their families throughout the transition to a digital system. I greatly value your opinion.

The workshop is Phase 1 of a larger Trust-wide study looking at the impact that becoming a digital hospital has on patient, family and staff experience, interactions and outcomes before and after EPR goes Live in April 2019. Findings from this phase will inform the development of the survey for each group of participants who are taking part in Phase 2, the next phase of the study.

Data Protection Privacy Notice

UCL Great Ormond Street Institute of Child Health (UCL GOS ICH) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL GOS ICH will keep identifiable information about you for 15 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The research team from Great Ormond Street Hospital will keep your name and contact details confidential and will not pass this information to UCL GOS ICH. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from UCL GOS ICH and regulatory organisations may look at your research records to check the accuracy of the research study. UCL GOS ICH will only receive information without any identifying information. The people who analyse the information will not be able to find out your name or contact details. Photographs will be used only with expressed consent, as described.

You can find out more about how we use your information by contacting Lee Shailer, the Data Protection Officer, at data-protection@ucl.ac.uk.

Who should I contact if I have any questions?

[redacted]

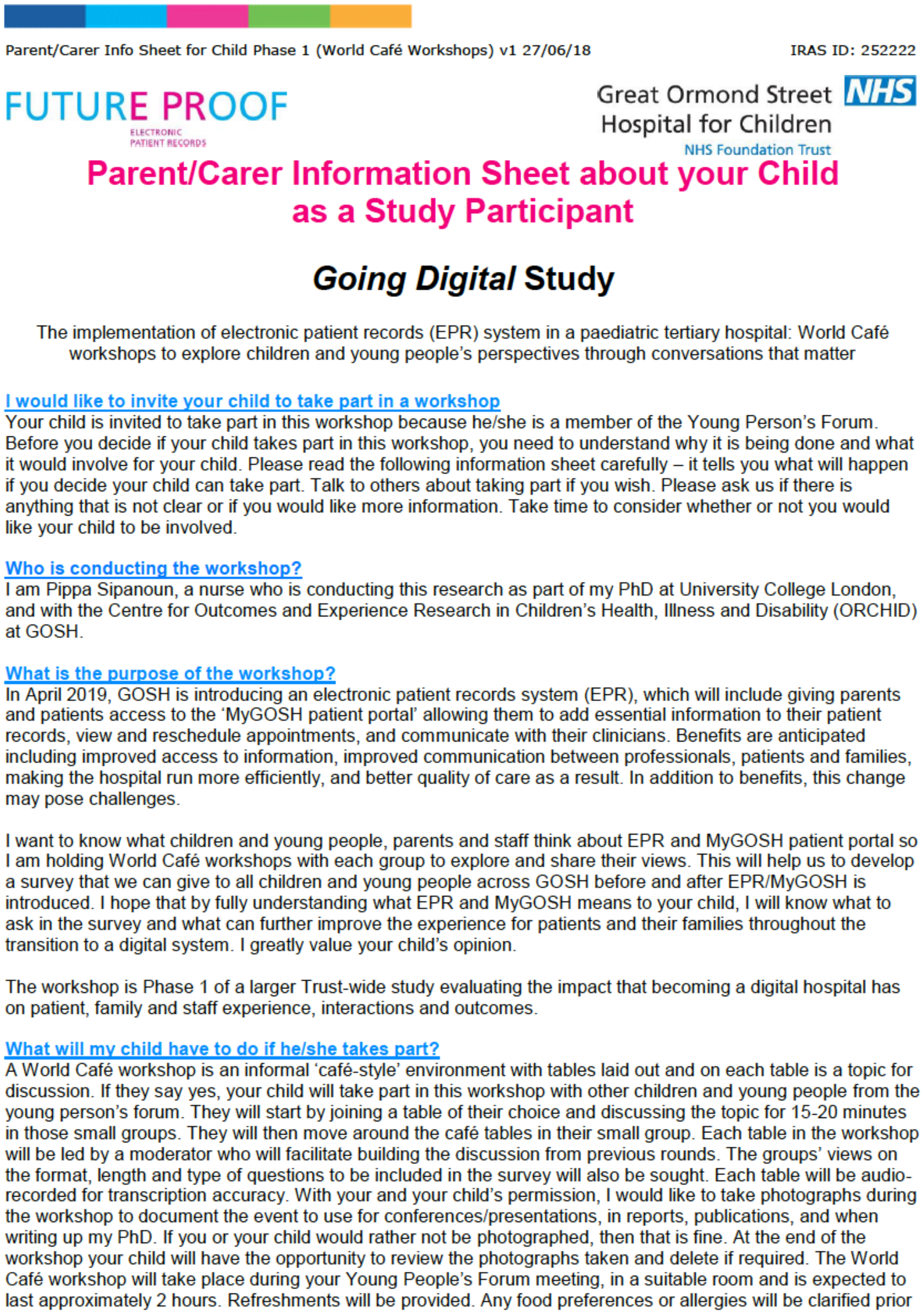
What if I have any concerns about the study?

If you have any concerns or other questions about this study or the way it has been carried out, please talk to a member of the research team. If you remain unhappy, or wish to comment in any other way, you can contact the Patient Advice and Liaison Service (PALs) on 020 7829 7862 or email: pals@gosh.nhs.uk

Thank you for taking the time to read this leaflet

This study is being funded by Great Ormond Street Hospital for Children

Appendix 14: Phase 1 participant information sheet parent/carer for child



Parent/Carer Info Sheet for Child Phase 1 (World Café Workshops) v1 27/06/18 IRAS ID: 252222

FUTURE PROOF
ELECTRONIC PATIENT RECORDS

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Parent/Carer Information Sheet about your Child as a Study Participant

Going Digital Study

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshops to explore children and young people's perspectives through conversations that matter

I would like to invite your child to take part in a workshop

Your child is invited to take part in this workshop because he/she is a member of the Young Person's Forum. Before you decide if your child takes part in this workshop, you need to understand why it is being done and what it would involve for your child. Please read the following information sheet carefully – it tells you what will happen if you decide your child can take part. Talk to others about taking part if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to consider whether or not you would like your child to be involved.

Who is conducting the workshop?

I am Pippa Sipanoun, a nurse who is conducting this research as part of my PhD at University College London, and with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at GOSH.

What is the purpose of the workshop?

In April 2019, GOSH is introducing an electronic patient records system (EPR), which will include giving parents and patients access to the 'MyGOSH patient portal' allowing them to add essential information to their patient records, view and reschedule appointments, and communicate with their clinicians. Benefits are anticipated including improved access to information, improved communication between professionals, patients and families, making the hospital run more efficiently, and better quality of care as a result. In addition to benefits, this change may pose challenges.

I want to know what children and young people, parents and staff think about EPR and MyGOSH patient portal so I am holding World Café workshops with each group to explore and share their views. This will help us to develop a survey that we can give to all children and young people across GOSH before and after EPR/MyGOSH is introduced. I hope that by fully understanding what EPR and MyGOSH means to your child, I will know what to ask in the survey and what can further improve the experience for patients and their families throughout the transition to a digital system. I greatly value your child's opinion.

The workshop is Phase 1 of a larger Trust-wide study evaluating the impact that becoming a digital hospital has on patient, family and staff experience, interactions and outcomes.

What will my child have to do if he/she takes part?

A World Café workshop is an informal 'café-style' environment with tables laid out and on each table is a topic for discussion. If they say yes, your child will take part in this workshop with other children and young people from the young person's forum. They will start by joining a table of their choice and discussing the topic for 15-20 minutes in those small groups. They will then move around the café tables in their small group. Each table in the workshop will be led by a moderator who will facilitate building the discussion from previous rounds. The groups' views on the format, length and type of questions to be included in the survey will also be sought. Each table will be audio-recorded for transcription accuracy. With your and your child's permission, I would like to take photographs during the workshop to document the event to use for conferences/presentations, in reports, publications, and when writing up my PhD. If you or your child would rather not be photographed, then that is fine. At the end of the workshop your child will have the opportunity to review the photographs taken and delete if required. The World Café workshop will take place during your Young People's Forum meeting, in a suitable room and is expected to last approximately 2 hours. Refreshments will be provided. Any food preferences or allergies will be clarified prior to the workshop.

Does my child have to take part?
No, your child does not have to take part. Participation is completely voluntary and even if you/your child say yes now your child is free to stop at any time, without giving a reason.

What are the disadvantages of taking part?
Taking part in this workshop will require some of your child's time although this will be during one of your child's Young People's Forum meetings so will not take up additional time.

What are the advantages of taking part?
I cannot promise that taking part in this study will benefit you or your child personally, although you may value the opportunity for your child to share their views in the knowledge that their contribution will help shape EPR and MyGOSH in the future. I value your child's opinion and their views are an important contribution to this study.

Will my child's data be kept confidential?
Yes. All information collected during this study will be kept confidential, which means only the research team will be able to see it. If I share any results, these will be kept anonymous, which means that your child will not be able to be identified. The only reason I would break confidentiality and share any information is if I felt concerned about your or your child's safety.

What if my child doesn't want to carry on with the study?
If you/your child agrees to take part in the study your child has the right to stop at any time, without giving a reason. If your child chooses to withdraw, the care of you or your child will not be affected in any way. However, with your permission I would still like to use the data collected up to that point.

How will the data be kept secure and what happens to the data at the end of the study?
All paper data will be stored in a locked filing cabinet, which is located in a research office at GOSH only accessible by a swipe card. Personal identifiable data and consent forms will be stored separately to research data. Electronic data is stored on password protected servers accessed by Trust computers and encrypted laptops. Photographs taken during the workshops will be stored using password-protected software and used only with expressed consent (your permission). Personal data will only be stored and accessed for up to 6 months after the end of the full 3 year study. Research data will be stored in accordance with GOSH Trust and UCL policies.

What will happen to the results of the study?
All World Café participants will be invited to receive a copy of the survey once developed to pilot it. A report of the study findings will be available upon request. The results will be published and presented so they can be shared with other healthcare professionals and researchers. All data that is shared will be anonymised so that children and young people, parents and staff members cannot be identified.

Can I also take part in a workshop to share my views?
Yes, I am holding a World Café workshop for parents/carers so please contact me if you would like to be involved.

Data Protection Privacy Notice
UCL Great Ormond Street Institute of Child Health (UCL GOS ICH) is the sponsor for this study based in the United Kingdom. We will be using information from you/your child in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL GOS ICH will keep identifiable information about you/your child for 15 years after the study has finished. Your rights to access, change or move your/your child's information are limited, as we need to manage your/your child's information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you/your child that we have already obtained. To safeguard your/your child's rights, we will use the minimum personally-identifiable information possible.

The research team from Great Ormond Street Hospital will keep your/your child's name and contact details confidential and will not pass this information to UCL GOS ICH. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from UCL GOS ICH and regulatory organisations may look at your/your child's research records to check the accuracy of the research study. UCL GOS ICH will only receive information without any identifying information. The people who analyse the information will not be able to find out your/your child's name or contact details. Photographs will be used only with expressed consent, as described.

You can find out more about how we use your information by contacting Lee Shailer, the Data Protection Officer, at data-protection@ucl.ac.uk.

Who should I contact if I have any questions?

[redacted]

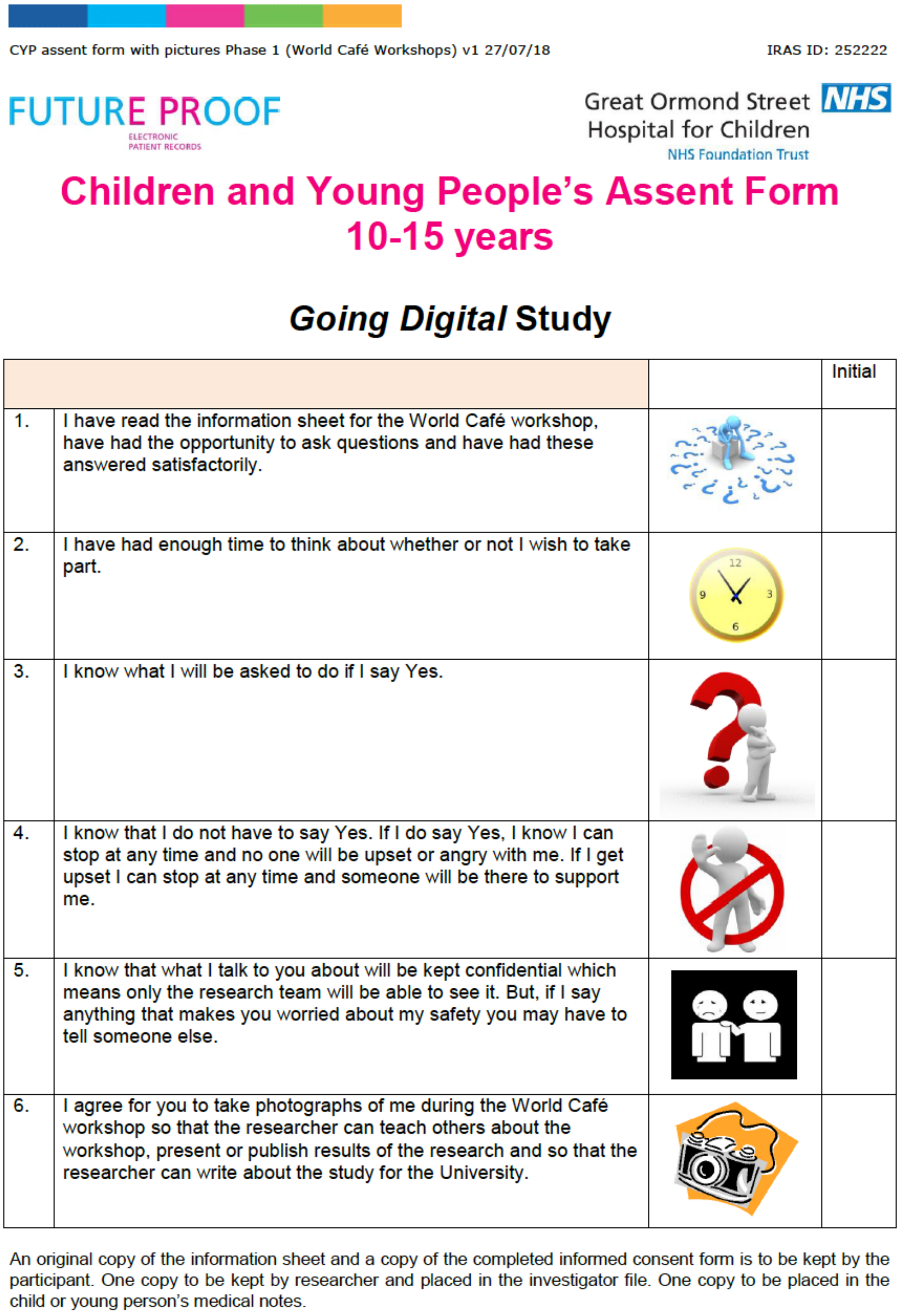
What if I have any concerns about the study?

If you have any concerns or other questions about this study or the way it has been carried out, please talk to a member of the research team. If you remain unhappy, or wish to comment in any other way, you can contact the Patient Advice and Liaison Service (PALs) on 020 7829 7862 or email: pals@gosh.nhs.uk

Thank you for taking the time to read this leaflet

This study is being funded by Great Ormond Street Hospital for Children

Appendix 15 – Phase 1 assent form 10-15 years



CYP assent form with pictures Phase 1 (World Café Workshops) v1 27/07/18 IRAS ID: 252222

FUTURE PROOF
ELECTRONIC PATIENT RECORDS

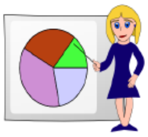
Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Children and Young People's Assent Form 10-15 years

Going Digital Study

			Initial
1.	I have read the information sheet for the World Café workshop, have had the opportunity to ask questions and have had these answered satisfactorily.		
2.	I have had enough time to think about whether or not I wish to take part.		
3.	I know what I will be asked to do if I say Yes.		
4.	I know that I do not have to say Yes. If I do say Yes, I know I can stop at any time and no one will be upset or angry with me. If I get upset I can stop at any time and someone will be there to support me.		
5.	I know that what I talk to you about will be kept confidential which means only the research team will be able to see it. But, if I say anything that makes you worried about my safety you may have to tell someone else.		
6.	I agree for you to take photographs of me during the World Café workshop so that the researcher can teach others about the workshop, present or publish results of the research and so that the researcher can write about the study for the University.		

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file. One copy to be placed in the child or young person's medical notes.

7.	I agree for you to share some of the things I have said with other researchers, students and professionals so they can learn but only if you do not use my real name.		
8.	I agree for you to audio record my activities.		
9.	I agree to take part in the World Café workshop.		

__________________________ ______________ __________________
Full name of Child Date Signature

__________________________ ______________ __________________
Full name of Parent Date Signature

__________________________ ______________ __________________
Full name of Person Obtaining Consent Date Signature

Who should I contact if I have any questions?

[redacted]

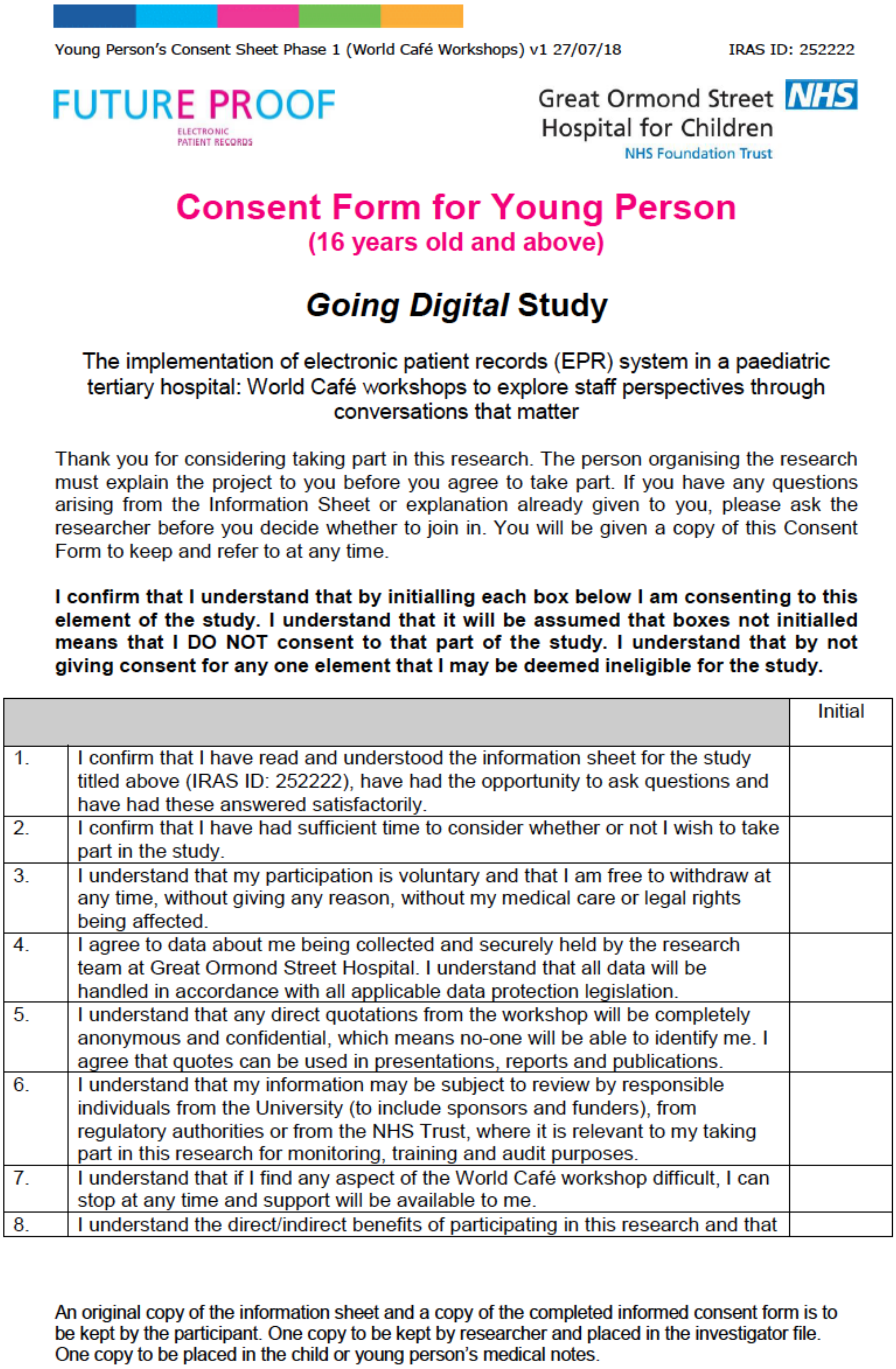
Thank you for taking the time to read this
This study is being funded by Great Ormond Street Hospital for Children

orchid
Centre For Outcomes And Experience Research In Children's Health, Illness And Disability

UCL

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file. One copy to be placed in the child or young person's medical notes.

Appendix 16 – Phase 1 informed consent form ≥16 years



Young Person's Consent Sheet Phase 1 (World Café Workshops) v1 27/07/18 IRAS ID: 252222

FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Consent Form for Young Person
(16 years old and above)

Going Digital Study

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshops to explore staff perspectives through conversations that matter

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that boxes not initialled means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Initial
1.	I confirm that I have read and understood the information sheet for the study titled above (IRAS ID: 252222), have had the opportunity to ask questions and have had these answered satisfactorily.	
2.	I confirm that I have had sufficient time to consider whether or not I wish to take part in the study.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
4.	I agree to data about me being collected and securely held by the research team at Great Ormond Street Hospital. I understand that all data will be handled in accordance with all applicable data protection legislation.	
5.	I understand that any direct quotations from the workshop will be completely anonymous and confidential, which means no-one will be able to identify me. I agree that quotes can be used in presentations, reports and publications.	
6.	I understand that my information may be subject to review by responsible individuals from the University (to include sponsors and funders), from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research for monitoring, training and audit purposes.	
7.	I understand that if I find any aspect of the World Café workshop difficult, I can stop at any time and support will be available to me.	
8.	I understand the direct/indirect benefits of participating in this research and that	

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file. One copy to be placed in the child or young person's medical notes.

	I will be reimbursed for my travel, where relevant.	
9.	I understand that the data from the workshop will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I agree to the workshop being audio-recorded.	
11.	I agree to photographs of my child being taken during the World Café Workshop. The photographs will be stored using password protected software and will be used during dissemination of the research findings at conferences and presentations, and for the writing up of the researcher's PhD.	
12.	I agree to take part in the World Café workshop.	
13.	I agree to being sent the survey, which has been informed by the workshop, to pilot it (please supply e-mail address).	

Full name of Young Person ____________ Date ____________ Signature ____________

E-mail address ____________

Full name of Person Obtaining Consent ____________ Date ____________ Signature ____________

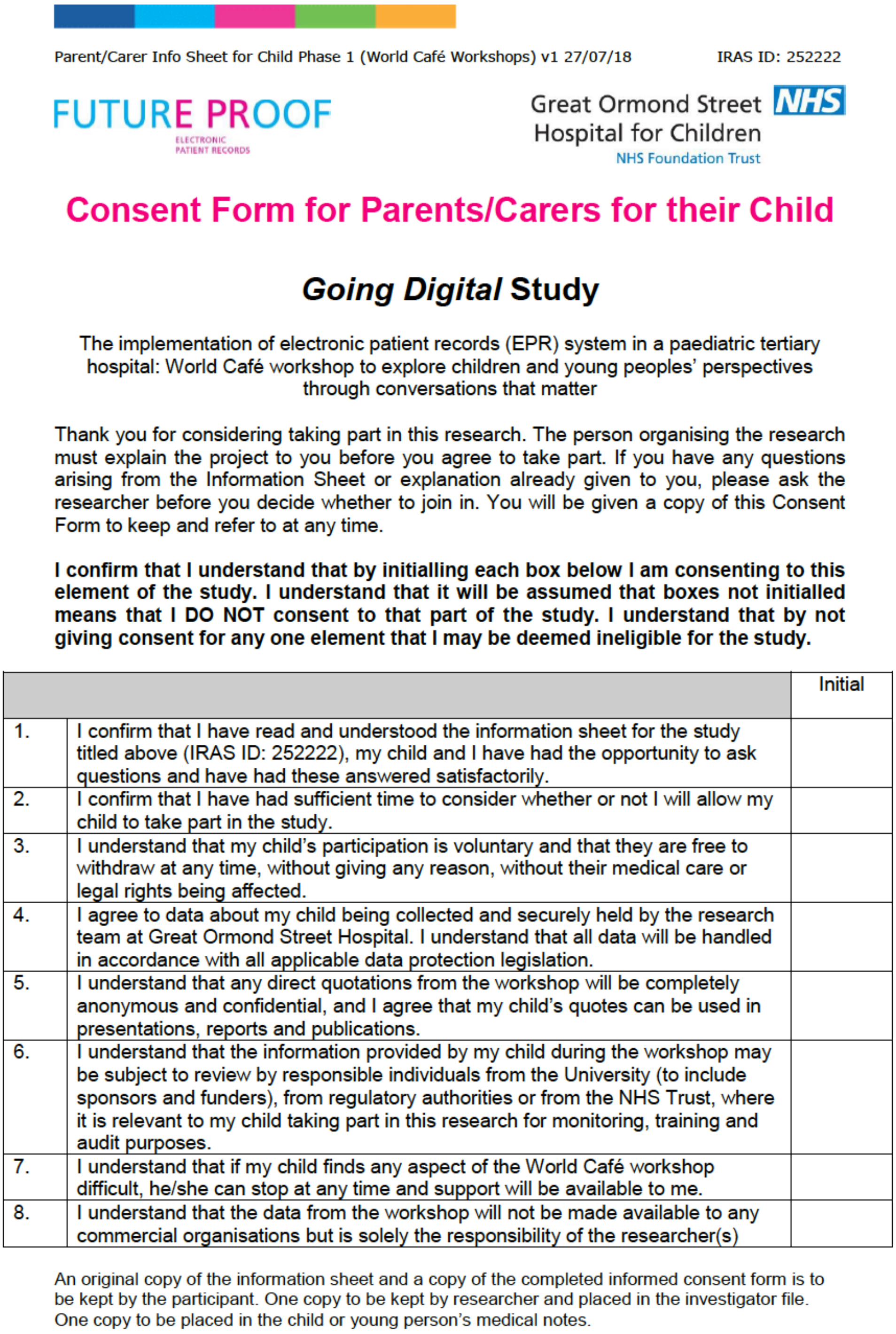
Who should I contact if I have any questions?

[redacted]

Thank you for taking the time to read this leaflet
This study is being funded by Great Ormond Street Hospital for Children

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file. One copy to be placed in the child or young person's medical notes.

Appendix 17 – Phase 1 informed consent form parents for their child



Parent/Carer Info Sheet for Child Phase 1 (World Café Workshops) v1 27/07/18 IRAS ID: 252222

FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Consent Form for Parents/Carers for their Child

Going Digital Study

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshop to explore children and young peoples' perspectives through conversations that matter

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that boxes not initialled means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Initial
1.	I confirm that I have read and understood the information sheet for the study titled above (IRAS ID: 252222), my child and I have had the opportunity to ask questions and have had these answered satisfactorily.	
2.	I confirm that I have had sufficient time to consider whether or not I will allow my child to take part in the study.	
3.	I understand that my child's participation is voluntary and that they are free to withdraw at any time, without giving any reason, without their medical care or legal rights being affected.	
4.	I agree to data about my child being collected and securely held by the research team at Great Ormond Street Hospital. I understand that all data will be handled in accordance with all applicable data protection legislation.	
5.	I understand that any direct quotations from the workshop will be completely anonymous and confidential, and I agree that my child's quotes can be used in presentations, reports and publications.	
6.	I understand that the information provided by my child during the workshop may be subject to review by responsible individuals from the University (to include sponsors and funders), from regulatory authorities or from the NHS Trust, where it is relevant to my child taking part in this research for monitoring, training and audit purposes.	
7.	I understand that if my child finds any aspect of the World Café workshop difficult, he/she can stop at any time and support will be available to me.	
8.	I understand that the data from the workshop will not be made available to any commercial organisations but is solely the responsibility of the researcher(s)	

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file. One copy to be placed in the child or young person's medical notes.

	undertaking this study.	
9.	I agree to the workshop being audio-recorded.	
10.	I agree to photographs of my child being taken during the World Café workshop. The photographs will be stored using password protected software and will be used during dissemination of the research findings at conferences and presentations, and for the writing up of the researcher's PhD.	
11.	I agree to my child taking part in the World Café workshop.	
12.	I agree to my child being sent the survey, which has been informed by the workshop, to pilot it (please supply e-mail address).	
13.	I would like a copy of this consent form (please supply e-mail address).	

Full name of Child

Full name of Parent Date Signature

Parent's e-mail address

Full name of Person Obtaining Consent Date Signature

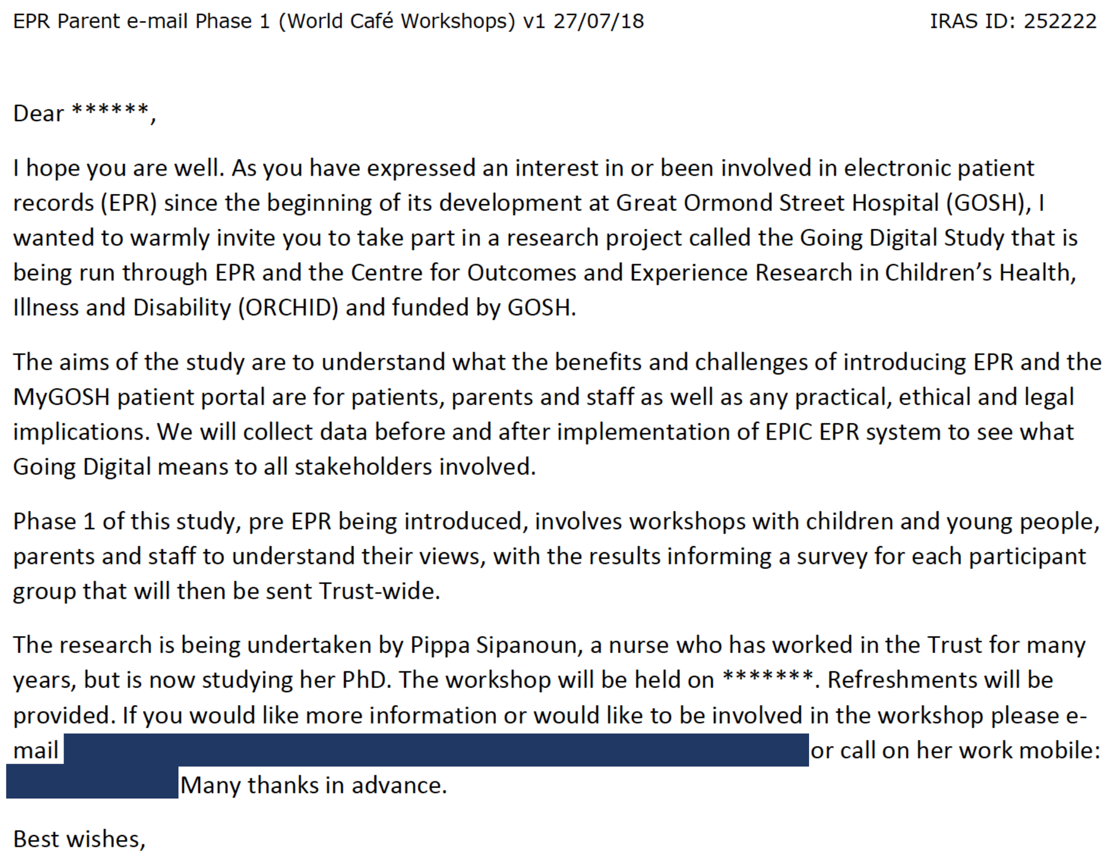
Who should I contact if I have any questions?

[redacted]

Thank you for taking the time to read this
This study is being funded by Great Ormond Street Hospital for Children

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file. One copy to be placed in the child or young person's medical notes.

Appendix 18 – Phase 1 email invitation to parent/carer



EPR Parent e-mail Phase 1 (World Café Workshops) v1 27/07/18 IRAS ID: 252222

Dear ******,

I hope you are well. As you have expressed an interest in or been involved in electronic patient records (EPR) since the beginning of its development at Great Ormond Street Hospital (GOSH), I wanted to warmly invite you to take part in a research project called the Going Digital Study that is being run through EPR and the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) and funded by GOSH.

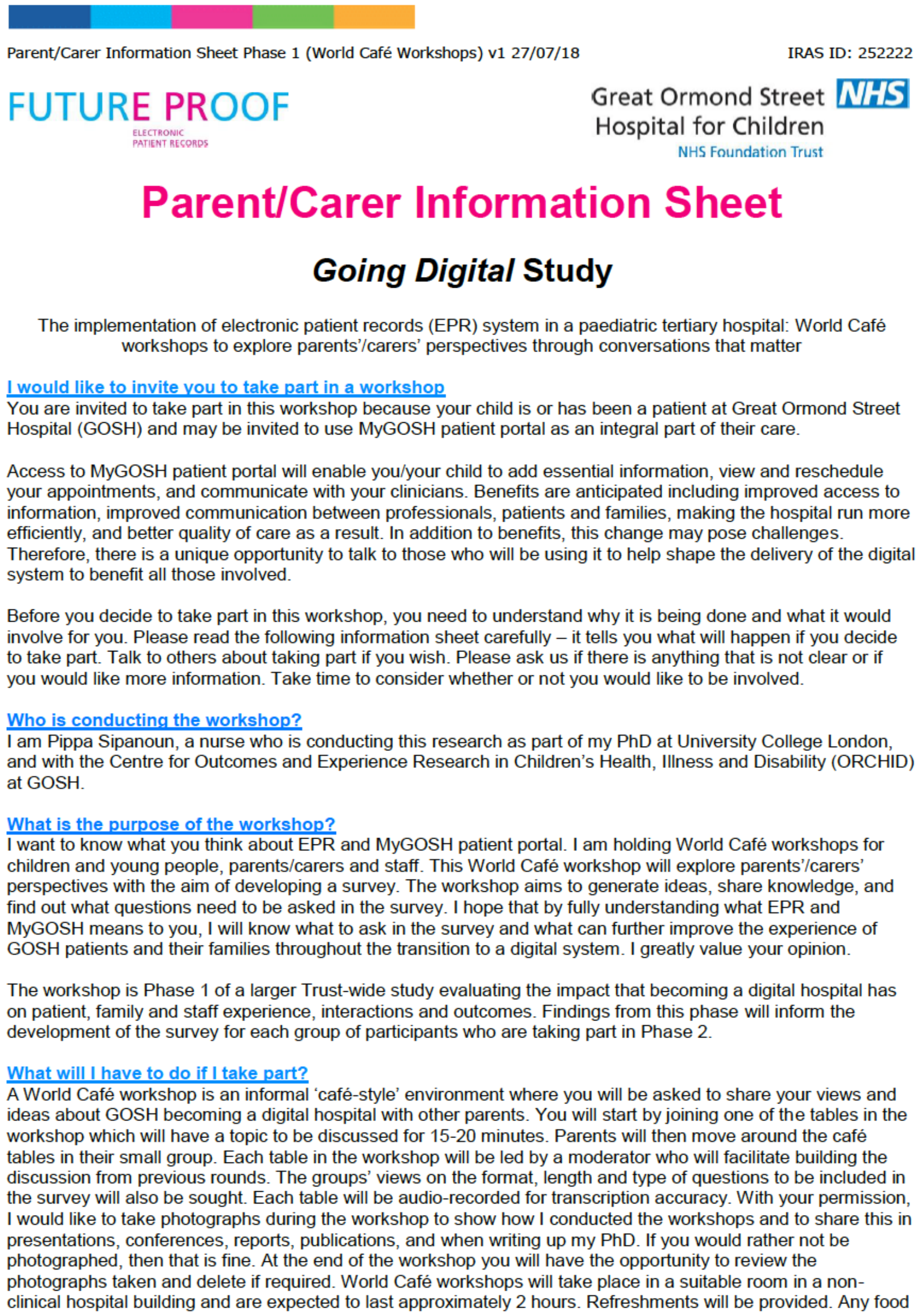
The aims of the study are to understand what the benefits and challenges of introducing EPR and the MyGOSH patient portal are for patients, parents and staff as well as any practical, ethical and legal implications. We will collect data before and after implementation of EPIC EPR system to see what Going Digital means to all stakeholders involved.

Phase 1 of this study, pre EPR being introduced, involves workshops with children and young people, parents and staff to understand their views, with the results informing a survey for each participant group that will then be sent Trust-wide.

The research is being undertaken by Pippa Sipanoun, a nurse who has worked in the Trust for many years, but is now studying her PhD. The workshop will be held on *******. Refreshments will be provided. If you would like more information or would like to be involved in the workshop please e-mail [redacted] or call on her work mobile: [redacted] Many thanks in advance.

Best wishes,

Appendix 19 – Phase 1 participant information sheet parent/carer



FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Parent/Carer Information Sheet

Going Digital Study

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshops to explore parents'/carers' perspectives through conversations that matter

I would like to invite you to take part in a workshop

You are invited to take part in this workshop because your child is or has been a patient at Great Ormond Street Hospital (GOSH) and may be invited to use MyGOSH patient portal as an integral part of their care.

Access to MyGOSH patient portal will enable you/your child to add essential information, view and reschedule your appointments, and communicate with your clinicians. Benefits are anticipated including improved access to information, improved communication between professionals, patients and families, making the hospital run more efficiently, and better quality of care as a result. In addition to benefits, this change may pose challenges. Therefore, there is a unique opportunity to talk to those who will be using it to help shape the delivery of the digital system to benefit all those involved.

Before you decide to take part in this workshop, you need to understand why it is being done and what it would involve for you. Please read the following information sheet carefully – it tells you what will happen if you decide to take part. Talk to others about taking part if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to consider whether or not you would like to be involved.

Who is conducting the workshop?

I am Pippa Sipanoun, a nurse who is conducting this research as part of my PhD at University College London, and with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at GOSH.

What is the purpose of the workshop?

I want to know what you think about EPR and MyGOSH patient portal. I am holding World Café workshops for children and young people, parents/carers and staff. This World Café workshop will explore parents'/carers' perspectives with the aim of developing a survey. The workshop aims to generate ideas, share knowledge, and find out what questions need to be asked in the survey. I hope that by fully understanding what EPR and MyGOSH means to you, I will know what to ask in the survey and what can further improve the experience of GOSH patients and their families throughout the transition to a digital system. I greatly value your opinion.

The workshop is Phase 1 of a larger Trust-wide study evaluating the impact that becoming a digital hospital has on patient, family and staff experience, interactions and outcomes. Findings from this phase will inform the development of the survey for each group of participants who are taking part in Phase 2.

What will I have to do if I take part?

A World Café workshop is an informal 'café-style' environment where you will be asked to share your views and ideas about GOSH becoming a digital hospital with other parents. You will start by joining one of the tables in the workshop which will have a topic to be discussed for 15-20 minutes. Parents will then move around the café tables in their small group. Each table in the workshop will be led by a moderator who will facilitate building the discussion from previous rounds. The groups' views on the format, length and type of questions to be included in the survey will also be sought. Each table will be audio-recorded for transcription accuracy. With your permission, I would like to take photographs during the workshop to show how I conducted the workshops and to share this in presentations, conferences, reports, publications, and when writing up my PhD. If you would rather not be photographed, then that is fine. At the end of the workshop you will have the opportunity to review the photographs taken and delete if required. World Café workshops will take place in a suitable room in a non-clinical hospital building and are expected to last approximately 2 hours. Refreshments will be provided. Any food value your expertise as a parent and your views are an important contribution to this study.

Will my data be kept confidential?

Yes. All information collected during this study will be kept confidential, which means only the research team will be able to see it. If I share any results, these will be kept anonymous, which means that you will not be able to be identified. The only reason I would break confidentiality and share any information is if I felt concerned about your or your child's safety.

What if I don't want to carry on with the study?

If you agree to take part in the study you have the right to stop at any time, without giving a reason. If you choose to withdraw, the care of you and your child will not be affected in any way. However, with your permission I would still like to use the data collected up to that point.

How will the data be kept secure and what happens to the data at the end of the study?

All paper data will be stored in a locked filing cabinet, which is located in a research office at GOSH only accessible by a swipe card. Personal identifiable data and consent forms will be stored separately to research data. Electronic data is stored on password protected servers accessed by Trust computers and encrypted laptops. Photographs taken during the workshops will be stored using password-protected software and used only with expressed consent. At the end of the study personal data will only be stored and accessed for up to 6 months, unless a report of study findings is requested, then until end of study (3 years). Research data will be stored in accordance with GOSH Trust and UCL policies.

What will happen to the results of the study?

All World Café participants will be invited to receive a copy of the survey once developed to pilot it. A report of the study findings will be available upon request. The results will be published and presented so they can be shared with other healthcare professionals and researchers. All data that is shared will be anonymised so that children and young people, parents and staff members cannot be identified.

Data Protection Privacy Notice

UCL Great Ormond Street Institute of Child Health (UCL GOS ICH) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. UCL GOS ICH will keep identifiable information about you for 15 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The research team from Great Ormond Street Hospital will keep your name and contact details confidential and will not pass this information to UCL GOS ICH. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from UCL GOS ICH and regulatory organisations may look at your research records to check the accuracy of the research study. UCL GOS ICH will only receive information without any identifying information. The people who analyse the information will not be able to find out your name or contact details. Photographs will be used only with expressed consent, as described.

You can find out more about how we use your information by contacting Lee Shailer, the Data Protection Officer, at data-protection@ucl.ac.uk.

Who should I contact if I have any questions?

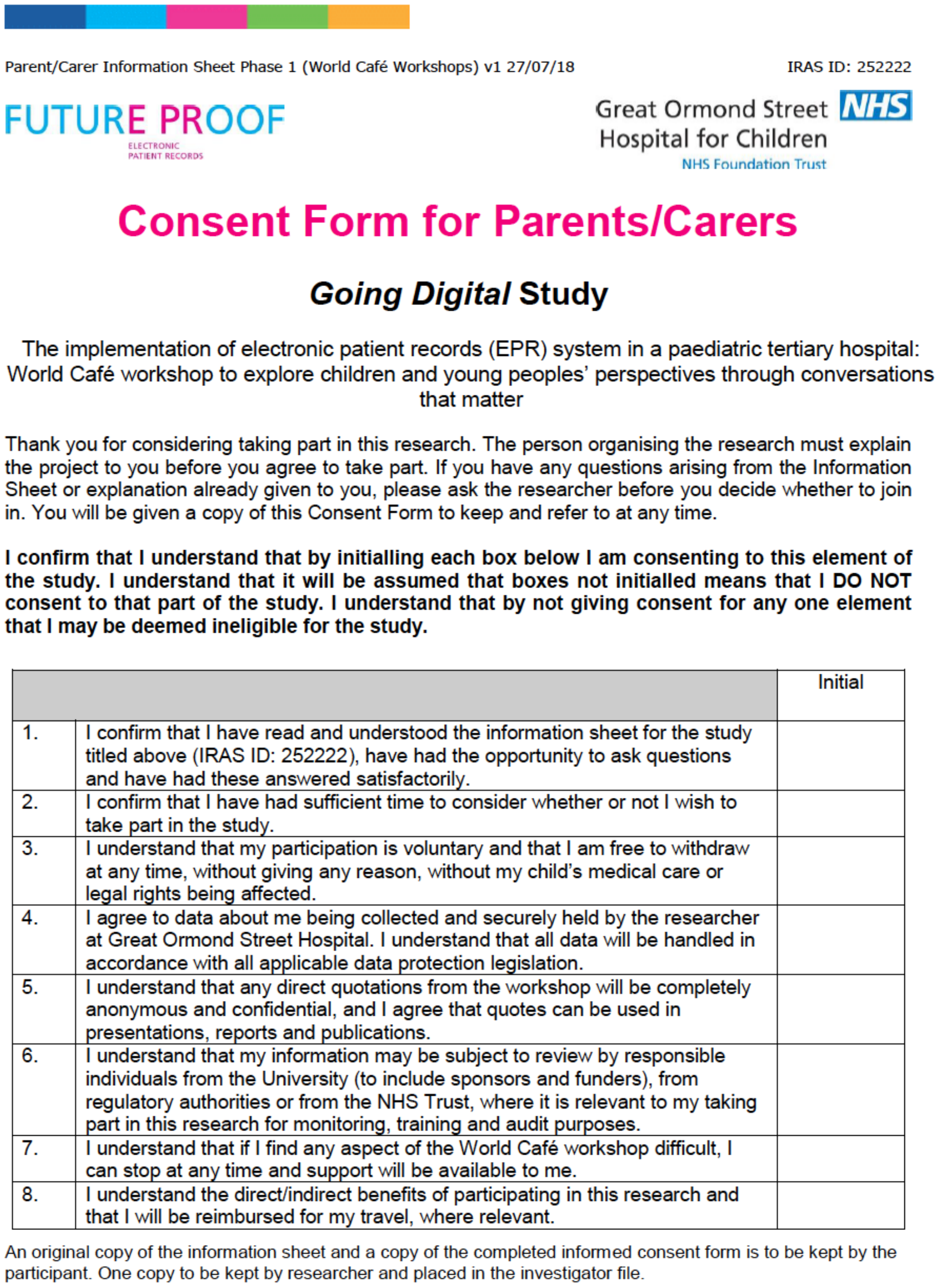
[redacted]

What if I have any concerns about the study?

If you have any concerns or other questions about this study or the way it has been carried out, please talk to a member of the research team. If you remain unhappy, or wish to comment in any other way, you can contact the Patient Advice and Liaison Service (PALs) on 020 7829 7862 or email: pals@gosh.nhs.uk

Thank you for taking the time to read this leaflet
This study is being funded by Great Ormond Street Hospital for Children

Appendix 20 – Phase 1 informed consent form parent/carer



Parent/Carer Information Sheet Phase 1 (World Café Workshops) v1 27/07/18

IRAS ID: 252222

FUTURE PROOF
ELECTRONIC PATIENT RECORDS

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Consent Form for Parents/Carers

Going Digital Study

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshop to explore children and young peoples' perspectives through conversations that matter

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that boxes not initialled means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Initial
1.	I confirm that I have read and understood the information sheet for the study titled above (IRAS ID: 252222), have had the opportunity to ask questions and have had these answered satisfactorily.	
2.	I confirm that I have had sufficient time to consider whether or not I wish to take part in the study.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child's medical care or legal rights being affected.	
4.	I agree to data about me being collected and securely held by the researcher at Great Ormond Street Hospital. I understand that all data will be handled in accordance with all applicable data protection legislation.	
5.	I understand that any direct quotations from the workshop will be completely anonymous and confidential, and I agree that quotes can be used in presentations, reports and publications.	
6.	I understand that my information may be subject to review by responsible individuals from the University (to include sponsors and funders), from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research for monitoring, training and audit purposes.	
7.	I understand that if I find any aspect of the World Café workshop difficult, I can stop at any time and support will be available to me.	
8.	I understand the direct/indirect benefits of participating in this research and that I will be reimbursed for my travel, where relevant.	

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file.

9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I agree to the workshop being audio-recorded.	
11.	I agree to photographs of me being taken during the World Café workshop. The photographs will be stored using password protected software and will be used during dissemination of the research findings at conferences and presentations, and for the writing up of the researcher's PhD.	
12.	I agree to take part in the Wold Café workshop.	
13.	I agree to being sent the survey, which has been informed by the workshop, to pilot it (please supply e-mail address).	

Full name of Parent Date Signature

Parent's e-mail address Telephone number:

Full name of Person Obtaining Consent Date Signature

Who should I contact if I have any questions?

[redacted]

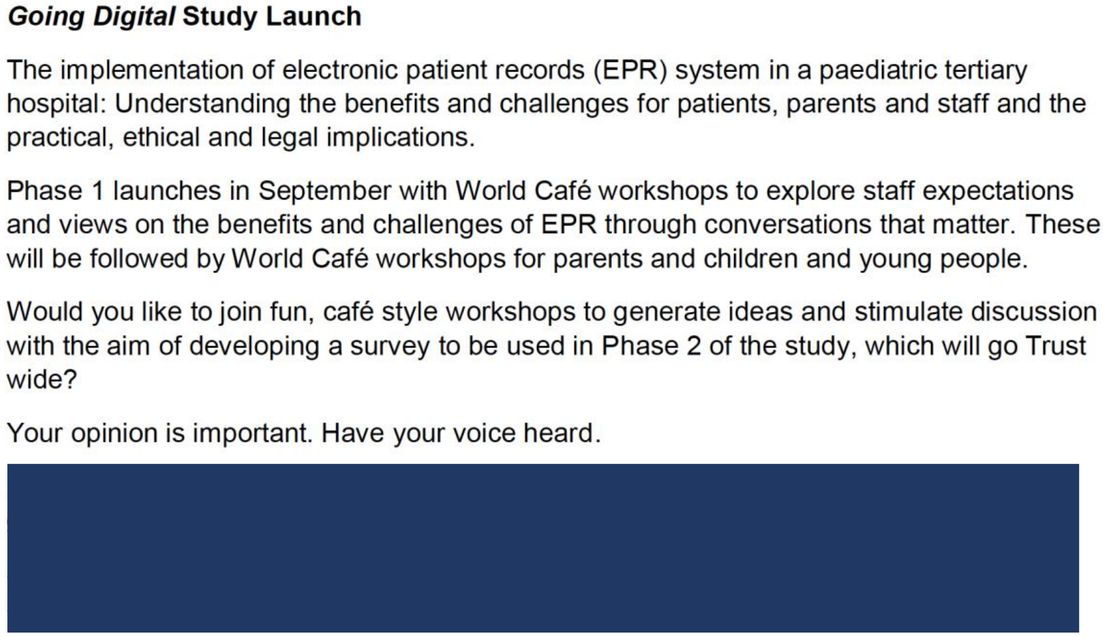
Thank you for taking the time to read this leaflet

This study is being funded by Great Ormond Street Hospital for Children

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file.

Appendix 21 – Phase 1 staff recruitment information

EPR Newsletter:



Going Digital Study Launch

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications.

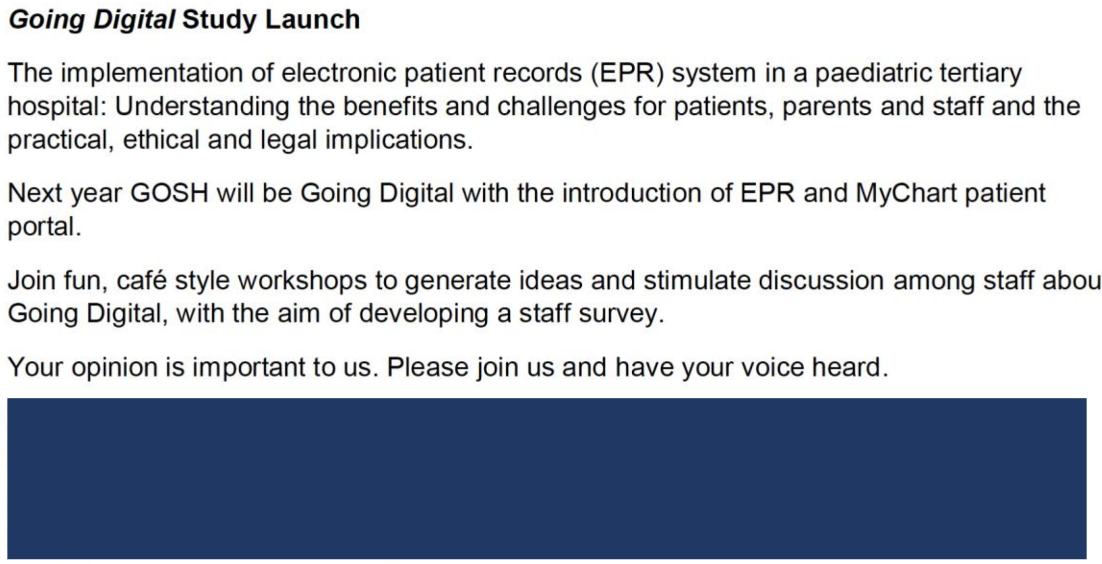
Phase 1 launches in September with World Café workshops to explore staff expectations and views on the benefits and challenges of EPR through conversations that matter. These will be followed by World Café workshops for parents and children and young people.

Would you like to join fun, café style workshops to generate ideas and stimulate discussion with the aim of developing a survey to be used in Phase 2 of the study, which will go Trust wide?

Your opinion is important. Have your voice heard.

[redacted]

Trust Newsletter:



Going Digital Study Launch

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications.

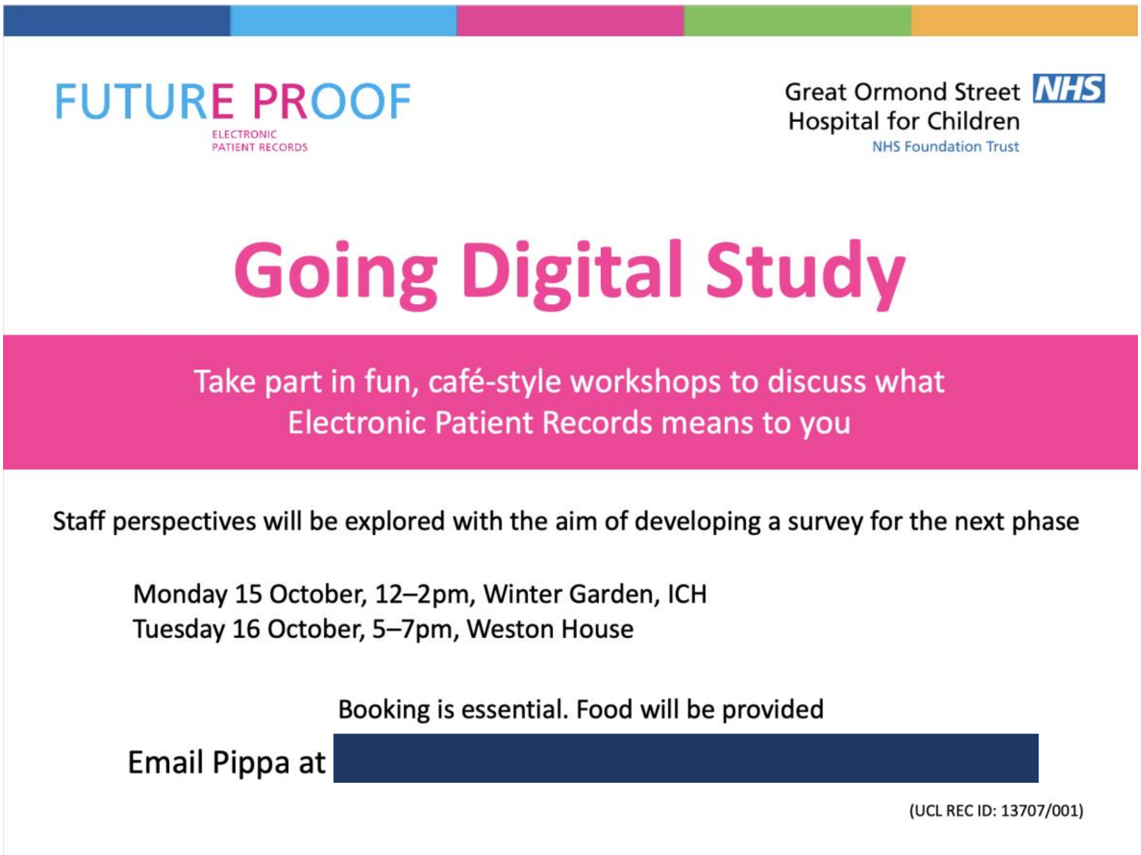
Next year GOSH will be Going Digital with the introduction of EPR and MyChart patient portal.

Join fun, café style workshops to generate ideas and stimulate discussion among staff about Going Digital, with the aim of developing a staff survey.

Your opinion is important to us. Please join us and have your voice heard.

[redacted]

Trust screensaver:



FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Going Digital Study

Take part in fun, café-style workshops to discuss what Electronic Patient Records means to you

Staff perspectives will be explored with the aim of developing a survey for the next phase

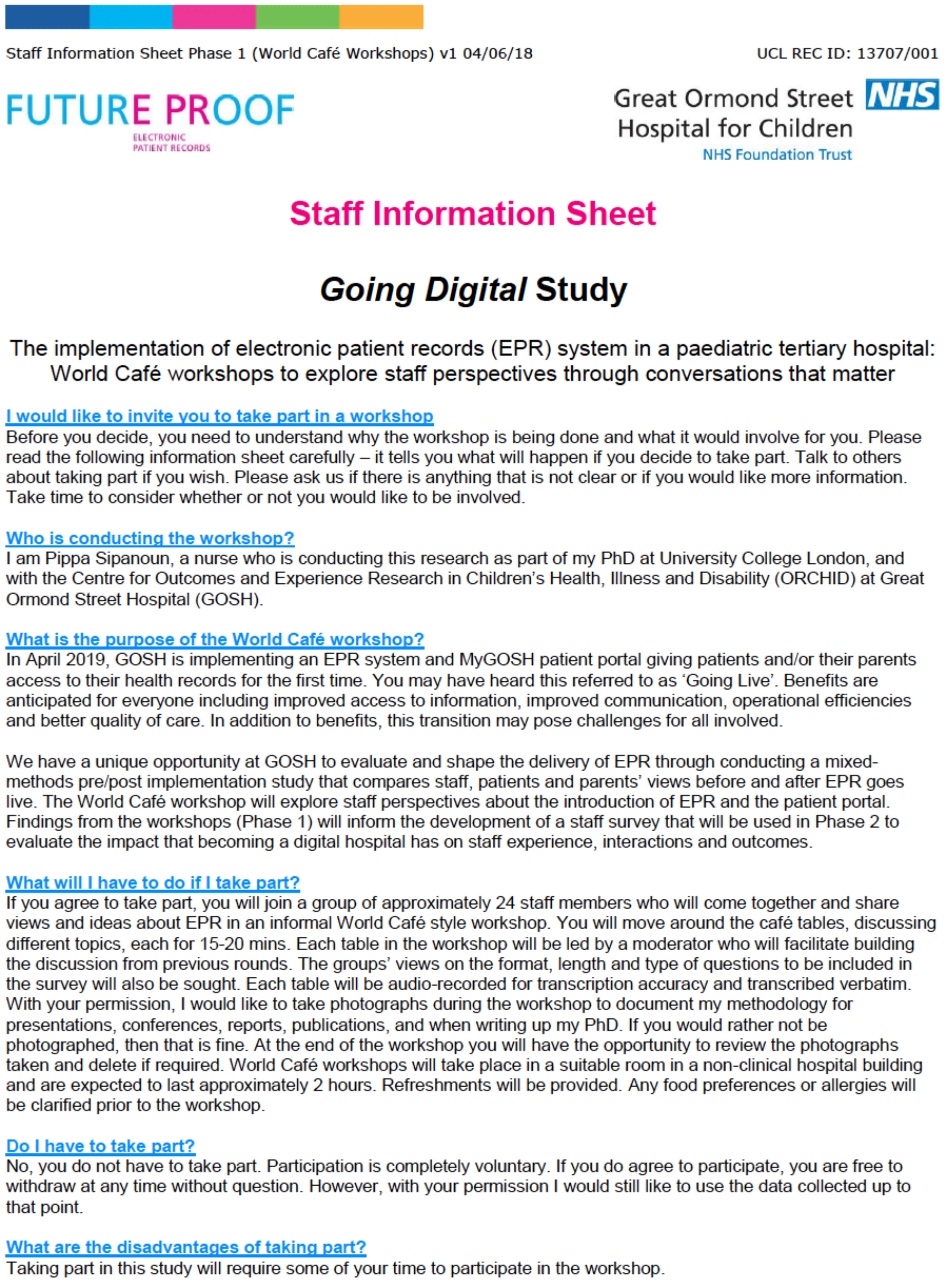
Monday 15 October, 12–2pm, Winter Garden, ICH
Tuesday 16 October, 5–7pm, Weston House

Booking is essential. Food will be provided

Email Pippa at [redacted]

(UCL REC ID: 13707/001)

Appendix 22 – Phase 1 participant information sheet staff



Staff Information Sheet Phase 1 (World Café Workshops) v1 04/06/18

UCL REC ID: 13707/001

FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

Great Ormond Street NHS
Hospital for Children
NHS Foundation Trust

Staff Information Sheet

Going Digital Study

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshops to explore staff perspectives through conversations that matter

I would like to invite you to take part in a workshop

Before you decide, you need to understand why the workshop is being done and what it would involve for you. Please read the following information sheet carefully – it tells you what will happen if you decide to take part. Talk to others about taking part if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to consider whether or not you would like to be involved.

Who is conducting the workshop?

I am Pippa Sipanoun, a nurse who is conducting this research as part of my PhD at University College London, and with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at Great Ormond Street Hospital (GOSH).

What is the purpose of the World Café workshop?

In April 2019, GOSH is implementing an EPR system and MyGOSH patient portal giving patients and/or their parents access to their health records for the first time. You may have heard this referred to as 'Going Live'. Benefits are anticipated for everyone including improved access to information, improved communication, operational efficiencies and better quality of care. In addition to benefits, this transition may pose challenges for all involved.

We have a unique opportunity at GOSH to evaluate and shape the delivery of EPR through conducting a mixed-methods pre/post implementation study that compares staff, patients and parents' views before and after EPR goes live. The World Café workshop will explore staff perspectives about the introduction of EPR and the patient portal. Findings from the workshops (Phase 1) will inform the development of a staff survey that will be used in Phase 2 to evaluate the impact that becoming a digital hospital has on staff experience, interactions and outcomes.

What will I have to do if I take part?

If you agree to take part, you will join a group of approximately 24 staff members who will come together and share views and ideas about EPR in an informal World Café style workshop. You will move around the café tables, discussing different topics, each for 15-20 mins. Each table in the workshop will be led by a moderator who will facilitate building the discussion from previous rounds. The groups' views on the format, length and type of questions to be included in the survey will also be sought. Each table will be audio-recorded for transcription accuracy and transcribed verbatim. With your permission, I would like to take photographs during the workshop to document my methodology for presentations, conferences, reports, publications, and when writing up my PhD. If you would rather not be photographed, then that is fine. At the end of the workshop you will have the opportunity to review the photographs taken and delete if required. World Café workshops will take place in a suitable room in a non-clinical hospital building and are expected to last approximately 2 hours. Refreshments will be provided. Any food preferences or allergies will be clarified prior to the workshop.

Do I have to take part?

No, you do not have to take part. Participation is completely voluntary. If you do agree to participate, you are free to withdraw at any time without question. However, with your permission I would still like to use the data collected up to that point.

What are the disadvantages of taking part?

Taking part in this study will require some of your time to participate in the workshop.

What are the advantages of taking part?

I cannot promise that taking part in this study will benefit you personally, although you may value the opportunity to share your views in the knowledge that your contribution will help shape EPR and MyGOSH for the future. I value your expertise and your views are an important contribution to this study.

Confidentiality

All information collected during the course of the research will be kept confidential and will be used solely for the purposes of the research and its dissemination. Only members of the research team, sponsor and regulatory bodies will have access to the data collected, all of which will be anonymised so that no participants can be identified.

How will the data be kept secure and what happens to the data at the end of the study?

All paper data will be stored in a locked filing cabinet, which is located in a research office at GOSH only accessible by a swipe card. Personal identifiable data and consent forms will be stored separately to research data. Electronic data is stored on password protected servers accessed by Trust computers and encrypted laptops. Photographs taken during the workshops will be stored using password-protected software and used only with expressed consent. Personal data will only be stored and accessed for up to 6 months after the end of the full 3 year study. Research data will be stored in accordance with GOSH Trust and UCL policies.

What will happen to the results of the study?

With your consent you will receive a copy of the survey once developed to pilot it. A report of the study findings will be available upon request. The results will be published and presented so they can be shared with other healthcare professionals and researchers. All data that is shared will be anonymised so that children and young people, parents and staff members cannot be identified.

Data Protection Privacy Notice

The data controller for this project will be University College London (UCL. The UCL Data Protection office provides oversight of UCL activities involving the processing of personal data, and can be contacted on data-protection@ucl.ac.uk. UCL's Data Protection Officer (Lee Shailer) can also be contacted at data-protection@ucl.ac.uk. Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be performance of a task in the public interest. Your personal data will be processed so long as it is required for the research project. If I am able to anonymise or pseudonymise the personal data you provide I will undertake this, and will endeavor to minimize the processing of personal data wherever possible. If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individual-rights/.

Who should I contact if I have any questions?

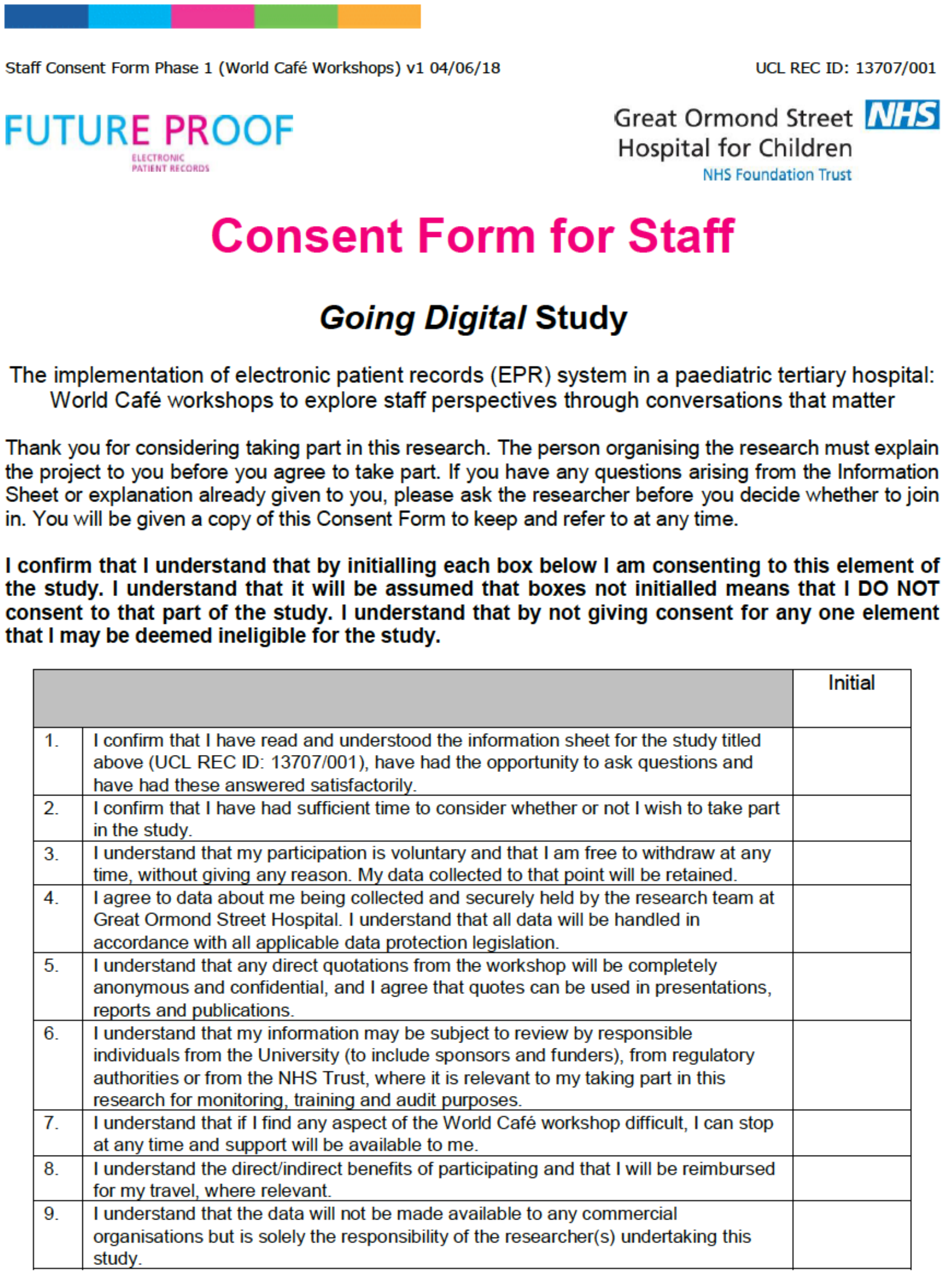
[redacted]

If you wish to raise a complaint about any aspect of this research please contact the Chief Investigator. If you feel that your complaint has not been handled to your satisfaction please contact the Chair of the UCL Research Ethics Committee: ethics@ucl.ac.uk

Thank you for taking the time to read this leaflet

This study is being funded by the Great Ormond Street Hospital for Children

Appendix 23 – Phase 1 informed consent form staff



FUTURE PROOF
ELECTRONIC PATIENT RECORDS

Great Ormond Street Hospital for Children NHS Foundation Trust

Consent Form for Staff

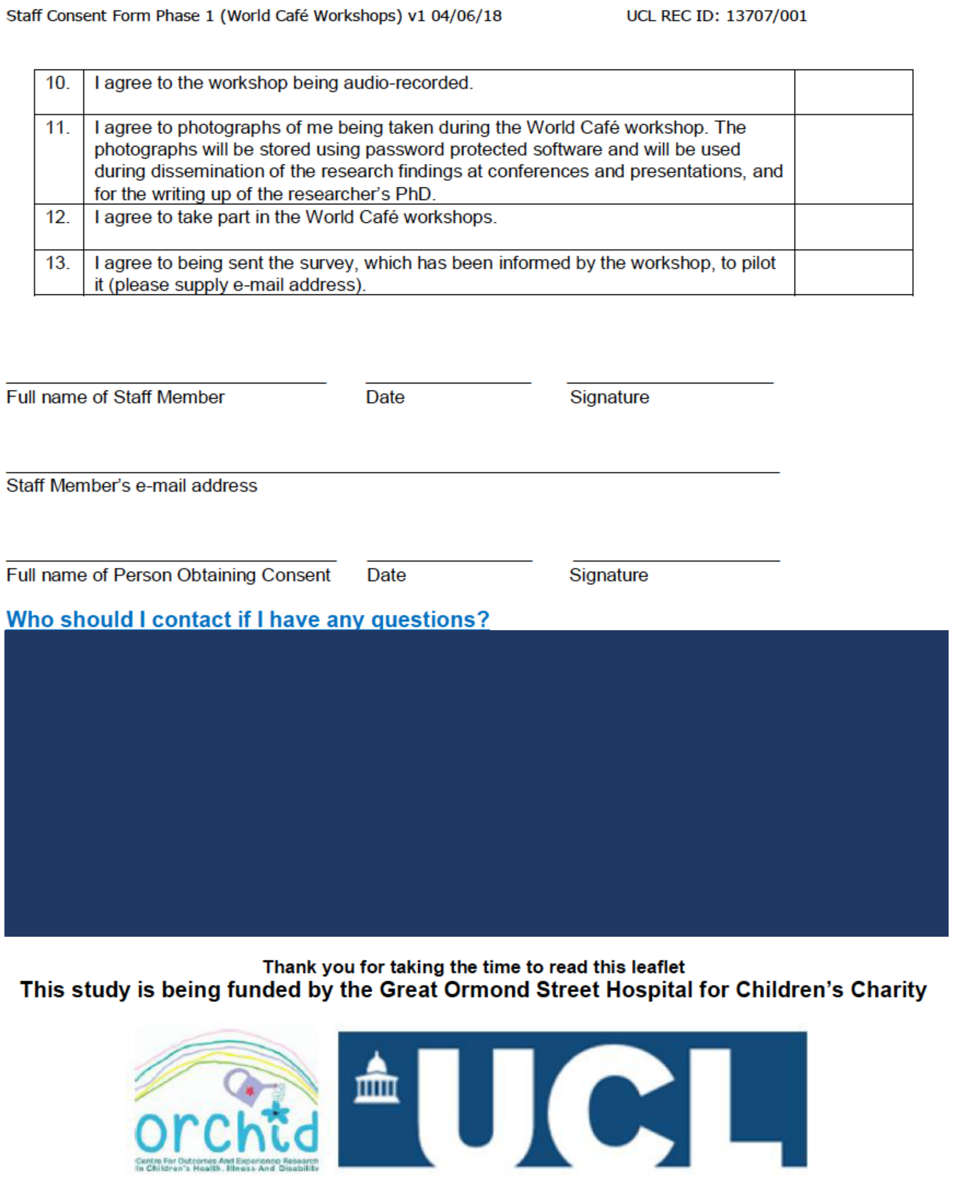
Going Digital Study

The implementation of electronic patient records (EPR) system in a paediatric tertiary hospital: World Café workshops to explore staff perspectives through conversations that matter

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that boxes not initialled means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Initial
1.	I confirm that I have read and understood the information sheet for the study titled above (UCL REC ID: 13707/001), have had the opportunity to ask questions and have had these answered satisfactorily.	
2.	I confirm that I have had sufficient time to consider whether or not I wish to take part in the study.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. My data collected to that point will be retained.	
4.	I agree to data about me being collected and securely held by the research team at Great Ormond Street Hospital. I understand that all data will be handled in accordance with all applicable data protection legislation.	
5.	I understand that any direct quotations from the workshop will be completely anonymous and confidential, and I agree that quotes can be used in presentations, reports and publications.	
6.	I understand that my information may be subject to review by responsible individuals from the University (to include sponsors and funders), from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research for monitoring, training and audit purposes.	
7.	I understand that if I find any aspect of the World Café workshop difficult, I can stop at any time and support will be available to me.	
8.	I understand the direct/indirect benefits of participating and that I will be reimbursed for my travel, where relevant.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	



Staff Consent Form Phase 1 (World Café Workshops) v1 04/06/18 UCL REC ID: 13707/001

10.	I agree to the workshop being audio-recorded.	
11.	I agree to photographs of me being taken during the World Café workshop. The photographs will be stored using password protected software and will be used during dissemination of the research findings at conferences and presentations, and for the writing up of the researcher's PhD.	
12.	I agree to take part in the World Café workshops.	
13.	I agree to being sent the survey, which has been informed by the workshop, to pilot it (please supply e-mail address).	

Full name of Staff Member ______ Date ______ Signature ______

Staff Member's e-mail address ______

Full name of Person Obtaining Consent ______ Date ______ Signature ______

Who should I contact if I have any questions?

[redacted]

Thank you for taking the time to read this leaflet

This study is being funded by the Great Ormond Street Hospital for Children's Charity

Appendix 24 – World café workshop topic guide

Example from the children's and young people's workshop.

There will be four tables within the World Café covering:

- Benefits of using EPR and MyGOSH
- Challenges of using EPR and MyGOSH
- Information and support needs when using EPR and MyGOSH
- Ethical and legal considerations of using an EPR system

Participants will divide into groups, each joining a table of their choice to start discussing a topic. Each session will last approximately 15-20 minutes. The moderators facilitate discussion about the benefits, challenges, information/support needs and legal/ethical implications. An additional researcher will take notes. Each table's discussion will be audio recorded with the participants' consent. At the end of the session 5-10 minutes will be spent asking questions to the group specific to the survey such as:

- How long should the survey be?
- How long would you like the survey to be available for?
- In what format would you like it? Electronic/paper?

Moderators will then move to an alternative table to discuss a different topic. There will also be a few minutes between each topic/table change for comfort breaks and refreshments.

Time will be allowed at the end of the workshop to show the photographs so that participants can review and delete, as appropriate.

Possible questions for each table to aide discussion:

1. **Benefits of using EPR and MyGOSH**
    - What do you hope to gain from GOSH using an EPR system?

- How do you foresee it benefitting you?
- What positive impact do you think using EPR will have on your day-to-day routine when coming to or staying in the hospital?
- What positive impact do you think using an EPR system have on care, children, their families, and the hospital?
- How will MyGOSH be useful to you?

Prompts: time/efficiencies/communication/clinics/access to information

2. **Challenges of EPR and MyGOSH**
    - What do you think the challenges of using MyGOSH might be for you?
    - What do you think the challenges of using an EPR system might be for the hospital?
    - What do you think the challenges of using MyGOSH might be for other patients/families at GOSH?
    - Are you worried about any aspect of having to use an EPR system/MyGOSH?
    - How can the challenges be remedied?

Prompts: time/efficiencies/communication/clinics/access to information/equal access/language (jargon/different languages)

3. **Information and support needs when using EPR and MyGOSH**

- What would you like to know about before EPR goes live in April 2019?
- What would you like to know about MyGOSH before using it?
- What support do you think needs to be available for you before, during and after implementation of MyGOSH?
- How long do you think support needs to be available for you after the system goes live?

Prompts: technical support/emotional support/accessing results/understanding MyGOSH content/understanding MyGOSH functionality/expectations for InBasket messaging response times

4. **Ethical and legal considerations of using EPR and MyGOSH?**

- Can you think of any ethical considerations associated with using an EPR system?
- Can you think of any legal considerations associated with using an EPR system?
- Can you think of any ethical considerations associated with children/families using MyGOSH patient portal?
- Can you think of any legal considerations associated with children/families using MyGOSH patient portal?
- Why do you think these are important?
- What do you think can be done to reassure people?

Prompts: ages for accessing MyGOSH/sole access at 16 years of age, not being given access, privacy of health information, sharing of health information

To help participants from the YPF think about the implications of GOSH becoming a digital hospital and to stimulate discussion about what the issues might be for different children and young people, each table will be given a scenario to related to the table’s topic. The moderators will ask the group to reflect on each scenario, drawing out views and building on each previous discussion.

Appendix 25 – World café workshop scenarios/ questions

Example from the children's and young people's workshop.

Benefits

- You will be able to message the important people in your care team through the portal. Do you think you would use this function?
- Your care team will put teaching and information on the portal to help you understand your condition and for you to achieve your best potential. Will you use this information?
- You will be able to take your information with you when transitioning to adult care. What do you think about that?

Challenges

- GOSH will no longer be keeping paper patient notes. How do you feel about everything being electronic?
- Do you feel that your personal information will be safe on an electronic system?
- A young person has been using their MyGOSH on the ward. They have gone to have an X-ray but not logged off from the system. Why could this be a problem?

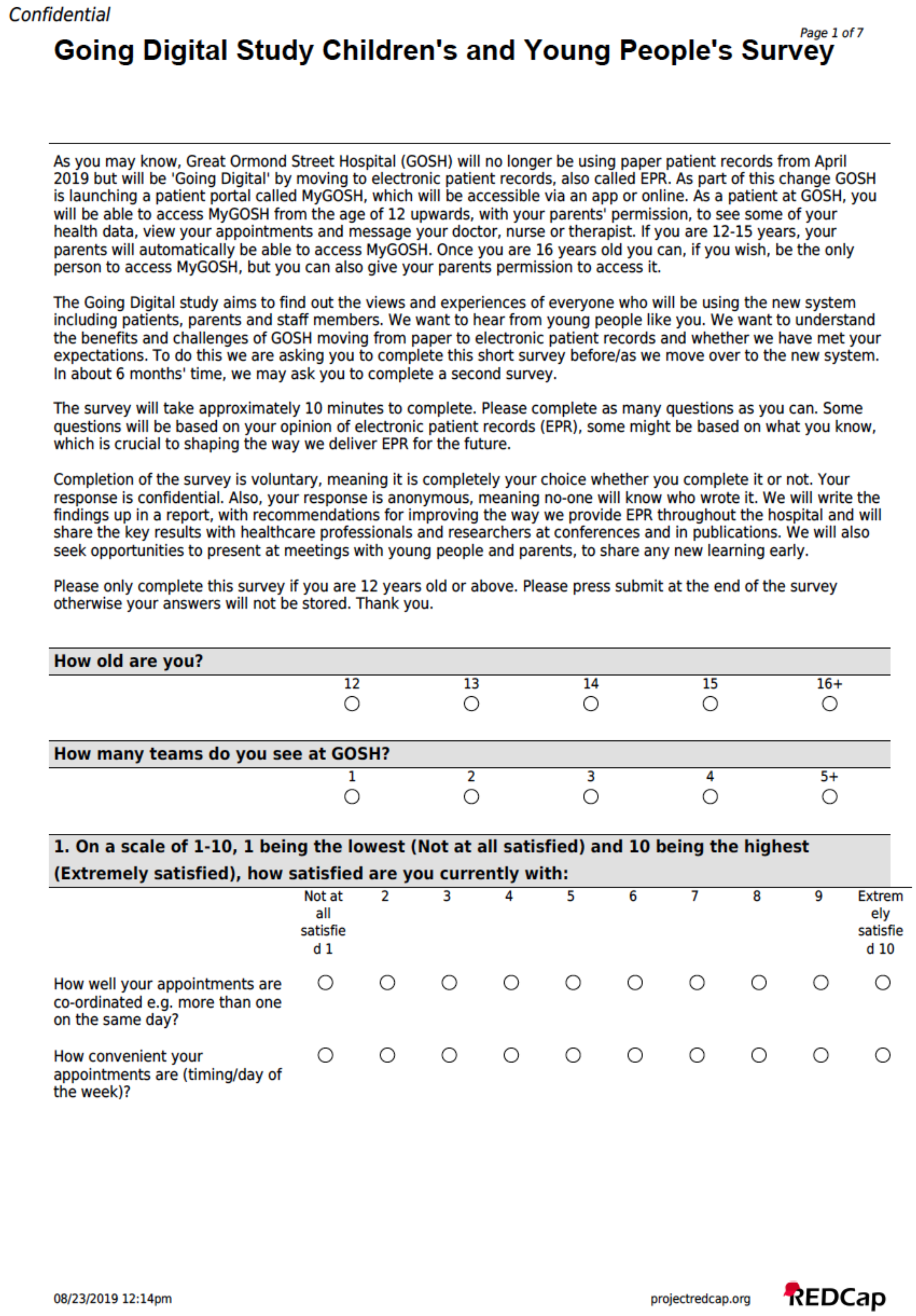
Info/support needs

- You have been to the hospital today and had some important tests done. You are waiting for the results to be released onto MyGOSH. When you see the results you have some questions about them as some are marked in red. It is now Friday evening. What will you do? How do you feel?
- What sort of technical support will you need when using MyGOSH?
- What sort of emotional support will you need when using MyGOSH?

Ethics/law

- Your friend, who has the same condition as you, has been posting their results on a Facebook group you both belong to. How do you feel about that? Would you put your results on there too? What do you think could happen to that information?
- You want to have access to MyGOSH, but your parents don’t want you to. How do you feel about that?
- You speak English but your parents don’t speak it as well as you. You will need to translate some medical information for them. What do you think the impact of this will be on you?
- You are a member of a Facebook group with other patients/siblings. Some members are posting messages from their doctors/nurses/ clinicians. Discuss

Appendix 26 – Children’s and young people’s baseline survey[xx]



Going Digital Study Children's and Young People's Survey

As you may know, Great Ormond Street Hospital (GOSH) will no longer be using paper patient records from April 2019 but will be 'Going Digital' by moving to electronic patient records, also called EPR. As part of this change GOSH is launching a patient portal called MyGOSH, which will be accessible via an app or online. As a patient at GOSH, you will be able to access MyGOSH from the age of 12 upwards, with your parents' permission, to see some of your health data, view your appointments and message your doctor, nurse or therapist. If you are 12-15 years, your parents will automatically be able to access MyGOSH. Once you are 16 years old you can, if you wish, be the only person to access MyGOSH, but you can also give your parents permission to access it.

The Going Digital study aims to find out the views and experiences of everyone who will be using the new system including patients, parents and staff members. We want to hear from young people like you. We want to understand the benefits and challenges of GOSH moving from paper to electronic patient records and whether we have met your expectations. To do this we are asking you to complete this short survey before/as we move over to the new system. In about 6 months' time, we may ask you to complete a second survey.

The survey will take approximately 10 minutes to complete. Please complete as many questions as you can. Some questions will be based on your opinion of electronic patient records (EPR), some might be based on what you know, which is crucial to shaping the way we deliver EPR for the future.

Completion of the survey is voluntary, meaning it is completely your choice whether you complete it or not. Your response is confidential. Also, your response is anonymous, meaning no-one will know who wrote it. We will write the findings up in a report, with recommendations for improving the way we provide EPR throughout the hospital and will share the key results with healthcare professionals and researchers at conferences and in publications. We will also seek opportunities to present at meetings with young people and parents, to share any new learning early.

Please only complete this survey if you are 12 years old or above. Please press submit at the end of the survey otherwise your answers will not be stored. Thank you.

How old are you?

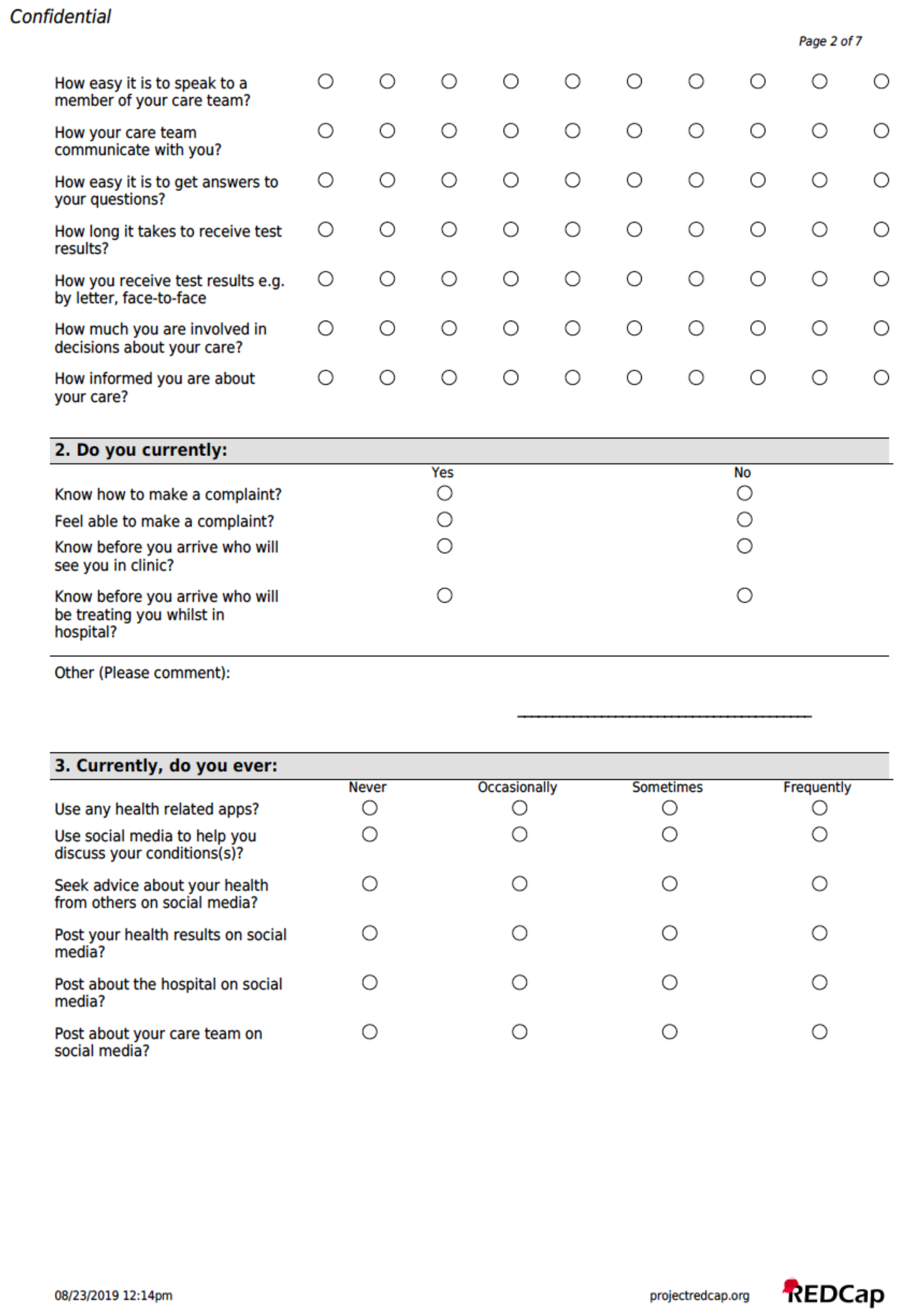
12	13	14	15	16+
○	○	○	○	○

How many teams do you see at GOSH?

1	2	3	4	5+
○	○	○	○	○

1. On a scale of 1-10, 1 being the lowest (Not at all satisfied) and 10 being the highest (Extremely satisfied), how satisfied are you currently with:

	Not at all satisfied 1	2	3	4	5	6	7	8	9	Extremely satisfied 10
How well your appointments are co-ordinated e.g. more than one on the same day?	○	○	○	○	○	○	○	○	○	○
How convenient your appointments are (timing/day of the week)?	○	○	○	○	○	○	○	○	○	○



Confidential

Page 2 of 7

How easy it is to speak to a member of your care team?	○	○	○	○	○	○	○	○	○	○
How your care team communicate with you?	○	○	○	○	○	○	○	○	○	○
How easy it is to get answers to your questions?	○	○	○	○	○	○	○	○	○	○
How long it takes to receive test results?	○	○	○	○	○	○	○	○	○	○
How you receive test results e.g. by letter, face-to-face	○	○	○	○	○	○	○	○	○	○
How much you are involved in decisions about your care?	○	○	○	○	○	○	○	○	○	○
How informed you are about your care?	○	○	○	○	○	○	○	○	○	○

2. Do you currently:

	Yes	No
Know how to make a complaint?	○	○
Feel able to make a complaint?	○	○
Know before you arrive who will see you in clinic?	○	○
Know before you arrive who will be treating you whilst in hospital?	○	○

Other (Please comment): ____

3. Currently, do you ever:

	Never	Occasionally	Sometimes	Frequently
Use any health related apps?	○	○	○	○
Use social media to help you discuss your conditions(s)?	○	○	○	○
Seek advice about your health from others on social media?	○	○	○	○
Post your health results on social media?	○	○	○	○
Post about the hospital on social media?	○	○	○	○
Post about your care team on social media?	○	○	○	○

08/23/2019 12:14pm

projectredcap.org

[xx] Please note that the pdf version of the surveys may not format in a fully aligned manner. The online version is aligned.

4. Please tick how much you disagree or agree with the following statements. MyGOSH will enable me to:

	Strongly disagree	Disagree	Agree	Strongly Agree	Don't know
Change appointments online with my parents to a convenient day/time	○	○	○	○	○
View my health results online	○	○	○	○	○
Communicate more easily with my care team	○	○	○	○	○
Access my up-to-date health data when I need it	○	○	○	○	○
Feel more involved in my care	○	○	○	○	○
Feel well informed about my care	○	○	○	○	○
Be more informed about my condition(s)	○	○	○	○	○
Feel more in control of my condition(s)	○	○	○	○	○
Feel in control of my health data	○	○	○	○	○
Check my health data is correct	○	○	○	○	○
See who is looking after me	○	○	○	○	○
Prepare me for coming to hospital	○	○	○	○	○
Prepare for moving to adult services	○	○	○	○	○

5. MyGOSH will improve:

	Strongly disagree	Disagree	Agree	Strongly Agree
Communication between me and my care team	○	○	○	○
Communication between my care team and my parents	○	○	○	○
Communication between teams looking after me	○	○	○	○
Knowledge my care team has about me and my condition(s)	○	○	○	○
Co-ordination of my care	○	○	○	○
The amount of involvement I have in decisions about my care	○	○	○	○
The amount of involvement my parents have in decisions about my care	○	○	○	○

6. I worry that MyGOSH will:

	Strongly disagree	Disagree	Agree	Strongly agree
Be difficult to use	○	○	○	○
Be difficult for my parents to use	○	○	○	○
Be difficult to access	○	○	○	○
Be difficult to understand	○	○	○	○
Cause me anxiety	○	○	○	○
Cause my parents anxiety	○	○	○	○
Cause conflict between staff and my parents	○	○	○	○
Cause conflict between me and my parents	○	○	○	○
Cause conflict between me and my care team	○	○	○	○
Not keep my health data safe from hacking	○	○	○	○
Not keep my health data confidential	○	○	○	○

7. I worry that:

	Strongly disagree	Disagree	Agree	Strongly Agree
I will not always have internet access to use MyGOSH	○	○	○	○
I will need support when accessing my results	○	○	○	○
I will read something I don't understand	○	○	○	○
I will read something I didn't want to read	○	○	○	○
I will not get answers to my questions quickly enough	○	○	○	○
I will constantly be reminded of my condition(s)	○	○	○	○
There will not be a paper back-up (copy) of my health data	○	○	○	○

8. I also worry that:

	Strongly disagree	Disagree	Agree	Strongly agree
Going from GOSH to a hospital without EPR will be difficult	○	○	○	○
My doctor/nurse/therapist will spend too long looking at a computer screen in clinic	○	○	○	○
There will be a loss of face-to-face contact	○	○	○	○
Someone may write the wrong patient's details in my online medical notes	○	○	○	○
The system may not cope with the amount of people using it	○	○	○	○
When using my health data for research, people will be able to identify me	○	○	○	○

9. I want to know:

	Strongly disagree	Disagree	Agree	Strongly agree
My health data is safe from hacking	○	○	○	○
My health data is backed up	○	○	○	○
My health data will be kept private	○	○	○	○
Who is looking at my health data	○	○	○	○
Which doctor/nurse/therapist I will see at the hospital	○	○	○	○
What happens when the system goes down	○	○	○	○
If there will be guidance on how to use MyGOSH	○	○	○	○
If there will be guidance on using the messaging service	○	○	○	○
I will get the technical help I need when using MyGOSH	○	○	○	○
I will get the emotional support I need when using MyGOSH	○	○	○	○

10. Do you think the lower age limit of 12 for being able to access MyGOSH (with your parents' consent) is okay?

	Yes	No
	○	○

Other (Please comment): ______________________________

11. When I turn 16, I will give permission for my parents to access MyGOSH (if you are already 16 or above will you give your parents permission)?

	Yes	No	Not sure
	○	○	○

Other (Please comment): ______________________________

12. I feel well informed about MyGOSH.

	Very	Somewhat	Not at all
	○	○	○

Other (Please comment): ______________________________

13. MyGOSH will be difficult for some people to access. Please tick if you have concerns about being able to access MyGOSH for any of the following reasons:

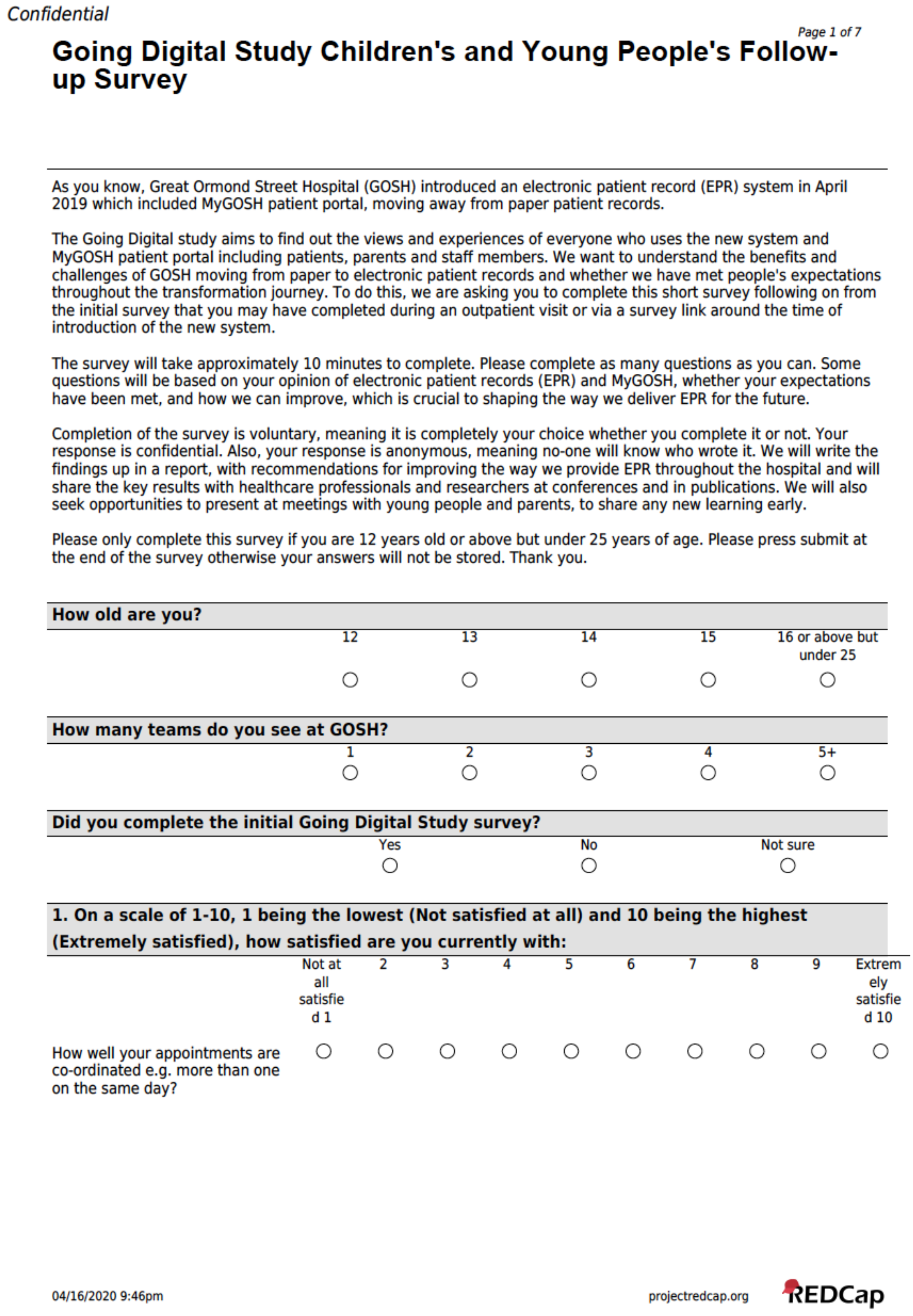
☐ English is not your first language
☐ English is not your parent's first language
☐ You are not confident using a computer/electronic device
☐ You have a learning disability
☐ Your parent has a learning disability
☐ You have a sensory impairment (sight/hearing)
☐ Your parent has a sensory impairment (sight/hearing)
☐ You have a physical impairment
☐ Your parent has a physical impairment
☐ You may be too ill to use it
☐ Your parent may be too ill to use it

Other (Please state):

Thank you for taking the time to complete this survey. We value any opinions you choose to share with us. If there is anything you think we should have asked you about the EPR system or MyGOSH please comment and use the space provided. Also, if you would like to be sent the follow-up survey please provide your e-mail below:

[redacted]

Appendix 27 – Children's and young people's follow-up survey



Going Digital Study Children's and Young People's Follow-up Survey

---

As you know, Great Ormond Street Hospital (GOSH) introduced an electronic patient record (EPR) system in April 2019 which included MyGOSH patient portal, moving away from paper patient records.

The Going Digital study aims to find out the views and experiences of everyone who uses the new system and MyGOSH patient portal including patients, parents and staff members. We want to understand the benefits and challenges of GOSH moving from paper to electronic patient records and whether we have met people's expectations throughout the transformation journey. To do this, we are asking you to complete this short survey following on from the initial survey that you may have completed during an outpatient visit or via a survey link around the time of introduction of the new system.

The survey will take approximately 10 minutes to complete. Please complete as many questions as you can. Some questions will be based on your opinion of electronic patient records (EPR) and MyGOSH, whether your expectations have been met, and how we can improve, which is crucial to shaping the way we deliver EPR for the future.

Completion of the survey is voluntary, meaning it is completely your choice whether you complete it or not. Your response is confidential. Also, your response is anonymous, meaning no-one will know who wrote it. We will write the findings up in a report, with recommendations for improving the way we provide EPR throughout the hospital and will share the key results with healthcare professionals and researchers at conferences and in publications. We will also seek opportunities to present at meetings with young people and parents, to share any new learning early.

Please only complete this survey if you are 12 years old or above but under 25 years of age. Please press submit at the end of the survey otherwise your answers will not be stored. Thank you.

How old are you?

12	13	14	15	16 or above but under 25
○	○	○	○	○

How many teams do you see at GOSH?

1	2	3	4	5+
○	○	○	○	○

Did you complete the initial Going Digital Study survey?

Yes	No	Not sure
○	○	○

1. On a scale of 1-10, 1 being the lowest (Not satisfied at all) and 10 being the highest (Extremely satisfied), how satisfied are you currently with:

	Not at all satisfied 1	2	3	4	5	6	7	8	9	Extremely satisfied 10
How well your appointments are co-ordinated e.g. more than one on the same day?	○	○	○	○	○	○	○	○	○	○

How convenient your appointments are (timing/day of the week)?	○	○	○	○	○	○	○	○	○	○
How easy it is to speak to a member of your care team?	○	○	○	○	○	○	○	○	○	○
How your care team communicate with you?	○	○	○	○	○	○	○	○	○	○
How easy it is to get answers to your questions?	○	○	○	○	○	○	○	○	○	○
How long it takes to receive test results?	○	○	○	○	○	○	○	○	○	○
How you receive test results e.g. by letter, face-to-face	○	○	○	○	○	○	○	○	○	○
How much you are involved in decisions about your care?	○	○	○	○	○	○	○	○	○	○
How informed you are about your care?	○	○	○	○	○	○	○	○	○	○

2. Do you currently:

	Yes	No
Know how to make a complaint?	○	○
Feel able to make a complaint?	○	○
Know before you arrive who will see you in clinic?	○	○
Know before you arrive who will be treating you whilst in hospital?	○	○

Other (Please comment): ________________________________

3. Currently, do you ever:

	Never	Occasionally	Sometimes	Frequently
Use any health related apps?	○	○	○	○
Use social media to help you discuss your conditions(s)?	○	○	○	○
Seek advice about your health from others on social media?	○	○	○	○
Post your health results on social media?	○	○	○	○
Post about the hospital on social media?	○	○	○	○

Post about your care team on social media?	○	○	○	○

4. Please tick how much you disagree or agree with the following statements. MyGOSH enables me to:

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Change appointments online with my parents to a convenient day/time	○	○	○	○	○
View my health results online	○	○	○	○	○
Communicate more easily with my care team	○	○	○	○	○
Access my up-to-date health data when I need it	○	○	○	○	○
Feel more involved in my care	○	○	○	○	○
Feel well informed about my care	○	○	○	○	○
Be more informed about my condition(s)	○	○	○	○	○
Feel more in control of my condition(s)	○	○	○	○	○
Feel in control of my health data	○	○	○	○	○
Check my health data is correct	○	○	○	○	○
See who is looking after me	○	○	○	○	○
Prepare me for coming to hospital	○	○	○	○	○
Prepare me for moving to adult services	○	○	○	○	○

5. MyGOSH has improved:

	Strongly disagree	Disagree	Agree	Strongly agree
Communication between me and my care team	○	○	○	○
Communication between my care team and my parents	○	○	○	○
Communication between teams looking after me	○	○	○	○
Knowledge my care team has about me and my condition(s)	○	○	○	○
Co-ordination of my care	○	○	○	○
The amount of involvement I have in decisions about my care	○	○	○	○

The amount of involvement my parents have in decisions about my care	○	○	○	○

6. MyGOSH:

	Strongly disagree	Disagree	Agree	Strongly agree
Is difficult to use	○	○	○	○
Is difficult for my parents to use	○	○	○	○
Is difficult to access	○	○	○	○
Is difficult to understand	○	○	○	○
Causes me anxiety	○	○	○	○
Causes my parents anxiety	○	○	○	○
Causes conflict between staff and my parents	○	○	○	○
Causes conflict between me and my parents	○	○	○	○
Causes conflict between me and my care team	○	○	○	○

7. Do you disagree or agree with the following statements:

	Strongly disagree	Disagree	Agree	Strongly agree
I don't always have internet access to use MyGOSH	○	○	○	○
I need support when accessing my results	○	○	○	○
I have read something I don't understand	○	○	○	○
I have read something I didn't want to read	○	○	○	○
I do not get answers to my questions quickly enough	○	○	○	○
I am constantly reminded of my condition(s)	○	○	○	○
I worry there is not a paper back-up (copy) of my health data	○	○	○	○

8. I have found that:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Going from GOSH to a hospital without EPR is difficult	○	○	○	○	○
My doctor/nurse/therapist spend too long looking at a computer screen in clinic	○	○	○	○	○
There is a loss of face-to-face contact	○	○	○	○	○

	Strongly disagree	Disagree	Agree	Strongly agree
The system does not cope with the amount of people using it	○	○	○	○

9. I know:

	Strongly disagree	Disagree	Agree	Strongly agree
My health data is safe from hacking	○	○	○	○
My health data is backed up	○	○	○	○
My health data is kept private	○	○	○	○
Who is looking at my health data	○	○	○	○
In advance which doctor/nurse/therapist I will see at the hospital	○	○	○	○
What happens when the system goes down	○	○	○	○
There is guidance on how to use MyGOSH	○	○	○	○
There is guidance on using the messaging service	○	○	○	○
I get the technical help I need when using MyGOSH	○	○	○	○
I get the emotional support I need when using MyGOSH	○	○	○	○

10. Do you think the lower age limit of 12 for being able to access MyGOSH (with your parents' consent) is okay?

Yes	No
○	○

Other (Please comment): ________________________________

11. When I turn 16 I will give permission for my parents to access MyGOSH (if you are already 16 or above will you give your parents permission)?

	Yes	No	Not sure
	○	○	○

Other (Please comment): ______________________________

12. I feel well informed about MyGOSH.

	Very	Somewhat	Not at all
	○	○	○

Other (Please comment): ______________________________

13. MyGOSH is difficult for some people to access. Please tick if you have concerns about being able to access MyGOSH for any of the following reasons:

☐ English is not your first language
☐ English is not your parent's first language
☐ You are not confident using a computer/electronic device
☐ You have a learning difficulty or disability
☐ Your parent has a learning difficulty or disability
☐ You have a sensory impairment (sight/hearing)
☐ Your parent has a sensory impairment (sight/hearing)
☐ You have a physical impairment
☐ Your parent has a physical impairment
☐ You may be too ill to use it
☐ Your parent may be too ill to use it

Other (Please state):

14. Please tell us a little about you and your family:

Who lives at home with you?

☐ Mother
☐ Father
☐ Legal Guardian / person with parental responsibility
☐ Brother/s
☐ Sister/s
☐ Other family
☐ Other

What languages are spoken at home? ______________________________

Your ethnicity

○ White British
○ White Irish
○ Any other white background
○ Mixed - white and black Caribbean
○ Mixed - White and black African
○ Mixed - White and Asian
○ Any other mixed background
○ Indian
○ Pakistani
○ Bangladeshi
○ Any other Asian background
○ Black or black British - Caribbean
○ Black or black British - African
○ Any other black background
○ Chinese
○ Any other background

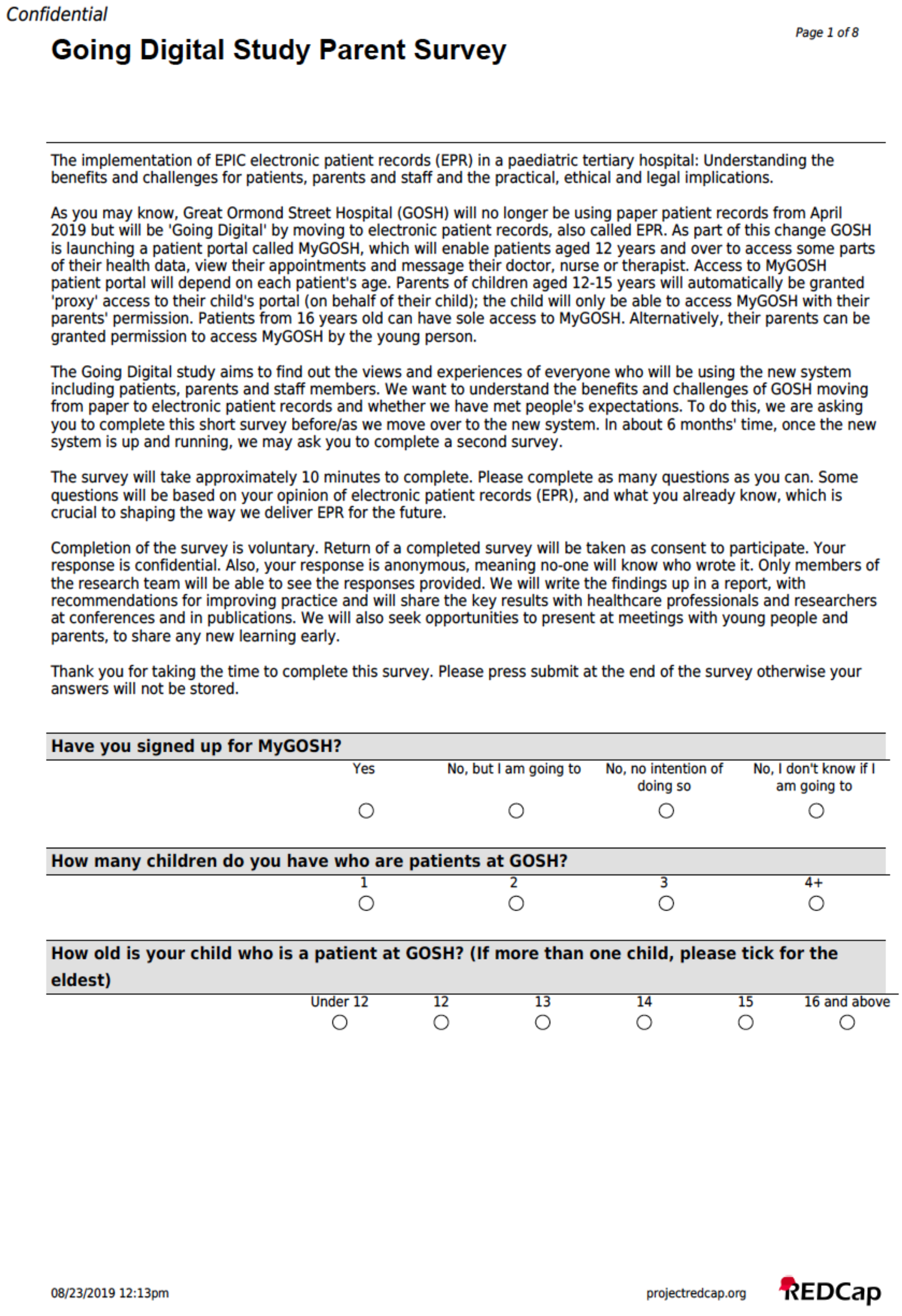
Your sex:

○ Male
○ Female
○ Prefer not to say

Thank you for taking the time to complete this survey. We value any opinions you choose to share with us. If there is anything you think we should have asked you about the EPR system or MyGOSH please comment and use the space provided.

Please press submit otherwise your response will not be stored. Many thanks.

Appendix 28 – Parent baseline survey



Confidential

Page 1 of 8

Going Digital Study Parent Survey

The implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications.

As you may know, Great Ormond Street Hospital (GOSH) will no longer be using paper patient records from April 2019 but will be 'Going Digital' by moving to electronic patient records, also called EPR. As part of this change GOSH is launching a patient portal called MyGOSH, which will enable patients aged 12 years and over to access some parts of their health data, view their appointments and message their doctor, nurse or therapist. Access to MyGOSH patient portal will depend on each patient's age. Parents of children aged 12-15 years will automatically be granted 'proxy' access to their child's portal (on behalf of their child); the child will only be able to access MyGOSH with their parents' permission. Patients from 16 years old can have sole access to MyGOSH. Alternatively, their parents can be granted permission to access MyGOSH by the young person.

The Going Digital study aims to find out the views and experiences of everyone who will be using the new system including patients, parents and staff members. We want to understand the benefits and challenges of GOSH moving from paper to electronic patient records and whether we have met people's expectations. To do this, we are asking you to complete this short survey before/as we move over to the new system. In about 6 months' time, once the new system is up and running, we may ask you to complete a second survey.

The survey will take approximately 10 minutes to complete. Please complete as many questions as you can. Some questions will be based on your opinion of electronic patient records (EPR), and what you already know, which is crucial to shaping the way we deliver EPR for the future.

Completion of the survey is voluntary. Return of a completed survey will be taken as consent to participate. Your response is confidential. Also, your response is anonymous, meaning no-one will know who wrote it. Only members of the research team will be able to see the responses provided. We will write the findings up in a report, with recommendations for improving practice and will share the key results with healthcare professionals and researchers at conferences and in publications. We will also seek opportunities to present at meetings with young people and parents, to share any new learning early.

Thank you for taking the time to complete this survey. Please press submit at the end of the survey otherwise your answers will not be stored.

Have you signed up for MyGOSH?

Yes	No, but I am going to	No, no intention of doing so	No, I don't know if I am going to
○	○	○	○

How many children do you have who are patients at GOSH?

1	2	3	4+
○	○	○	○

How old is your child who is a patient at GOSH? (If more than one child, please tick for the eldest)

Under 12	12	13	14	15	16 and above
○	○	○	○	○	○

How many teams does your child see at GOSH?

	1	2	3	4	5+
	○	○	○	○	○

1. On a scale of 1-10, 1 being the lowest (Not at all satisfied) and 10 being the highest (Extremely satisfied), how satisfied are you currently with:

	Not at all satisfied 1	2	3	4	5	6	7	8	9	Extremely satisfied 10
How appointments are booked?	○	○	○	○	○	○	○	○	○	○
How appointments are changed?	○	○	○	○	○	○	○	○	○	○
How appointments are co-ordinated e.g. more than one on the same day?	○	○	○	○	○	○	○	○	○	○
How convenient your appointments are (timing/day of the week)?	○	○	○	○	○	○	○	○	○	○
How long it takes to receive a clinic letter?	○	○	○	○	○	○	○	○	○	○
How easy it is to contact a member of your child's care team?	○	○	○	○	○	○	○	○	○	○
How your child's care team communicate with you?	○	○	○	○	○	○	○	○	○	○
How easy is it to get answers to your questions?	○	○	○	○	○	○	○	○	○	○
How long it takes to receive test results?	○	○	○	○	○	○	○	○	○	○
How you receive test results e.g. by letter, or face-to-face	○	○	○	○	○	○	○	○	○	○
How much you are involved in decisions about your child's care	○	○	○	○	○	○	○	○	○	○
How informed you are about your child's care?	○	○	○	○	○	○	○	○	○	○

2. Do you currently:

	Yes	No
Know how to make a complaint?	○	○
Feel able to make a complaint?	○	○
Know in advance who will see your child in clinic?	○	○

Know in advance who will be treating your child whilst in hospital?	○	○

Other (Please comment): ______________________________

3. Currently, do you ever:

	Never	Occasionally	Sometimes	Frequently
Use any health related apps?	○	○	○	○
Use social media to help you discuss your child's condition?	○	○	○	○
Seek health advice from other parents on social media?	○	○	○	○
Post your child's health results on social media?	○	○	○	○
Post about the hospital on social media?	○	○	○	○
Post about your child's care team on social media?	○	○	○	○

4. Currently, does your child ever:

	Never	Occasionally	Sometimes	Frequently	N/A	Don't know
Use any health related apps?	○	○	○	○	○	○
Use social media to help discuss their condition?	○	○	○	○	○	○
Seek health advice from others on social media?	○	○	○	○	○	○
Post their health results on social media?	○	○	○	○	○	○
Post about the hospital on social media?	○	○	○	○	○	○
Post about their care team on social media?	○	○	○	○	○	○

5. Please tick how much you disagree or agree with the following statements. MyGOSH will enable me to:

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Change appointments online to a convenient day/time	○	○	○	○	○
View my child's health results online	○	○	○	○	○
Communicate more easily with my child's care team	○	○	○	○	○
Access my child's up-to-date health data when I need it	○	○	○	○	○
Feel more involved in my child's care	○	○	○	○	○
Feel well informed about my child's care	○	○	○	○	○
Be more informed about my child's condition(s)	○	○	○	○	○
Feel more in control of my child's condition(s)	○	○	○	○	○
Feel in control of my child's health data	○	○	○	○	○
Check my child's health data is correct	○	○	○	○	○
Prepare my child for coming to hospital	○	○	○	○	○
Prepare my child for moving to adult services	○	○	○	○	○

6. MyGOSH will improve:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Communication between staff and me	○	○	○	○	○
Communication between staff and my child	○	○	○	○	○
Communication between teams looking after my child	○	○	○	○	○
Knowledge my child's care team has about my child's condition(s)	○	○	○	○	○
Co-ordination of my child's care	○	○	○	○	○
The amount of involvement of my child in decisions about their care	○	○	○	○	○

The amount of parental involvement in decisions about their child's care	○	○	○	○	○

7. I worry that MyGOSH will:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Be difficult to use	○	○	○	○	○
Be difficult for my child to use	○	○	○	○	○
Be difficult to access	○	○	○	○	○
Be difficult for me to understand	○	○	○	○	○
Be difficult for my child to understand	○	○	○	○	○
Cause me anxiety	○	○	○	○	○
Cause my child anxiety	○	○	○	○	○
Cause conflict between staff and me	○	○	○	○	○
Cause conflict between me and my child	○	○	○	○	○
Cause conflict between staff and my child	○	○	○	○	○
Not keep my child's data safe from hacking	○	○	○	○	○
Not keep my child's health data confidential	○	○	○	○	○

8. I worry that:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
I will not always have internet access to use MyGOSH	○	○	○	○	○
I will need support when accessing my child's results	○	○	○	○	○
My child will need support when accessing results	○	○	○	○	○
I will read something I don't understand	○	○	○	○	○
My child will read something they don't understand	○	○	○	○	○
My child will read something I don't want them to read	○	○	○	○	○
I will not get answers to my questions quickly enough	○	○	○	○	○

There will not be a paper copy (back-up) of my child's health data	○	○	○	○	○

9. I also worry that:

	Strongly disagree	Disagree	Agree	Strongly agree
Going from GOSH to a hospital without EPR will be difficult:	○	○	○	○
My child's care team will spend too long looking at a computer screen in clinic	○	○	○	○
There will be a loss of face-to-face contact	○	○	○	○
Someone may write the wrong patient's details in my child's online medical notes	○	○	○	○
The system may not cope with the amount of people using it	○	○	○	○
When using my child's data for research, people will be able to identify my child	○	○	○	○

10. I want to know:

	Strongly disagree	Disagree	Agree	Strongly agree
My child's health data is safe from hacking	○	○	○	○
My child's health data is backed up	○	○	○	○
My child's health data will be kept private	○	○	○	○
Who is looking at my child's health data	○	○	○	○
Which doctor/nurse/therapist my child will see at the hospital	○	○	○	○
What happens when the system goes down	○	○	○	○
If there is guidance on how to use MyGOSH	○	○	○	○
If there will be guidance on using the messaging service	○	○	○	○
I will get the technical help I need when accessing MyGOSH	○	○	○	○

I will get the emotional support I need when accessing MyGOSH	○	○	○	○

11. Do you think the lower age limit of 12 for being able to access MyGOSH with your consent is acceptable?

Yes	No
○	○

Other (Please comment):

____

12. On a scale of 1-10, 1 being the lowest (Extremely unhappy) and 10 being the highest (Extremely happy) how happy are you about your child (who is 12 years or older):

	Extremely unhappy 1	2	3	4	5	6	7	8	9	Extremely happy 10	N/A
Accessing MyGOSH?	○	○	○	○	○	○	○	○	○	○	○
Accessing their results online?	○	○	○	○	○	○	○	○	○	○	○
Being able to contact their care team through MyGOSH?	○	○	○	○	○	○	○	○	○	○	○
Being able to view some of their health data?	○	○	○	○	○	○	○	○	○	○	○
Posting about their condition(s) on social media?	○	○	○	○	○	○	○	○	○	○	○
Posting their health results on social media?	○	○	○	○	○	○	○	○	○	○	○
Having sole access to their health data from the age old 16 (if they are able/if they so wish)?	○	○	○	○	○	○	○	○	○	○	○

Other (Please comment):

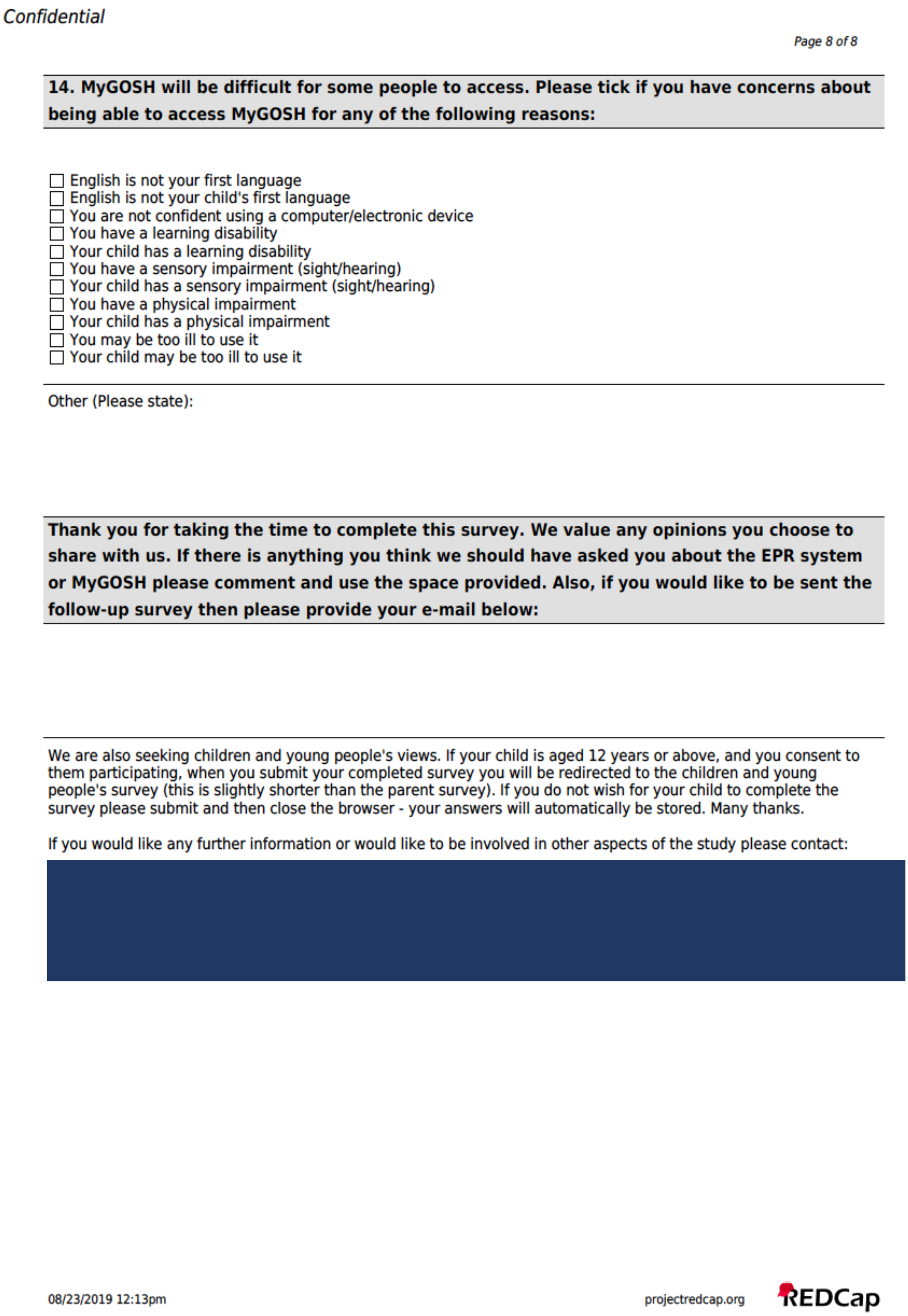
____

13. I feel well informed about the new EPR system.

Very	Somewhat	Not at all
○	○	○

Other (Please comment):

____



14. MyGOSH will be difficult for some people to access. Please tick if you have concerns about being able to access MyGOSH for any of the following reasons:

☐ English is not your first language
☐ English is not your child's first language
☐ You are not confident using a computer/electronic device
☐ You have a learning disability
☐ Your child has a learning disability
☐ You have a sensory impairment (sight/hearing)
☐ Your child has a sensory impairment (sight/hearing)
☐ You have a physical impairment
☐ Your child has a physical impairment
☐ You may be too ill to use it
☐ Your child may be too ill to use it

Other (Please state):

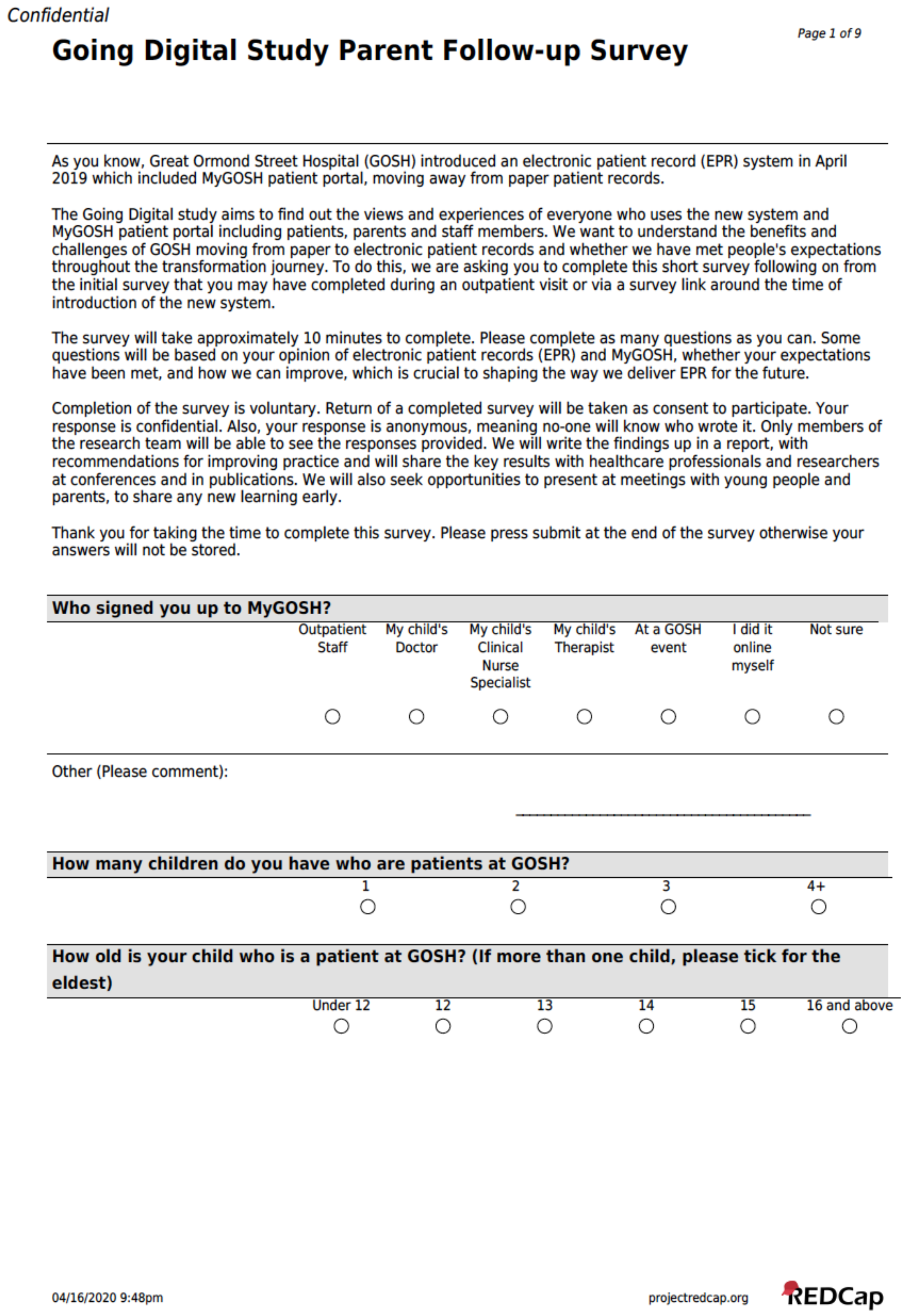
Thank you for taking the time to complete this survey. We value any opinions you choose to share with us. If there is anything you think we should have asked you about the EPR system or MyGOSH please comment and use the space provided. Also, if you would like to be sent the follow-up survey then please provide your e-mail below:

We are also seeking children and young people's views. If your child is aged 12 years or above, and you consent to them participating, when you submit your completed survey you will be redirected to the children and young people's survey (this is slightly shorter than the parent survey). If you do not wish for your child to complete the survey please submit and then close the browser - your answers will automatically be stored. Many thanks.

If you would like any further information or would like to be involved in other aspects of the study please contact:

[redacted]

Appendix 29 – Parent follow-up survey



Confidential

Page 1 of 9

Going Digital Study Parent Follow-up Survey

As you know, Great Ormond Street Hospital (GOSH) introduced an electronic patient record (EPR) system in April 2019 which included MyGOSH patient portal, moving away from paper patient records.

The Going Digital study aims to find out the views and experiences of everyone who uses the new system and MyGOSH patient portal including patients, parents and staff members. We want to understand the benefits and challenges of GOSH moving from paper to electronic patient records and whether we have met people's expectations throughout the transformation journey. To do this, we are asking you to complete this short survey following on from the initial survey that you may have completed during an outpatient visit or via a survey link around the time of introduction of the new system.

The survey will take approximately 10 minutes to complete. Please complete as many questions as you can. Some questions will be based on your opinion of electronic patient records (EPR) and MyGOSH, whether your expectations have been met, and how we can improve, which is crucial to shaping the way we deliver EPR for the future.

Completion of the survey is voluntary. Return of a completed survey will be taken as consent to participate. Your response is confidential. Also, your response is anonymous, meaning no-one will know who wrote it. Only members of the research team will be able to see the responses provided. We will write the findings up in a report, with recommendations for improving practice and will share the key results with healthcare professionals and researchers at conferences and in publications. We will also seek opportunities to present at meetings with young people and parents, to share any new learning early.

Thank you for taking the time to complete this survey. Please press submit at the end of the survey otherwise your answers will not be stored.

Who signed you up to MyGOSH?

Outpatient Staff	My child's Doctor	My child's Clinical Nurse Specialist	My child's Therapist	At a GOSH event	I did it online myself	Not sure
○	○	○	○	○	○	○

Other (Please comment):

____

How many children do you have who are patients at GOSH?

1	2	3	4+
○	○	○	○

How old is your child who is a patient at GOSH? (If more than one child, please tick for the eldest)

Under 12	12	13	14	15	16 and above
○	○	○	○	○	○

04/16/2020 9:48pm

projectredcap.org REDCap

How many teams does your child see at GOSH?

	1	2	3	4	5+
	○	○	○	○	○

Did you complete the initial Going Digital Study survey?

	Yes	No	Not sure
	○	○	○

1. On a scale of 1-10, 1 being the lowest (Not satisfied at all) and 10 being the highest (Extremely satisfied), how satisfied are you currently with:

	Not at all satisfied 1	2	3	4	5	6	7	8	9	Extremely satisfied 10
How appointments are booked?	○	○	○	○	○	○	○	○	○	○
How appointments are changed?	○	○	○	○	○	○	○	○	○	○
How appointments are co-ordinated e.g. more than one on the same day?	○	○	○	○	○	○	○	○	○	○
How convenient your appointments are (timing/day of the week)?	○	○	○	○	○	○	○	○	○	○
How long it takes to receive a clinic letter?	○	○	○	○	○	○	○	○	○	○
How easy it is to contact a member of your child's care team?	○	○	○	○	○	○	○	○	○	○
How your child's care team communicate with you?	○	○	○	○	○	○	○	○	○	○
How easy is it to get answers to your questions?	○	○	○	○	○	○	○	○	○	○
How long it takes to receive test results?	○	○	○	○	○	○	○	○	○	○
How you receive test results e.g. by letter, or face-to-face	○	○	○	○	○	○	○	○	○	○
How much you are involved in decisions about your child's care	○	○	○	○	○	○	○	○	○	○
How informed you are about your child's care?	○	○	○	○	○	○	○	○	○	○

2. Since the new electronic system has been in place, do you:

	Yes	No
Know how to make a complaint?	○	○
Feel able to make a complaint?	○	○
Know in advance who will see your child in clinic?	○	○
Know in advance who will be treating your child whilst in hospital?	○	○

Other (Please comment): ______________________________

3. Currently, do you ever:

	Never	Occasionally	Sometimes	Frequently
Use any health related apps?	○	○	○	○
Use social media to help you discuss your child's condition?	○	○	○	○
Seek health advice from other parents on social media?	○	○	○	○
Post your child's health results on social media?	○	○	○	○
Post about the hospital on social media?	○	○	○	○
Post about your child's care team on social media?	○	○	○	○

4. Currently, does your child ever:

	Never	Occasionally	Sometimes	Frequently	N/A	Don't know
Use any health related apps?	○	○	○	○	○	○
Use social media to help discuss their condition?	○	○	○	○	○	○
Seek health advice from others on social media?	○	○	○	○	○	○
Post their health results on social media?	○	○	○	○	○	○
Post about the hospital on social media?	○	○	○	○	○	○
Post about their care team on social media?	○	○	○	○	○	○

5. Please tick how much you disagree or agree with the following statements. MyGOSH enables me to:

	Strongly disagree	Disagree	Agree	Strongly agree	Don't know
Change appointments online to a convenient day/time	○	○	○	○	○
View my child's health results online	○	○	○	○	○
Communicate more easily with my child's care team	○	○	○	○	○
Access my child's up-to-date health data when I need it	○	○	○	○	○
Feel more involved in my child's care	○	○	○	○	○
Feel well informed about my child's care	○	○	○	○	○
Be more informed about my child's condition(s)	○	○	○	○	○
Feel more in control of my child's condition(s)	○	○	○	○	○
Feel in control of my child's health data	○	○	○	○	○
Check my child's health data is correct	○	○	○	○	○
Prepare my child for coming to hospital	○	○	○	○	○
Prepare my child for moving to adult services	○	○	○	○	○

6. MyGOSH has improved:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Communication between staff and me	○	○	○	○	○
Communication between staff and my child	○	○	○	○	○
Communication between teams looking after my child	○	○	○	○	○
Knowledge my child's care team has about my child's condition(s)	○	○	○	○	○
Co-ordination of my child's care	○	○	○	○	○
The amount of involvement of my child in decisions about their care	○	○	○	○	○

The amount of parental involvement in decisions about their child's care	○	○	○	○	○

7. MyGOSH:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Is difficult to use	○	○	○	○	○
Is difficult for my child to use	○	○	○	○	○
Is difficult to access	○	○	○	○	○
Is difficult for me to understand	○	○	○	○	○
Is difficult for my child to understand	○	○	○	○	○
Causes me anxiety	○	○	○	○	○
Causes my child anxiety	○	○	○	○	○
Causes conflict between staff and me	○	○	○	○	○
Causes conflict between me and my child	○	○	○	○	○
Causes conflict between staff and my child	○	○	○	○	○

8. Do you disagree or agree with the following statements?

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
I don't always have internet access to use MyGOSH	○	○	○	○	○
I need support when accessing my child's results	○	○	○	○	○
My child needs support when accessing results	○	○	○	○	○
I have read something I don't understand	○	○	○	○	○
My child has read something they don't understand	○	○	○	○	○
My child has read something I don't want them to read	○	○	○	○	○
I do not get answers to my questions quickly enough	○	○	○	○	○
I worry that there is not a paper copy (back-up) of my child's health data	○	○	○	○	○

9. I have found that:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Going from GOSH to a hospital without EPR is difficult:	○	○	○	○	○
My child's care team spend too long looking at a computer screen in clinic	○	○	○	○	○
There is a loss of face-to-face contact	○	○	○	○	○

	Strongly disagree	Disagree	Agree	Strongly agree
The system does not cope with the amount of people using it	○	○	○	○

10. I know:

	Strongly disagree	Disagree	Agree	Strongly agree
My child's health data is safe from hacking	○	○	○	○
My child's health data is backed up	○	○	○	○
My child's health data will be kept private	○	○	○	○
Who is looking at my child's health data	○	○	○	○
In advance which doctor/nurse/therapist my child will see at the hospital	○	○	○	○
What happens when the system goes down	○	○	○	○
There is guidance on how to use MyGOSH	○	○	○	○
There is guidance on using the messaging service	○	○	○	○
I get the technical help I need when accessing MyGOSH	○	○	○	○
I get the emotional support I need when accessing MyGOSH	○	○	○	○

11. Do you think the lower age limit of 12 for being able to access MyGOSH with your consent is acceptable?

Yes	No
○	○

If no, please comment:

____

12. On a scale of 1-10, 1 being the lowest (Extremely unhappy) and 10 being the highest (Extremely happy) how happy are you about your child (who is 12 years or older):

	Extremely unhappy 1	2	3	4	5	6	7	8	9	Extremely happy 10	N/A
Accessing MyGOSH?	○	○	○	○	○	○	○	○	○	○	○
Accessing their results online?	○	○	○	○	○	○	○	○	○	○	○
Being able to contact their care team through MyGOSH?	○	○	○	○	○	○	○	○	○	○	○
Being able to view some of their health data?	○	○	○	○	○	○	○	○	○	○	○
Posting about their condition(s) on social media?	○	○	○	○	○	○	○	○	○	○	○
Posting their health results on social media?	○	○	○	○	○	○	○	○	○	○	○
Having sole access to their health data from the age old 16 (if they are able/if they so wish)?	○	○	○	○	○	○	○	○	○	○	○

Other (Please comment): ______________________________

13. I feel well informed about the electronic patient record system.

Very	Somewhat	Not at all
○	○	○

Other (Please comment): ______________________________

14. MyGOSH is difficult for some people to access. Please tick if you have concerns about being able to access MyGOSH for any of the following reasons:

☐ English is not your first language
☐ English is not your child's first language
☐ You are not confident using a computer/electronic device
☐ You have a learning difficulty or disability
☐ Your child has a learning difficulty or disability
☐ You have a sensory impairment (sight/hearing)
☐ Your child has a sensory impairment (sight/hearing)
☐ You have a physical impairment
☐ Your child has a physical impairment
☐ You may be too ill to use it
☐ Your child may be too ill to use it

Other (Please state):

15. Please tell us a little about your family:

Who lives at home with your child?

☐ Mother
☐ Father
☐ Legal Guardian / person with parental responsibility
☐ Sibling/s
☐ Other family
☐ Other

What languages are spoken at home?

____

Who is completing this survey?

○ Mother
○ Father
○ Legal guardian / person with parental responsibility
○ Other

Parent demographics:

Your age range:

○ < 20
○ 20-29
○ 30-39
○ 40-49
○ >50

Your ethnicity:

○ White British
○ White Irish
○ Any other white background
○ Mixed - white and black Caribbean
○ Mixed - White and black African
○ Mixed - White and Asian
○ Any other mixed background
○ Indian
○ Pakistani
○ Bangladeshi
○ Any other Asian background
○ Black or black British - Caribbean
○ Black or black British - African
○ Any other black background
○ Chinese
○ Any other background

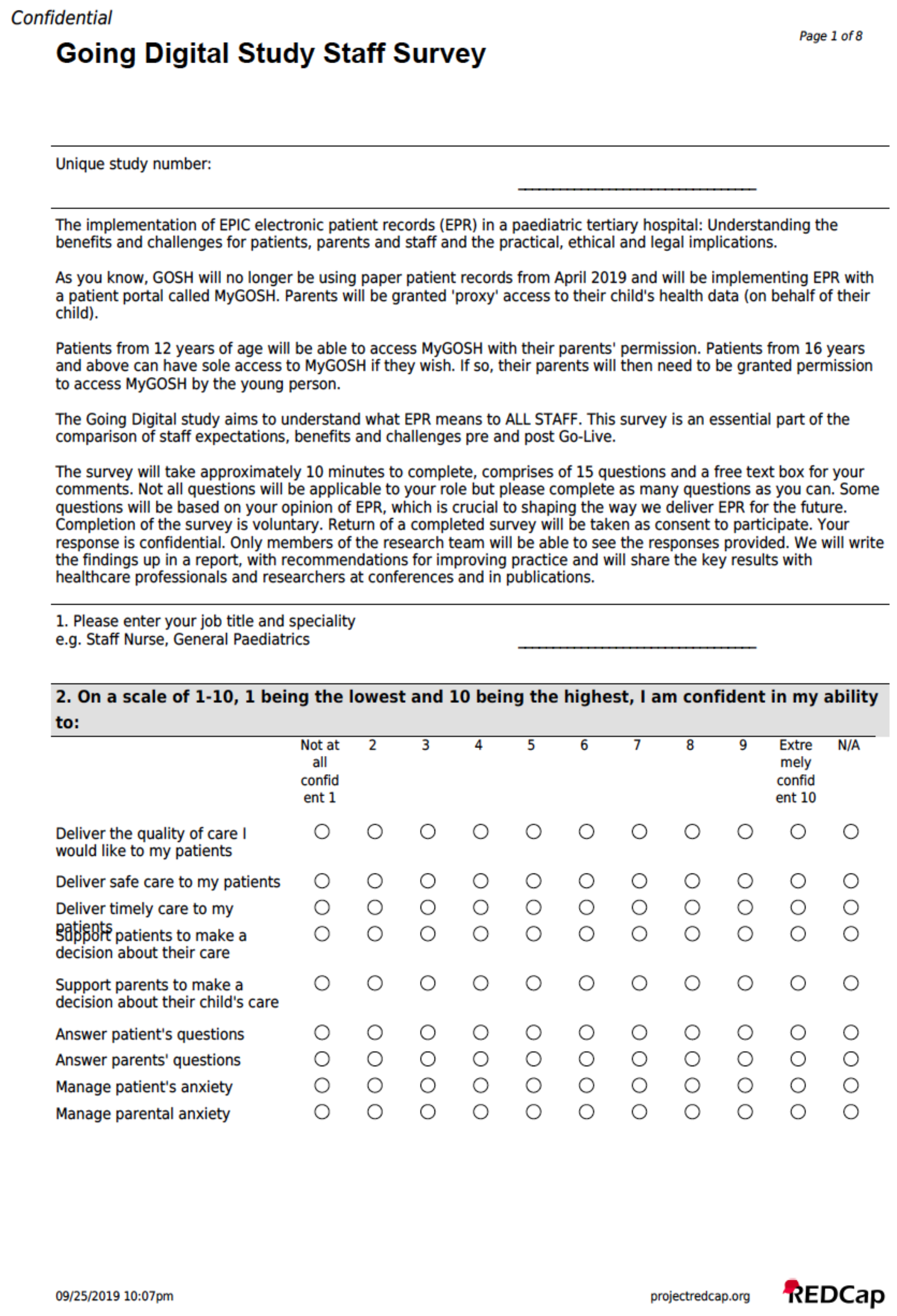
Thank you for taking the time to complete this survey. We value any opinions you choose to share with us. If there is anything you think we should have asked you about the EPR system or MyGOSH please comment and use the space provided. Also, if you would like to be sent the follow-up survey then please provide your e-mail below:

We are also seeking children and young people's views. If your child is aged 12-15 years of age, and you consent to them participating, when you submit your completed survey you will be redirected to the children and young people's survey (this is slightly shorter than the parent survey). If you do not wish for your child to complete the survey please press submit and then close the browser - your answers will automatically be stored. If your son or daughter is between 16 and 25 years of age, and has signed up to MyGOSH, they will automatically receive a copy of the children and young people's survey. Many thanks.

If you would like any further information please contact:

[redacted]

Appendix 30 – Staff baseline survey



Confidential

Page 1 of 8

Going Digital Study Staff Survey

Unique study number: ________________________

The implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications.

As you know, GOSH will no longer be using paper patient records from April 2019 and will be implementing EPR with a patient portal called MyGOSH. Parents will be granted 'proxy' access to their child's health data (on behalf of their child).

Patients from 12 years of age will be able to access MyGOSH with their parents' permission. Patients from 16 years and above can have sole access to MyGOSH if they wish. If so, their parents will then need to be granted permission to access MyGOSH by the young person.

The Going Digital study aims to understand what EPR means to ALL STAFF. This survey is an essential part of the comparison of staff expectations, benefits and challenges pre and post Go-Live.

The survey will take approximately 10 minutes to complete, comprises of 15 questions and a free text box for your comments. Not all questions will be applicable to your role but please complete as many questions as you can. Some questions will be based on your opinion of EPR, which is crucial to shaping the way we deliver EPR for the future. Completion of the survey is voluntary. Return of a completed survey will be taken as consent to participate. Your response is confidential. Only members of the research team will be able to see the responses provided. We will write the findings up in a report, with recommendations for improving practice and will share the key results with healthcare professionals and researchers at conferences and in publications.

1. Please enter your job title and speciality
e.g. Staff Nurse, General Paediatrics ________________________

2. On a scale of 1-10, 1 being the lowest and 10 being the highest, I am confident in my ability to:

	Not at all confident 1	2	3	4	5	6	7	8	9	Extremely confident 10	N/A
Deliver the quality of care I would like to my patients	○	○	○	○	○	○	○	○	○	○	○
Deliver safe care to my patients	○	○	○	○	○	○	○	○	○	○	○
Deliver timely care to my patients	○	○	○	○	○	○	○	○	○	○	○
Support patients to make a decision about their care	○	○	○	○	○	○	○	○	○	○	○
Support parents to make a decision about their child's care	○	○	○	○	○	○	○	○	○	○	○
Answer patient's questions	○	○	○	○	○	○	○	○	○	○	○
Answer parents' questions	○	○	○	○	○	○	○	○	○	○	○
Manage patient's anxiety	○	○	○	○	○	○	○	○	○	○	○
Manage parental anxiety	○	○	○	○	○	○	○	○	○	○	○

09/25/2019 10:07pm projectredcap.org REDCap

Manage conflict	○	○	○	○	○	○	○	○	○	○	○

3. On a scale of 1-10, 1 being the lowest and 10 being the highest, I am confident in my ability to:

	Not at all confident 1	2	3	4	5	6	7	8	9	Extremely confident 10	N/A
Assess the competence of a child to make a decision about their care	○	○	○	○	○	○	○	○	○	○	○
Accurately establish who has parental responsibility	○	○	○	○	○	○	○	○	○	○	○

4. Overall, the access that patients currently have to their health data is not enough.

Strongly Disagree	Disagree	Agree	Strongly Agree
○	○	○	○

5. I have concerns about children accessing their health data.

Strongly disagree	Disagree	Agree	Strongly agree
○	○	○	○

6. EPR will improve my ability to:

	Strongly disagree	Disagree	Agree	Strongly Agree	N/A
Collaborate with other staff within my speciality/area	○	○	○	○	○
Collaborate with staff from other specialities/areas	○	○	○	○	○
Collaborate with outside agencies e.g. schools, GP practices	○	○	○	○	○
Provide joined-up (co-ordinated) care	○	○	○	○	○
Make decisions about patients in my care	○	○	○	○	○
Communicate with patients	○	○	○	○	○
Communicate with parents	○	○	○	○	○
Deliver consistent care	○	○	○	○	○
Access up-to-date information	○	○	○	○	○

7. EPR will improve patient safety by:

	Strongly disagree	Disagree	Agree	Strongly Agree	N/A
Having all the patient's information in one place	○	○	○	○	○
Reducing medication errors	○	○	○	○	○
Facilitating easier access to best practice guidelines	○	○	○	○	○
Facilitating regular medication reviews	○	○	○	○	○
Enabling me to monitor patients more easily	○	○	○	○	○
Enabling me to prioritise patients better	○	○	○	○	○
Enabling critical incidents to be analysed more easily	○	○	○	○	○
Standardising handover	○	○	○	○	○

8. EPR will make it easier to:

	Strongly disagree	Disagree	Agree	Strongly Agree
Do my job	○	○	○	○
Monitor patient safety	○	○	○	○
Allocate patients to the most appropriate nurse	○	○	○	○
Track events in real time	○	○	○	○
Keep patient notes up-to-date	○	○	○	○
Perform audits	○	○	○	○
Keep patients informed of their care plan	○	○	○	○
Keep parents informed of their child's care plan	○	○	○	○
Enable parents to co-ordinate their child's care	○	○	○	○
Identify safeguarding concerns	○	○	○	○

9. EPR will make it more difficult:

	Strongly disagree	Disagree	Agree	Strongly Agree
To do my job	○	○	○	○
To document what happens after a child dies	○	○	○	○
To maintain patient interaction during consultations	○	○	○	○
To maintain parent interaction during consultations	○	○	○	○
For me to think for myself	○	○	○	○
To manage patient expectations	○	○	○	○
To manage parental expectations	○	○	○	○
To care for patients if the system does down	○	○	○	○
To give prescribed medication if the system goes down	○	○	○	○

10. I am concerned there will not be:

	Strongly disagree	Disagree	Agree	Strongly agree
Adequate training	○	○	○	○
Adequate support during Go Live	○	○	○	○
Adequate support after Go Live	○	○	○	○
Enough staff to cope with the extra demands of EPR	○	○	○	○
Enough workstations	○	○	○	○
Enough tablets/devices	○	○	○	○
Long enough cables to reach patients when scanning namebands	○	○	○	○
Connectivity from outside the Trust e.g. when I am on call	○	○	○	○
The ability for home monitoring devices to sync with EPR	○	○	○	○
Enough signposting to technical help	○	○	○	○
Support if I identify an ethical dilemma relating to the use of MyGOSH	○	○	○	○

11. When using EPR I worry that:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
It will be difficult to use	○	○	○	○	○
I will take too long when using the new system	○	○	○	○	○
I will be unable to find what I need	○	○	○	○	○
I will fall behind with my work	○	○	○	○	○
Some groups will be unable to access EPR e.g. non-English speakers, those with learning disabilities or sensory impairment	○	○	○	○	○
Parents who haven't disclosed the diagnosis/prognosis to their child will not engage with MyGOSH	○	○	○	○	○
I will not have the permissions I need	○	○	○	○	○
I will lose WiFi connection when performing observations on a patient	○	○	○	○	○
I will teach it incorrectly to others	○	○	○	○	○
I will be de-skilled if EPR reminds me to do everything	○	○	○	○	○
Families may post about me on social media	○	○	○	○	○
Families may post about the hospital on social media	○	○	○	○	○
I will make more drug errors	○	○	○	○	○
There will be data breaches	○	○	○	○	○
There will be confidentiality breaches	○	○	○	○	○
The system will be hacked	○	○	○	○	○
Patients will need additional support when accessing results	○	○	○	○	○
Parents will need additional support when accessing their child's results	○	○	○	○	○

12. EPR will save me time due to:

	Strongly disagree	Disagree	Agree	Strongly agree
Less duplication of documentation	○	○	○	○
Quicker access - I will not have to login to multiple applications	○	○	○	○
Having all of the information in the same place	○	○	○	○
Electronic notes being chronological	○	○	○	○
Electronic notes being legible	○	○	○	○

13. MyGOSH patient portal will:

	Strongly disagree	Disagree	Agree	Strongly agree
Empower patients to take ownership of their health data	○	○	○	○
Mean that patients are more involved in decisions about their care	○	○	○	○
Help young people to prepare for transition to adult services	○	○	○	○
Improve patients' compliance with their treatment	○	○	○	○
Make it easier for patients to share their health data on social media	○	○	○	○
Mean that parents are more involved in decisions about their child's care	○	○	○	○
Empower parents to be partners in care	○	○	○	○
Make it easier for parents to share their child's health data on social media	○	○	○	○
Make it easier for parents to change their child's appointment	○	○	○	○
Reduce the amount of missed appointments	○	○	○	○
Ensure more effective use of clinic time	○	○	○	○

14. The messaging function via the portal will:

	Strongly disagree	Disagree	Agree	Strongly agree
Improve communication between staff and patients	○	○	○	○
Improve communication between staff and parents	○	○	○	○
Place additional burdens on clinicians	○	○	○	○
Place additional burdens on patients	○	○	○	○
Place additional burdens on parents	○	○	○	○
Cause conflict between parents and staff	○	○	○	○
Cause conflict between parents and their child	○	○	○	○

15. Releasing patient results via the portal will:

	Strongly disagree	Disagree	Agree	Strongly Agree
Enable patients to be more involved in their care	○	○	○	○
Enable parents to be more involved in their child's care	○	○	○	○
Increase patient anxiety	○	○	○	○
Increase parent anxiety	○	○	○	○
Make patients more likely to contact their clinician	○	○	○	○
Make parents more likely to contact their child's clinician	○	○	○	○
Make it more likely that patients will self-diagnose	○	○	○	○
Make it more likely that patients will self-treat	○	○	○	○
Make it more likely that parents will diagnose their child themselves	○	○	○	○
Make it more likely that parents will treat their child themselves	○	○	○	○

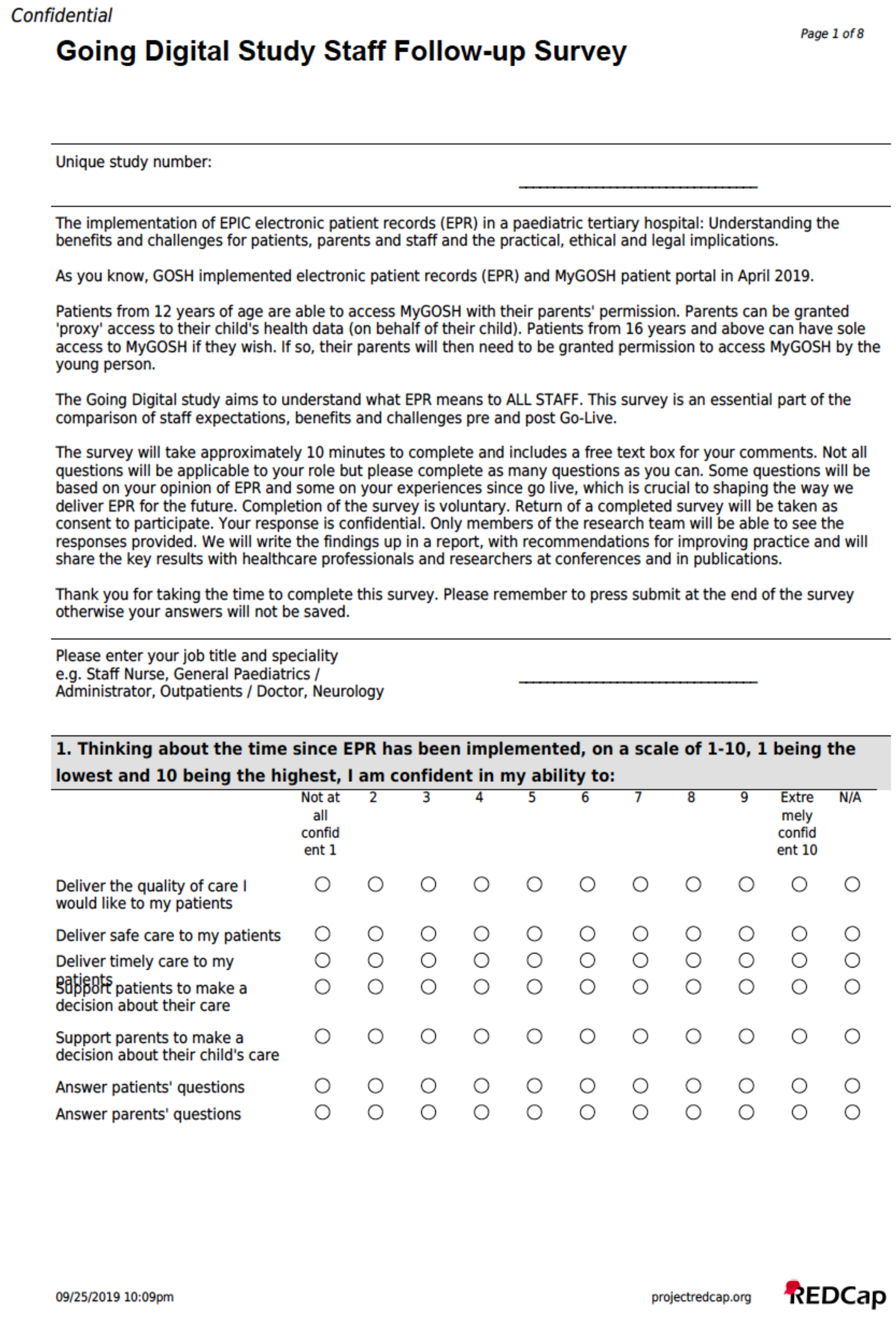
16. Thank you for taking the time to complete this survey. Your opinion is important to us. If there is anything you would like to comment further on please use the space provided: ______________________________

Data Protection Privacy Notice
UCL Great Ormond Street Institute of Child Health (UCL GOS ICH) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Great Ormond Street will keep identifiable information about you for 3-6 months after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible (job title, level of seniority and speciality).

The research team from Great Ormond Street Hospital will keep your job title, level of seniority and speciality confidential and will not pass this information to UCL GOS ICH. The research team will use this information as needed, making sure that relevant information about the study is recorded, and overseeing the quality of the study. Certain individuals from UCL GOS ICH and regulatory organisations may look at the research records to check the accuracy of the research study. UCL GOS ICH will only receive information without any identifying information. The people who analyse the information will not be able to find out your name or contact details because these will not be collected as part of the survey. You can find out more about how we use your information by contacting Lee Shailer, the Data Protection Officer, [redacted]

This research has been reviewed and approved by Health Research Authority Southeast London Research Ethics Committee IRAS ID: 248793; v1 11.01.19

Appendix 31 – Staff follow-up survey



Confidential

Page 1 of 8

Going Digital Study Staff Follow-up Survey

Unique study number: __________________________________

The implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications.

As you know, GOSH implemented electronic patient records (EPR) and MyGOSH patient portal in April 2019.

Patients from 12 years of age are able to access MyGOSH with their parents' permission. Parents can be granted 'proxy' access to their child's health data (on behalf of their child). Patients from 16 years and above can have sole access to MyGOSH if they wish. If so, their parents will then need to be granted permission to access MyGOSH by the young person.

The Going Digital study aims to understand what EPR means to ALL STAFF. This survey is an essential part of the comparison of staff expectations, benefits and challenges pre and post Go-Live.

The survey will take approximately 10 minutes to complete and includes a free text box for your comments. Not all questions will be applicable to your role but please complete as many questions as you can. Some questions will be based on your opinion of EPR and some on your experiences since go live, which is crucial to shaping the way we deliver EPR for the future. Completion of the survey is voluntary. Return of a completed survey will be taken as consent to participate. Your response is confidential. Only members of the research team will be able to see the responses provided. We will write the findings up in a report, with recommendations for improving practice and will share the key results with healthcare professionals and researchers at conferences and in publications.

Thank you for taking the time to complete this survey. Please remember to press submit at the end of the survey otherwise your answers will not be saved.

Please enter your job title and speciality
e.g. Staff Nurse, General Paediatrics /
Administrator, Outpatients / Doctor, Neurology __________________________________

1. Thinking about the time since EPR has been implemented, on a scale of 1-10, 1 being the lowest and 10 being the highest, I am confident in my ability to:

	Not at all confident 1	2	3	4	5	6	7	8	9	Extremely confident 10	N/A
Deliver the quality of care I would like to my patients	○	○	○	○	○	○	○	○	○	○	○
Deliver safe care to my patients	○	○	○	○	○	○	○	○	○	○	○
Deliver timely care to my patients	○	○	○	○	○	○	○	○	○	○	○
Support patients to make a decision about their care	○	○	○	○	○	○	○	○	○	○	○
Support parents to make a decision about their child's care	○	○	○	○	○	○	○	○	○	○	○
Answer patients' questions	○	○	○	○	○	○	○	○	○	○	○
Answer parents' questions	○	○	○	○	○	○	○	○	○	○	○

09/25/2019 10:09pm projectredcap.org REDCap

Manage patients' anxiety	○	○	○	○	○	○	○	○	○	○	○
Manage parental anxiety	○	○	○	○	○	○	○	○	○	○	○
Manage conflict	○	○	○	○	○	○	○	○	○	○	○

2. Thinking about the time since EPR has been implemented, on a scale of 1-10, 1 being the lowest and 10 being the highest, I am confident in my ability to:

	Not at all confident 1	2	3	4	5	6	7	8	9	Extremely confident 10	N/A
Assess the competence of a child to make a decision about their care	○	○	○	○	○	○	○	○	○	○	○
Accurately establish who has parental responsibility	○	○	○	○	○	○	○	○	○	○	○

3. EPR improves my ability to:

	Strongly disagree	Disagree	Agree	Strongly Agree	N/A
Collaborate with other staff within my speciality/area	○	○	○	○	○
Collaborate with staff from other specialities/areas	○	○	○	○	○
Collaborate with outside agencies e.g. schools, GP practices	○	○	○	○	○
Provide joined-up (co-ordinated) care	○	○	○	○	○
Make decisions about patients in my care	○	○	○	○	○
Communicate with patients	○	○	○	○	○
Communicate with parents	○	○	○	○	○
Deliver consistent care	○	○	○	○	○
Access up-to-date information	○	○	○	○	○

4. EPR improves patient safety by:

	Strongly disagree	Disagree	Agree	Strongly Agree	N/A
Having all the patient's information in one place	○	○	○	○	○
Reducing medication errors	○	○	○	○	○
Facilitating easier access to best practice guidelines	○	○	○	○	○
Facilitating regular medication reviews	○	○	○	○	○
Enabling me to monitor patients more easily	○	○	○	○	○
Enabling me to prioritise patients better	○	○	○	○	○
Enabling critical incidents to be analysed more easily	○	○	○	○	○
Standardising handover	○	○	○	○	○

5. EPR makes it easier to:

	Strongly disagree	Disagree	Agree	Strongly Agree
Do my job	○	○	○	○
Monitor patient safety	○	○	○	○
Track events in real time	○	○	○	○
Keep patient notes up-to-date	○	○	○	○
Keep patients informed of their care plan	○	○	○	○
Keep parents informed of their child's care plan	○	○	○	○
Enable parents to co-ordinate their child's care	○	○	○	○
Identify safeguarding concerns	○	○	○	○

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Allocate patients to the most appropriate nurse	○	○	○	○	○
Perform audits	○	○	○	○	○

6. EPR makes it more difficult:

	Strongly disagree	Disagree	Agree	Strongly Agree
To do my job	○	○	○	○
To maintain patient interaction during consultations	○	○	○	○
To maintain parent interaction during consultations	○	○	○	○
For me to think for myself	○	○	○	○
To manage patient expectations	○	○	○	○
To manage parental expectations	○	○	○	○

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
To document what happens after a child dies	○	○	○	○	○
To care for patients if the system goes down	○	○	○	○	○
To give prescribed medication if the system goes down	○	○	○	○	○

7. Do you disagree or agree with the following statements? There:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
Was adequate training	○	○	○	○	○
Was adequate support during go live	○	○	○	○	○
Was adequate support after go live	○	○	○	○	○
Is enough staff to cope with the extra demands of EPR	○	○	○	○	○
Are enough workstations	○	○	○	○	○
Are enough tablets/devices	○	○	○	○	○
Are long enough cables to reach patients when scanning name bands	○	○	○	○	○
Is connectivity from outside the Trust e.g. when I am on call	○	○	○	○	○
Is the ability for home monitoring devices to sync with EPR	○	○	○	○	○
Is enough signposting to technical help	○	○	○	○	○

Is support if I identify an ethical dilemma relating to the use of MyGOSH	○	○	○	○	○

Please comment:

____

8. When using EPR:

	Strongly disagree	Disagree	Agree	Strongly agree	N/A
It was difficult to use	○	○	○	○	○
It takes too long when using the new system	○	○	○	○	○
I am unable to find what I need	○	○	○	○	○
I fall behind with my work	○	○	○	○	○
Some groups are unable to access EPR e.g. non-English speakers, those with learning disabilities or sensory impairment	○	○	○	○	○
Parents who haven't disclosed the diagnosis/prognosis to their child do not engage with MyGOSH	○	○	○	○	○
I do not have the permissions I need	○	○	○	○	○
I lose WiFi connection when performing observations on a patient	○	○	○	○	○
I have taught it incorrectly to others	○	○	○	○	○
I feel I am de-skilled because EPR reminds me to do everything	○	○	○	○	○
I worry families may post about me on social media	○	○	○	○	○
I worry families may post about the hospital on social media	○	○	○	○	○
I make more drug errors	○	○	○	○	○
I worry there are data breaches	○	○	○	○	○
I worry there are confidentiality breaches	○	○	○	○	○
I worry that the system will be hacked	○	○	○	○	○

Patients need additional support when accessing results	○	○	○	○	○
Parents need additional support when accessing their child's results	○	○	○	○	○

9. EPR saves me time due to:

	Strongly disagree	Disagree	Agree	Strongly agree
Less duplication of documentation	○	○	○	○
Quicker access - I do not have to login to multiple applications	○	○	○	○
All the information is in the same place	○	○	○	○
Electronic notes are chronological	○	○	○	○
Electronic notes are legible	○	○	○	○

10. Do you disagree or agree with the following statements? MyGOSH patient portal:

	Strongly disagree	Disagree	Agree	Strongly agree
Empowers patients to take ownership of their health data	○	○	○	○
Means that patients are more involved in decisions about their care	○	○	○	○
Helps young people to prepare for transition to adult services	○	○	○	○
Improves patients' compliance with their treatment	○	○	○	○
Makes it easier for patients to share their health data on social media	○	○	○	○
Means that parents are more involved in decisions about their child's care	○	○	○	○
Empowers parents to be partners in care	○	○	○	○
Makes it easier for parents to share their child's health data on social media	○	○	○	○
Makes it easier for parents to change their child's appointment	○	○	○	○
Reduces the amount of missed appointments	○	○	○	○
Ensures more effective use of clinic time	○	○	○	○

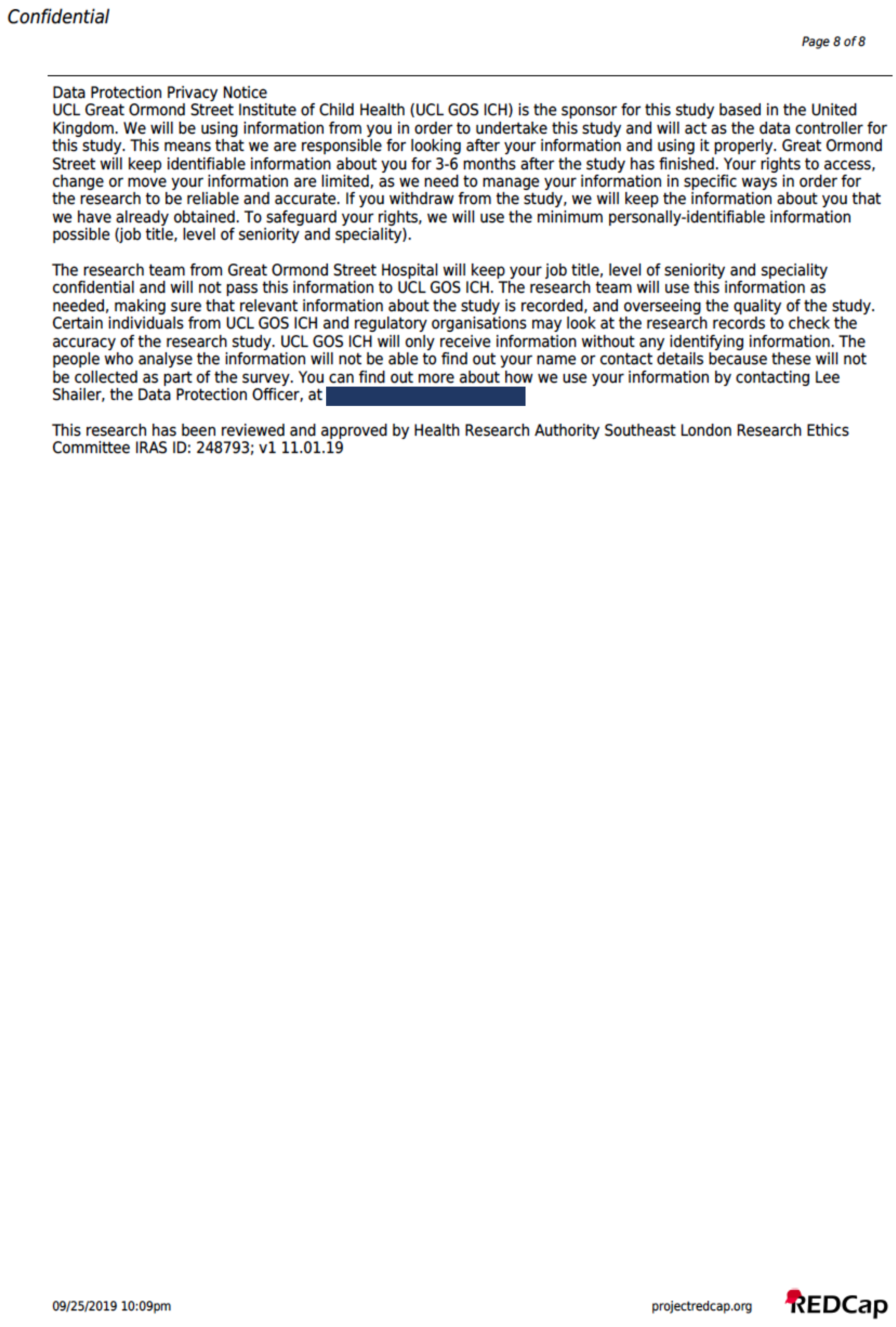
11. Do you disagree or agree with the following statements? The messaging function via the portal:

	Strongly disagree	Disagree	Agree	Strongly agree
Improves communication between staff and patients	○	○	○	○
Improves communication between staff and parents	○	○	○	○
Places additional burdens on clinicians	○	○	○	○
Places additional burdens on patients	○	○	○	○
Places additional burdens on parents	○	○	○	○
Causes conflict between parents and staff	○	○	○	○
Causes conflict between parents and their child	○	○	○	○

12. Do you disagree or agree with the following statements? Releasing patient results via the portal:

	Strongly disagree	Disagree	Agree	Strongly Agree
Enables patients to be more involved in their care	○	○	○	○
Enables parents to be more involved in their child's care	○	○	○	○
Increases patient anxiety	○	○	○	○
Increases parent anxiety	○	○	○	○
Makes patients more likely to contact their clinician	○	○	○	○
Makes parents more likely to contact their child's clinician	○	○	○	○
Makes it more likely that patients will self-diagnose	○	○	○	○
Makes it more likely that patients will self-treat	○	○	○	○
Makes it more likely that parents will diagnose their child themselves	○	○	○	○
Makes it more likely that parents will treat their child themselves	○	○	○	○

Thank you for taking the time to complete this survey. Your opinion is important to us. If there is anything you would like to comment further on please use the space provided: ______________________________



Data Protection Privacy Notice
UCL Great Ormond Street Institute of Child Health (UCL GOS ICH) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Great Ormond Street will keep identifiable information about you for 3-6 months after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible (job title, level of seniority and speciality).

The research team from Great Ormond Street Hospital will keep your job title, level of seniority and speciality confidential and will not pass this information to UCL GOS ICH. The research team will use this information as needed, making sure that relevant information about the study is recorded, and overseeing the quality of the study. Certain individuals from UCL GOS ICH and regulatory organisations may look at the research records to check the accuracy of the research study. UCL GOS ICH will only receive information without any identifying information. The people who analyse the information will not be able to find out your name or contact details because these will not be collected as part of the survey. You can find out more about how we use your information by contacting Lee Shailer, the Data Protection Officer, at [redacted]

This research has been reviewed and approved by Health Research Authority Southeast London Research Ethics Committee IRAS ID: 248793; v1 11.01.19

Appendix 32 – Parent interview schedule

Thank you so much for agreeing to participate in the Going Digital study interview. I am really interested to hear about your experiences so far around electronic patient record use and MyGOSH patient portal.

Checklist:

- Has the participant had the opportunity to read the participant information sheet? Do they have any questions about this?
- Has the participant read, signed, and returned the consent form?
- Do they understand that the interview is confidential and that only the researchers will hear what is said?
- Do they understand that if any quotes are used no one will be able to tell who said it?
- Are they happy for the interview to be recorded?
- Does the participant consent to participating in/starting the interview?
    - I wondered if you would first like to tell me about you and your family?
    - And about your child’s involvement in GOSH?
    - Looking back, how well informed do you think you were about EPR or MyGOSH patient portal? So, for example did you feel you were very well prepared or poorly prepared or somewhere in between?
    - What are the benefits of using MyGOSH for you?
    - What are the benefits of using MyGOSH for your child?
    - What do you think are the benefits for the hospital of having an EPR system and a patient portal?
    - Have you encountered any challenges using MyGOSH?
    - Has your child encountered any challenges?
    - What do you think the challenges are for the hospital?
    - Is there any information that would have been helpful for to have before you started using the new system?
    - Are there any aspects of MyGOSH you have needed support with? Prompts: technical help, accessing test results, understanding health information, contacting the care team, booking appointments

- Are there any aspects of MyGOSH your child has needed support with? Prompts: technical help, accessing test results, understanding health information, contacting the care team, booking appointments
- How has EPR changed your experience?
  Prompts: interactions with staff during clinic, coordination of care, communication with your care team
- How has MyGOSH changed your experience?
- Has this experience been impacted by COVID-19? How has it changed your experience? Prompts: have you had any appointments via telephone or video call? What was that like, how did it compare to face-to-face appointments? How is the communication with staff? How is the scheduling of appointments/procedures etc?
- Does your child use MyGOSH? How do you feel about this? For example, being able to access some of their own health records, being able to view their results and appointments and being able to message their care team?
- Is there anything that you worry about in relation to EPR/MyGOSH?
- When did you sign up to MyGOSH? If post lockdown – do you think you would have signed up if it wasn’t for Covid
- How do you feel about the age limit for children accessing MyGOSH (12 years of age)?
- How do you feel about your child having sole access to MyGOSH at the age of 16 (if they are able/if they so wish)?
- How do you think MyGOSH could help your child when transitioning (moving) into adult services? How has it been in reality?
- Do you think there are any ethical dilemmas related to using MyGOSH? (Ethics is thought of in terms of what is good, fair, or just)
- Do you think there are any legal dilemmas related to using MyGOSH? (Legal is thought of in terms of rules that we must follow and the law)
- Is there anything else you feel I should have asked you or that you would like to talk about?

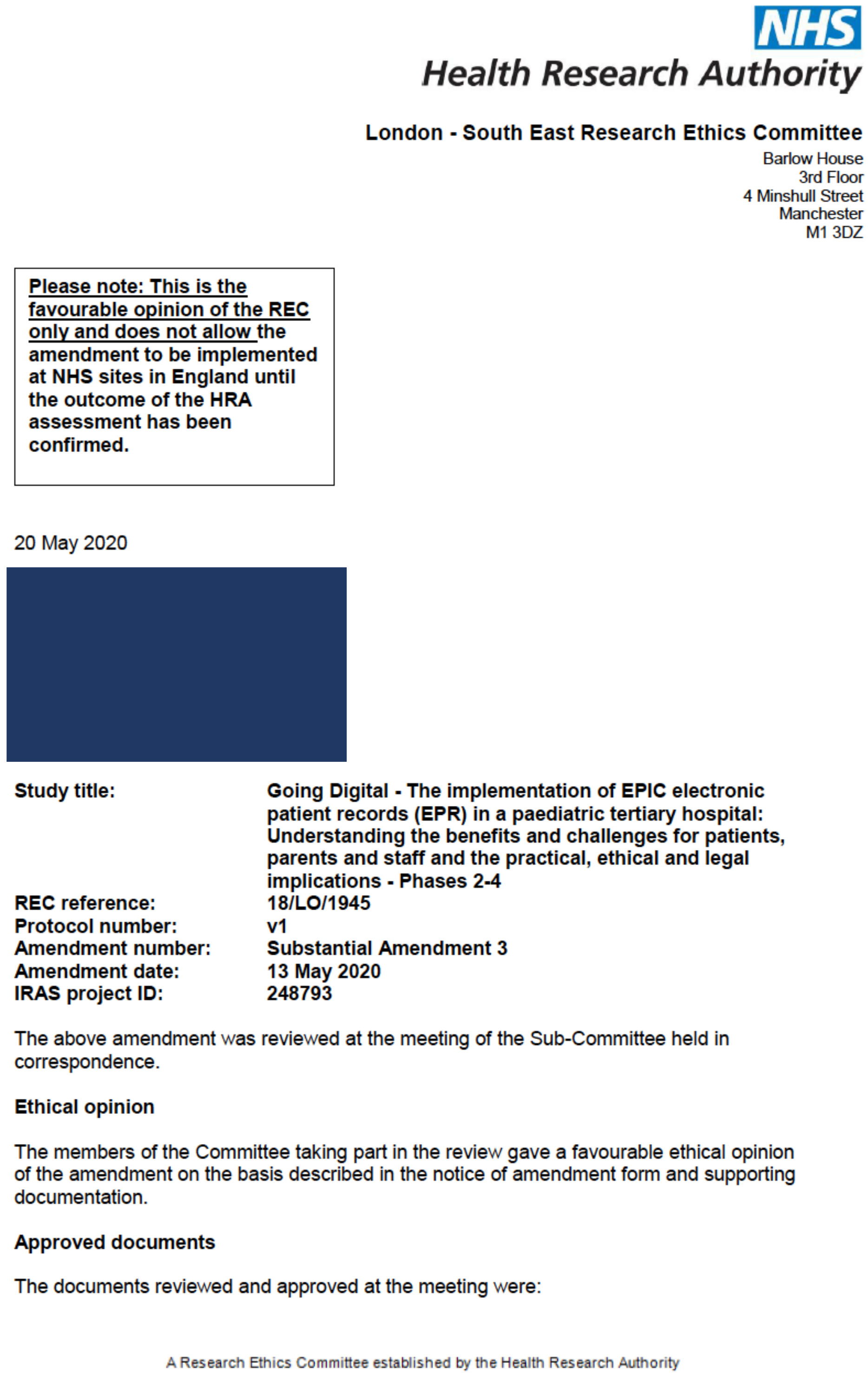
Thank you for taking the time to talk to me today. Your views are an essential contribution to the study.

Appendix 33 – Missing data table (CYP)

Children's and young people's survey	**T_1 *n*=280**	**T_2 *n*=174**
Variable	**Missing *n*= (%)**	**Missing *n*= (%)**
Coordination of appointments	13 (4.6)	22 (12.6)
Convenience of appointments	9 (3.2)	20 (11.5)
Ease of speaking to member of care team	19 (6.8)	22 (12.6)
Overall communication from care team	18 (6.4)	20 (11.5)
Ease of getting questions answered	24 (8.6)	23 (13.2)
Time to receiving test results	33 (11.7)	24 (13.8)
Mode of receiving test results	37 (13.2)	24 (13.8)
Involvement in decisions about your care	19 (6.8)	21 (12.1)
Informed about your care	21 (7.5)	19 (10.9)
Involvement my parents have in decisions about my care	36 (12.8)	20 (11.5)
Involvement I have in decisions about my care	35 (12.5)	21 (12.1)
Coordination of my care	37 (13.2)	21 (12.1)
Knowledge of my care team has about me and my condition(s)	35 (12.5)	22 (12.6)
Communication between teams looking after me	39 (13.9)	20 (11.5)
Communication between my care team and my parents	32 (11.4)	19 (10.9)
Communication between me and my care team	35 (12.5)	20 (11.5)
Emotional support	36 (12.8)	21 (12.1)
Technical help	31 (11.1)	23 (13.2)
Guidance on using InBasket messaging	31 (11.1)	24 (13.8)
Guidance on MyGOSH use	32 (11.4)	20 (11.5)
What happens when the system goes down	29 (10.4)	20 (11.5)
Which doctor/nurse/therapist I will see at the hospital	28 (10.0)	18 (10.3)
Who is looking at my health data	31 (11.1)	18 (10.3)
Health data privacy	28 (10.0)	18 (10.3)
Health data is back up	30 (10.7)	18 (10.3)
Safety of health data from hacking	28 (10.0)	18 (10.3)
Not getting answers to my questions quickly enough	30 (10.7)	18 (10.3)
Needing support when accessing results	26 (9.3)	17 (9.8)
Conflict between me and my care team	28 (10.0)	18 (10.3)
Conflict between me and my parents	27 (9.6)	18 (10.3)
Conflict between staff and my parents	28 (10.0)	20 (11.5)
Cause my parents anxiety	28 (10.0)	17 (9.8)
Cause me anxiety	28 (10.0)	17 (9.8)

Difficult to understand	30 (10.7)	17 (9.8)
Difficult to access	28 (10.0)	17 (9.8)
Difficult for my parents to use	26 (9.3)	17 (9.8)
Difficult to use	26 (9.3)	17 (9.8)
Constantly being reminded of my condition(s)	30 (10.7)	19 (10.9)
Reading something I don’t want to read	30 (10.7)	20 (11.5)
Reading something I don’t understand	30 (10.7)	19 (10.9)
Do you think the lower age limit of 12 years old for being able to access MyGOSH (with my parent’s consent) is acceptable?	32 (11.4)	21 (12.1)
When you turn 16 will you give permission for your parents to access MyGOSH?	33 (11.7)	16 (9.2)
I feel well informed about MyGOSH	34 (12.1)	17 (9.8)
Social media use to post about your care team	19 (6.8)	18 (10.3)
Social media use to post about the hospital	21 (7.5)	21 (12.1)
Social media use to post about your health results	17 (6.1)	18 (10.3)
Social media use to seek advice about your health	19 (6.8)	18 (10.3)
Social media use to help discuss your condition(s)	17 (6.1)	18 (10.3)
Use of health-related apps	18 (6.4)	18 (10.3)

Appendix 34 – Substantial amendment – survey demographics



NHS
Health Research Authority

London - South East Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

<u>Please note: This is the favourable opinion of the REC only and does not allow</u> the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

20 May 2020

[redacted]

Study title:	**Going Digital - The implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications - Phases 2-4**
REC reference:	**18/LO/1945**
Protocol number:	**v1**
Amendment number:	**Substantial Amendment 3**
Amendment date:	**13 May 2020**
IRAS project ID:	**248793**

The above amendment was reviewed at the meeting of the Sub-Committee held in correspondence.

Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering letter on headed paper		16 April 2020
Non-validated questionnaire [Children and Young People's Survey Tracked Changes]	2.0	16 April 2020
Non-validated questionnaire [Parent Survey Tracked Changes]	2.0	16 April 2020
Notice of Amendment (non-CTIMP)	Substantial Amendment 3	13 May 2020
Research protocol or project proposal [Clean (No Changes Made)]	5.0	16 April 2020

Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improving-research/learning/

18/LO/1945: **Please quote this number on all correspondence**

Yours sincerely

[redacted]

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Ms Philippa Sipanoun*

Subject: [EXTERNAL EMAIL] - IRAS PROJECT ID 248793, REC Reference 18/LO/1945 Confirmation of favourable opinion for substantial amendment

EXTERNAL EMAIL: This email originated from outside of the organisation. Do NOT click links or open attachments unless you recognise the sender and know that the content is safe. If in doubt, please contact [redacted]

Dear Ms Sipanoun

IRAS project ID:	248793
REC reference:	18/LO/1945
Short Study title:	Going Digital Study - Phases 2 - 4
Date complete amendment submission received:	13 May 2020
Amendment No./ Sponsor Ref:	Substantial Amendment 3
Amendment Date:	13 May 2020
Amendment Type:	**Substantial**
Outcome of HRA Assessment	**This email also constitutes HRA and HCRW Approval for the amendment, and you should not expect anything further.**

Appendix 35 – Missing data table/number of N/A responses (parents)[xxi][xxii]

Parent surveys	**T_1 *n*=1040**		**T_2 *n*=2905**	
Variable	**N/A *n*= (%)**	**Missing *n*= (%)**	**N/A *n*= (%)**	**Missing *n*= (%)**
Have you signed up to MyGOSH?	-	28 (2.7)	-	69 (2.4)
How many children do you have who are patients at GOSH?	-	20 (1.9)	-	26 (0.9)
How old is your child who is a patient at GOSH?	-	11 (1.1)	-	17 (0.6)
How many teams does your child see at GOSH?	-	44 (4.2)	-	31 (1.1)
How appointments are booked	-	27 (2.6)	-	28 (1.0)
How appointments are changed	-	52 (5.0)	-	80 (2.8)
Coordination of appointments	-	87 (8.4)	-	120 (4.1)
Convenience of appointments	-	38 (3.7)	-	42 (1.4)
Time to receiving clinic letter	-	45 (4.3)	-	57 (2.0)
Ease of speaking to member of care team	-	60 (5.8)	-	60 (2.1)
Overall communication from care team	-	48 (4.6)	-	42 (1.4)
Ease of getting questions answered	-	53 (5.1)	-	59 (2.0)
Time to receiving test results	-	103 (9.9)	-	136 (4.7)
Mode of receiving test results	-	102 (9.8)	-	138 (4.8)
Involvement in decisions about your child's care	-	53 (5.1)	-	57 (2.0)
Informed about your child's care	-	56 (5.4)	-	51 (1.8)
Check child's health data is correct	-	56 (5.4)	-	61 (2.1)
Feel in control of child's health data	-	63 (6.1)	-	49 (1.7)
Feel more in control of child's condition(s)	-	57 (5.5)	-	57 (2.0)

[xxi] Please note: '-' denotes there was no 'not applicable' option in the question

[xxii] Questions with a large number of N/A responses related to parents who had a child under 12 years of age

Feel more informed about child’s condition(s)	-	59 (5.7)	-	48 (1.7)
Feel well informed about child’s care	-	56 (5.4)	-	48 (1.7)
Feel more involved in child’s care	-	54 (5.2)	-	46 (1.6)
Access up-to-date health data	-	53 (5.2)	-	48 (1.7)
Easier communication with child’s care team	-	56 (5.4)	-	45 (1.5)
View results online	-	54 (5.2)	-	45 (1.5)
Change appointments online	-	49 (4.7)	-	45 (1.5)
Involvement in decisions about my child’s care	142 (13.7)	119 (11.4)	503 (17.3)	88 (3.0)
Involvement of my child in decisions about their care	208 (20.0)	113 (10.9)	906 (31.2)	77 (2.7)
Coordination of care	125 (12.0)	123 (11.8)	462 (15.9)	78 (2.7)
Knowledge of my child’s care team has about child’s condition(s)	124 (11.9)	116 (11.2)	484 (16.7)	82 (2.8)
Communication between teams looking after my child	136 (13.1)	112 (10.8)	702 (24.1)	84 (2.9)
Communication between care team and my child	221 (21.3)	112 (10.8)	1014 (34.9)	71 (2.4)
Communication between care team and me	125 (12.0)	110 (10.6)	384 (13.2)	62 (2.1)
Emotional support	-	108 (10.4)	-	238 (8.2)
Technical help	-	97 (9.3)	-	184 (6.3)
Guidance on using InBasket messaging	-	96 (9.2)	-	163 (5.6)
Guidance on MyGOSH use	-	94 (9.0)	-	143 (4.9)
What happens when the system goes down	-	97 (9.3)	-	149 (5.1)
Who my child will see at the hospital	-	92 (8.8)	-	128 (4.4)
Who is looking at my child’s health data	-	94 (9.0)	-	139 (4.8)
Privacy of my child’s health data	-	90 (8.7)	-	138 (4.8)
My child’s health data is backed up	-	87 (8.4)	-	141 (4.9)

My child's health data is safe from hacking	-	82 (7.9)	-	119 (4.1)
Not getting answers to my questions quick enough	114 (11.0)	106 (10.2)	506 (17.4)	97 (3.3)
My child needs support when accessing results	244 (23.5)	96 (9.2)	1577 (54.3)	84 (2.9)
I need support when accessing my child's results	69 (6.6)	95 (9.1)	146 (5.0)	74 (2.5)
Conflict between staff and my child	169 (16.3)	97 (9.3)	885 (30.5)	85 (2.9)
Conflict between me and my child	166 (16.0)	95 (9.1)	851 (29.3)	66 (2.3)
Conflict between me and staff	104 (10.0)	91 (8.8)	235 (8.1)	78 (2.7)
Cause my child anxiety	231 (22.2)	94 (9.0)	1305 (44.9)	76 (2.6)
Cause me anxiety	96 (9.2)	97 (9.3)	104 (3.6)	58 (2.0)
Difficult for my child to understand	267 (25.7)	91 (8.8)	1513 (52.1)	73 (2.5)
Difficult to understand	89 (8.6)	93 (8.9)	44 (1.5)	66 (2.3)
Difficult to access	95 (9.1)	94 (9.0)	52 (1.8)	53 (1.8)
Difficult for my child to use	288 (27.7)	90 (8.7)	1643 (56.6)	72 (2.5)
Difficult to use	95 (9.1)	82 (7.9)	52 (1.8)	58 (2.0)
My child reading something I don't want them to read	260 (25)	98 (9.4)	1585 (54.6)	103 (3.5)
My child reading something they don't want to read	246 (23.7)	98 (9.4)	1641 (56.5)	87 (3.0)
Reading something I don't understand	61 (5.9)	93 (8.9)	208 (7.2)	87 (3.0)
Do you think the lower age limit of 12 years old for being able to access MyGOSH with your consent is acceptable?	298 (28.7)	227 (21.8)	1207 (41.5)	382 (13.1)
I feel well informed about the electronic patient record system	-	173 (16.6)	-	106 (3.9)
Social media use to post about your child's care team	-	26 (2.5)	-	42 (1.4)
Social media use to post about the hospital	-	28 (2.7)	-	39 (1.3)
Social media use to post about your child's health results	-	24 (2.3)	-	31.1 (1.1)
Social media use to seek advice about your child's health	-	28 (2.7)	-	31.1 (1.1)

Social media use to help discuss your child’s condition(s)	-	26 (2.5)	-	34 (1.2)
Use of health-related apps	-	25 (2.4)	-	30 (1.0)
To post about their care team	52 (5.0)	33 (3.2)	242 (8.3)	60 (2.1)
To post about the hospital	53 (5.1)	30 (2.9)	243 (8.4)	42 (1.4)
To post about their health results	52 (5.0)	31 (3.0)	241 (8.3)	32 (1.1)
To seek advice about their health	53 (5.1)	35 (3.4)	240 (8.3)	33 (1.1)
To help discuss their conditions(s)	51 (4.9)	31 (3.0)	240 (8.3)	43 (1.5)
Health related app use	53 (5.1)	29 (2.8)	232 (8.0)	31 (1.1)
Accessing MyGOSH	298 (28.7)	227 (21.9)	1207 (41.6)	382 (13.1)
Accessing their results online	302 (29.1)	229 (22.1)	1185 (40.8)	419 (14.4)
Being able to contact their care team through MyGOSH	300 (28.9)	233 (22.4)	1197 (41.2)	411 (14.1)
Being able to view some of their health data	300 (28.9)	230 (22.2)	1185 (40.8)	407 (14.0)
Posting about their condition(s) on social media	314 (30.3)	235 (22.7)	1299 (44.7)	418 (14.4)
Posting their health results on social media	311 (30.0)	231 (22.3)	1291 (44.4)	426 (14.7)
Having sole access to their health data at 16 years of age	304 (29.3)	233 (22.4)	1217 (41.9)	441 (14.1)

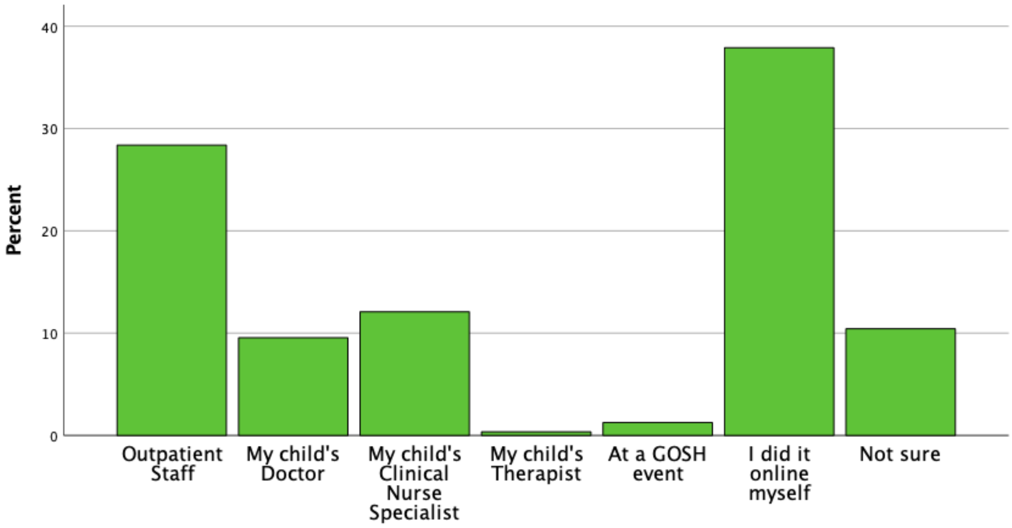
Appendix 36 – Parent survey collection – location/number

Location within GOSH Outpatients (paper survey – T_1)	**Responses *n*= (%)**
Homeopathic Building Level 5 – Hemophilia	6 (0.6)
Hippo (Homeopathic Building Level 4) – Neurology, Neurodisability, Metabolic	143 (13.8)
Hare (Homeopathic Building Level 2) – Multiple Specialities	147 (14.1)
Zebra (Homeopathic Building Level 1) – Multiple Specialities	127 (12.2)
Urodynamics	31 (3.0)
Max/Fax/Dental	24 (2.3)
Lagoon (Volunteers signing up families to MyGOSH)	21 (2.0)
Walrus – Cardiology	6 (0.6)
Cheetah then Falcon (Respiratory, Immunology, Cardiology, Inherited Cardiology, Genetics, Dermatology, Infectious Diseases, General Surgery, Endocrine and Rheumatology	259 (25.0)
Manta – Dubowitz Neuromuscular Centre, Neurodisability, Speech and Language Therapy, Ophthalmology, Dermatology, Spinal Surgery, Pre-admission Assessment	61 (5.9)
Rhino – Ear, Nose and Throat, Ophthalmology, Audiology, Specialist Neonatal and Paediatric Surgery	165 (15.9)
Child and Adolescent Mental Health Services	44 (4.3)
Total	**1037**
Survey sent electronically to Young People's Forum Members*	3 (0.3)
Grand Total	**1040**

*Survey sent electronically to 28 members of the Young People's Forum and their parents (and they were asked not to complete a paper copy if they came to clinic)

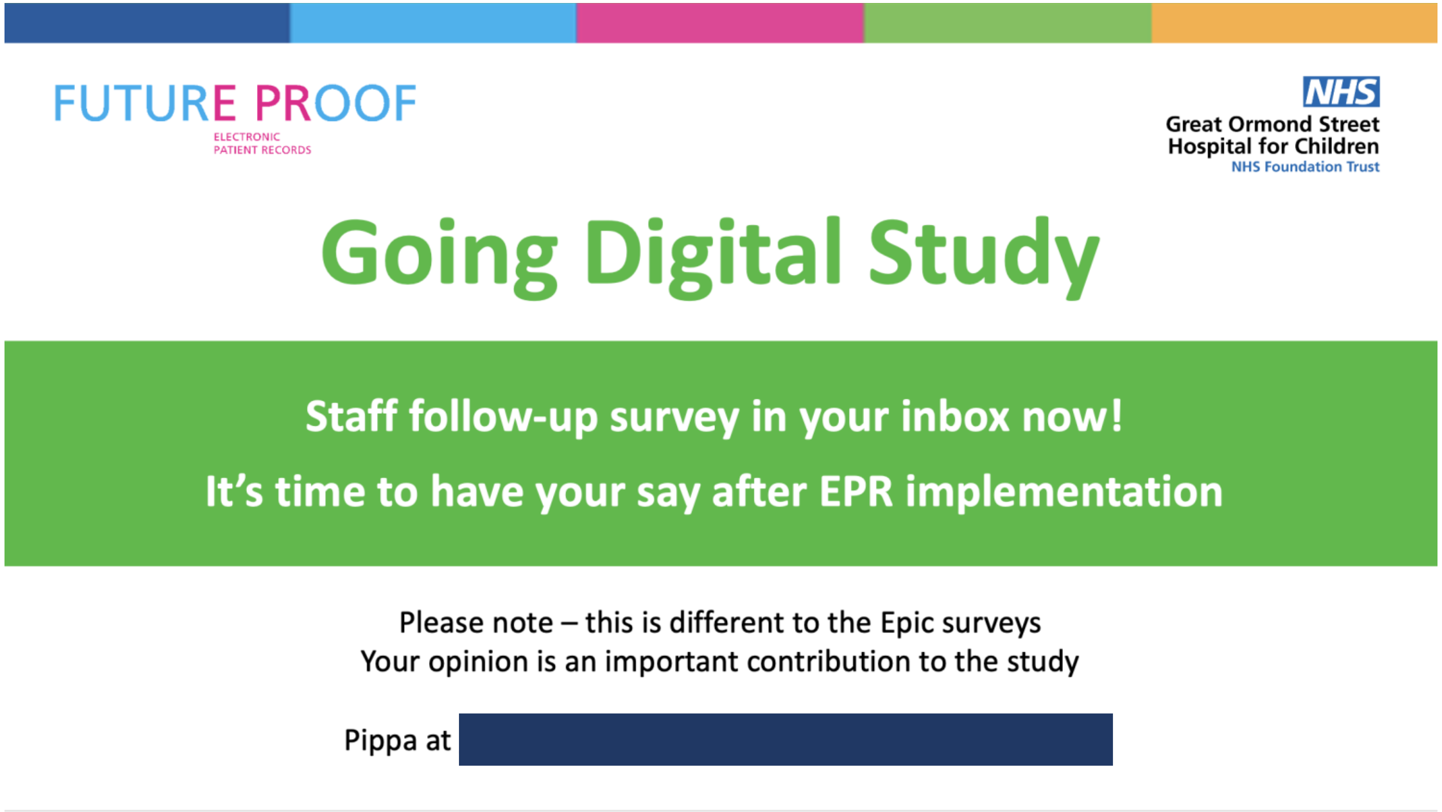
Appendix 37 – Who signed the parent up to MyGOSH

Parents were asked who signed them up to MyGOSH (*n*=2836)



The largest proportion (37.9%/*n*=1075) of parents signed themselves up to MyGOSH online, with outpatient staff signing up a further 28% (n=805).

Appendix 38 – Example of screensaver and banner



FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

NHS
Great Ormond Street
Hospital for Children
NHS Foundation Trust

Going Digital Study

Staff follow-up survey in your inbox now!

It's time to have your say after EPR implementation

Please note – this is different to the Epic surveys
Your opinion is an important contribution to the study

Pippa at [redacted]

Going Digital Study: There's still time to have your say via the staff follow-up survey

Appendix 39 – Missing data table/number of N/A responses (staff)[xxiii]

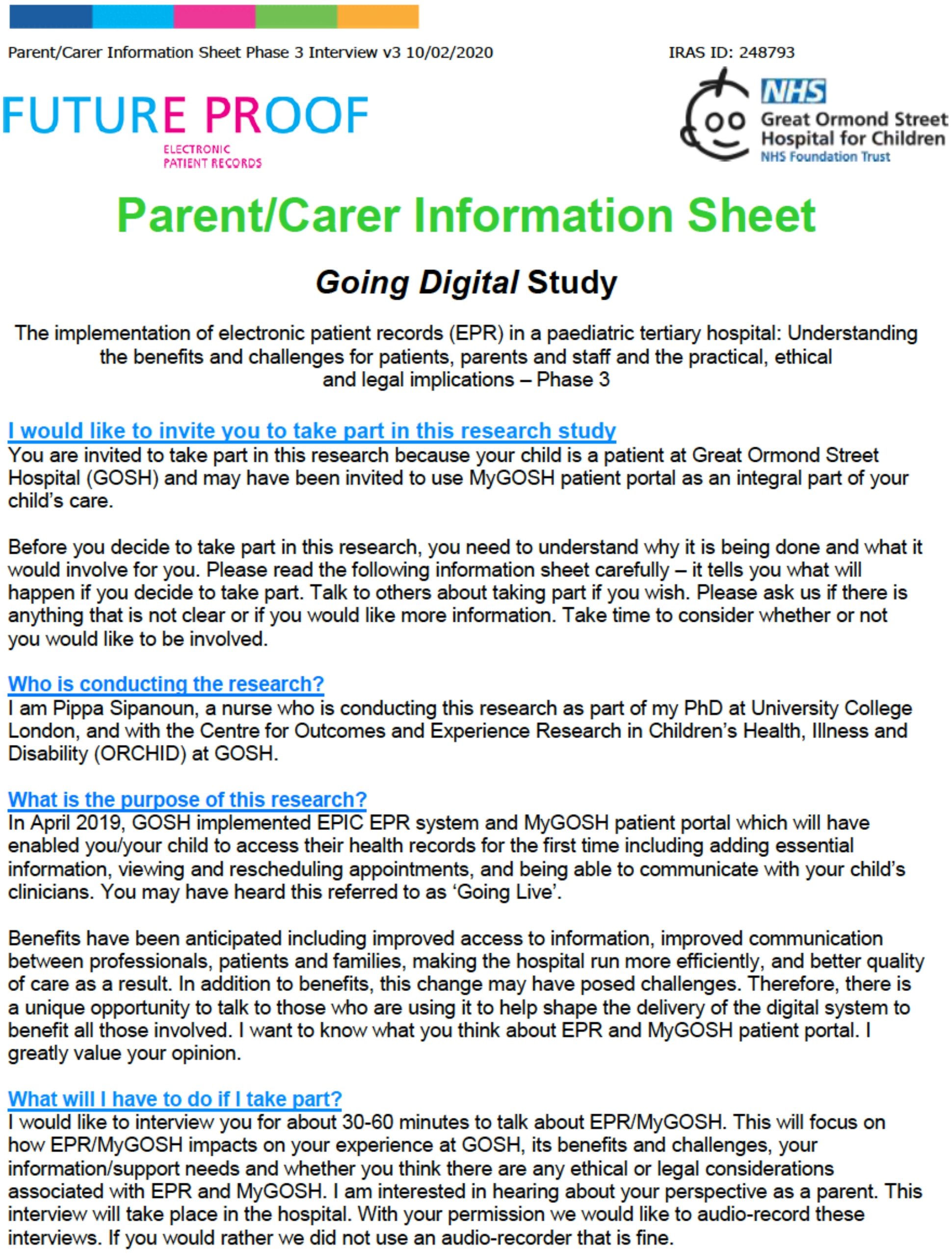
Staff surveys	**T_1 *n*=650**		**T_2 *n*=512**		**T_3 *n*=568**	
Variable	**No of N/A *n*= (%)**	**No of missing *n*= (%)**	**No of N/A *n*= (%)**	**No of missing *n*= (%)**	**No of N/A *n*= (%)**	**No of missing *n*= (%)**
Easier for staff to keep patients informed of care plan	-	60 (9.2)	-	64 (12.5)	-	67 (11.8)
Easier for staff to keep parents informed of care plan	-	60 (9.2)	-	65 (12.7)	-	62 (10.9)
Increased patient involvement in decisions about care	-	82 (12.6)	-	127 (24.8)	-	118 (20.8)
Increased parental involvement in decisions about care	-	91 (14.0)	-	132 (25.8)	-	129 (22.7)
Releasing results onto MyGOSH enables patients to be more involved in care	-	78 (12.0)	**-**	146 (28.5)	-	138 (24.3)
Releasing results onto MyGOSH enables parents to be more involved in care	-	80 (12.3)	-	146 (28.5)	-	134 (23.6)
Support patients to make a decision about their care	179 (27.5)	16 (2.5)	194 (37.9)	17 (3.3)	189 (33.2)	20 (3.5)
Support parents to make a decision about care	166 (25.5)	19 (2.9)	185 (36.1)	17 (3.3)	185 (32.5)	21 (3.7)
Answer patients' questions	139 (21.4)	17 (2.6)	154 (30.1)	16 (3.1)	156 (27.5)	19 (3.3)
Answer parents' questions	124 (19.1)	16 (2.5)	137 (26.8)	15 (2.9)	135 (23.8)	18 (3.2)

[xxiii] Please note: '-' denotes there was no 'not applicable' option in the question

Manage patient anxiety	159 (24.5)	16 (2.5)	177 (34.5)	20 (3.9)	172 (30.2)	22 (3.9)
Manage parent anxiety	143 (22.0)	17 (2.6)	161 (31.4)	18 (3.5)	156 (27.5)	23 (4.0)
Manage conflict	90 (13.8)	18 (2.8)	145 (28.3)	22 (4.3)	142 (25.0)	28 (4.9)
Results release via MyGOSH increases patient anxiety	-	88 (13.5)	-	158 (30.8)	-	143 (25.2)
Results release via MyGOSH increases parent anxiety	-	89 (13.7)	-	162 (31.6)	-	143 (25.2)
Patients need additional support when accessing results via MyGOSH	75 (11.5)	51 (7.8)	269 (52.5)	26 (5.1)	260 (45.8)	33 (5.8)
Parents need additional support when accessing results via MyGOSH	74 (11.4)	52 (8.0)	267 (52.1)	26 (5.1)	256 (45.1)	36 (6.3)
Managing patients’ expectations	-	76 (11.7)	-	81 (15.8)	-	85 (15.0)
Managing parents’ expectations	-	77 (11.8)	-	85 (16.6)	-	85 (15.0)
MyGOSH use makes it easier for parents to change their child’s appointment	-	94 (14.5)	-	138 (27.0)	-	134 (23.6)
MyGOSH use reduces the number of missed appointments	-	94 (14.5)	-	136 (26.6)	-	128 (22.5)
Improves my ability to collaborate with other staff in my speciality	68 (10.5)	6 (0.9)	53 (10.4)	5 (1.0)	47 (8.3)	9 (1.6)

Improves my ability to collaborate with staff from other specialities	60 (9.2)	10 (1.5)	50 (9.76)	17 (3.3)	54 (9.5)	9 (1.6)
Improves my ability to communicate with patients	136 (20.9)	15 (2.3)	172 (33.5)	13 (2.5)	177 (31.2)	14 (2.5)
Improves my ability to communicate with parents	122 (18.8)	19 (2.9)	151 (29.5)	14 (2.7)	144 (25.4)	17 (3.0)
InBasket messaging improves communication between staff and patients	-	77 (11.8)	-	132 (25.8)	-	127 (22.3)
InBasket messaging improves communication between staff and parents	-	80 (12.3)	-	139 (27.1)	-	126 (22.2)
Causes conflict between parents and child	-	101 (15.5)	-	160 (31.3)	-	142 (25.0)
Causes conflict between parents and staff	-	98 (15.1)	-	147 (8.7)	-	139 (24.4)
I worry families may post about me on social media	92 (14.2)	53 (8.2)	176 (34.4)	20 (3.9)	166 (29.2)	28 (4.9)
I worry families may post about the hospital on social media	82 (12.6)	53 (8.2)	160 (31.3)	17 (3.3)	157 (27.6)	33 (5.8)
Easier for patients to share health data on social media	-	95 (14.6)	-	137 (26.7)	-	140 (24.6)
Easier for parents to share their child’s health data on social media	-	95 (14.6)	-	138 (26.9)	-	139 (24.5)
Unable to access MyGOSH	76 (11.7)	50 (7.7)	283 (55.3)	22 (4.3)	254 (44.7)	33 (5.8)

Appendix 40 – Phase 3 parent interview participant information sheet



Parent/Carer Information Sheet Phase 3 Interview v3 10/02/2020

IRAS ID: 248793

FUTURE PROOF
ELECTRONIC
PATIENT RECORDS

NHS
Great Ormond Street
Hospital for Children
NHS Foundation Trust

Parent/Carer Information Sheet

Going Digital Study

The implementation of electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications – Phase 3

I would like to invite you to take part in this research study

You are invited to take part in this research because your child is a patient at Great Ormond Street Hospital (GOSH) and may have been invited to use MyGOSH patient portal as an integral part of your child's care.

Before you decide to take part in this research, you need to understand why it is being done and what it would involve for you. Please read the following information sheet carefully – it tells you what will happen if you decide to take part. Talk to others about taking part if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to consider whether or not you would like to be involved.

Who is conducting the research?

I am Pippa Sipanoun, a nurse who is conducting this research as part of my PhD at University College London, and with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at GOSH.

What is the purpose of this research?

In April 2019, GOSH implemented EPIC EPR system and MyGOSH patient portal which will have enabled you/your child to access their health records for the first time including adding essential information, viewing and rescheduling appointments, and being able to communicate with your child's clinicians. You may have heard this referred to as 'Going Live'.

Benefits have been anticipated including improved access to information, improved communication between professionals, patients and families, making the hospital run more efficiently, and better quality of care as a result. In addition to benefits, this change may have posed challenges. Therefore, there is a unique opportunity to talk to those who are using it to help shape the delivery of the digital system to benefit all those involved. I want to know what you think about EPR and MyGOSH patient portal. I greatly value your opinion.

What will I have to do if I take part?

I would like to interview you for about 30-60 minutes to talk about EPR/MyGOSH. This will focus on how EPR/MyGOSH impacts on your experience at GOSH, its benefits and challenges, your information/support needs and whether you think there are any ethical or legal considerations associated with EPR and MyGOSH. I am interested in hearing about your perspective as a parent. This interview will take place in the hospital. With your permission we would like to audio-record these interviews. If you would rather we did not use an audio-recorder that is fine.

What will my child have to do if I agree to take part?

I would like to hear your child's opinion as well as yours as I value both of your viewpoints. I will only ask your child to take part if you agree for us to invite him or her. If they are using MyGOSH patient portal as part of their care I would like to know what they think about using it. This would involve me communicating with them in whatever way they are able to and feel comfortable with. I will listen to your advice about what works best for your child. I have a separate information sheet for children and young people, which will explain their involvement in more detail.

Do I have to take part?

No, you do not have to take part. Participation is completely voluntary. If you do agree to participate, you are free to withdraw at any time without question.

What are the disadvantages of taking part?

Taking part in this study will mean giving up some of your time to talk to me about your experience. The interview will take place at a time that is convenient to you. It is not anticipated that the interview will cause any distress; however, if this does occur we can stop at any time and support will be available to you.

What are the advantages of taking part?

I cannot promise that taking part in this study will benefit you personally, although you may value the opportunity to share your views in the knowledge that your contribution will help shape EPR and MyGOSH for the future. I value your expertise as a parent and your views are an important contribution to this study.

Will my data be kept confidential?

Yes. All information collected during this study will be kept confidential, which means only the research team will be able to see it. If I share any results, these will be kept anonymous, which means that you will not be able to be identified. The only reason I would break confidentiality and share any information is if I felt concerned about your or your child's safety.

What if I don't want to carry on with the study?

If you agree to take part in the study you have the right to stop at any time, without giving a reason. If you choose to withdraw, the care of you and your child will not be affected in any way. However, with your permission I would still like to use the data collected up to that point.

How will the data be kept secure and what happens to the data at the end of the study?

All paper data will be stored in a locked filing cabinet, which is located in a research office at GOSH only accessible by a swipe card. Personal identifiable data and consent forms will be stored separately to research data. Electronic data is stored on password protected servers accessed by Trust computers and encrypted laptops. At the end of the study personal data will only be stored and accessed for up to 6 months, unless a report of study findings is requested, then until end of study (3 years). Research data will be stored in accordance with GOSH Trust policy. An end of study thesis will be submitted to UCL upon completion. The thesis will not contain any identifying information.

What will happen to the results of the study?

The results will be published and presented so they can be shared with other healthcare professionals and researchers. All data that is shared will be anonymised so that children and young people, parents and staff members cannot be identified. A report of the study findings will be available upon request.

Data Protection Privacy Notice

UCL Great Ormond Street Institute of Child Health (UCL GOS ICH) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Great Ormond Street will keep identifiable information about you for

3-6 months after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The research team from Great Ormond Street Hospital will keep your name and contact details confidential and will not pass this information to UCL GOS ICH. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from UCL GOS ICH and regulatory organisations may look at your research records to check the accuracy of the research study. UCL GOS ICH will only receive information without any identifying information. The people who analyse the information will not be able to find out your name or contact details.

You can find out more about how we use your information by contacting Lee Shailer, the Data Protection Officer, at data-protection@ucl.ac.uk.

What if I have any concerns about the study, EPR or MyGOSH?

If you have any concerns or other questions about this study or the way it has been carried out, please talk to a member of the research team. If you remain unhappy, or wish to comment in any other way, you can contact the Patient Advice and Liaison Service (PALs) on 020 7829 7862 or email: pals@gosh.nhs.uk. If you are worried about any aspect of EPR or MyGOSH you can speak to your clinical team or, if you prefer, you can contact PALS on the contact details above. Your child’s care will not be affected in any way by raising any concerns or seeking support.

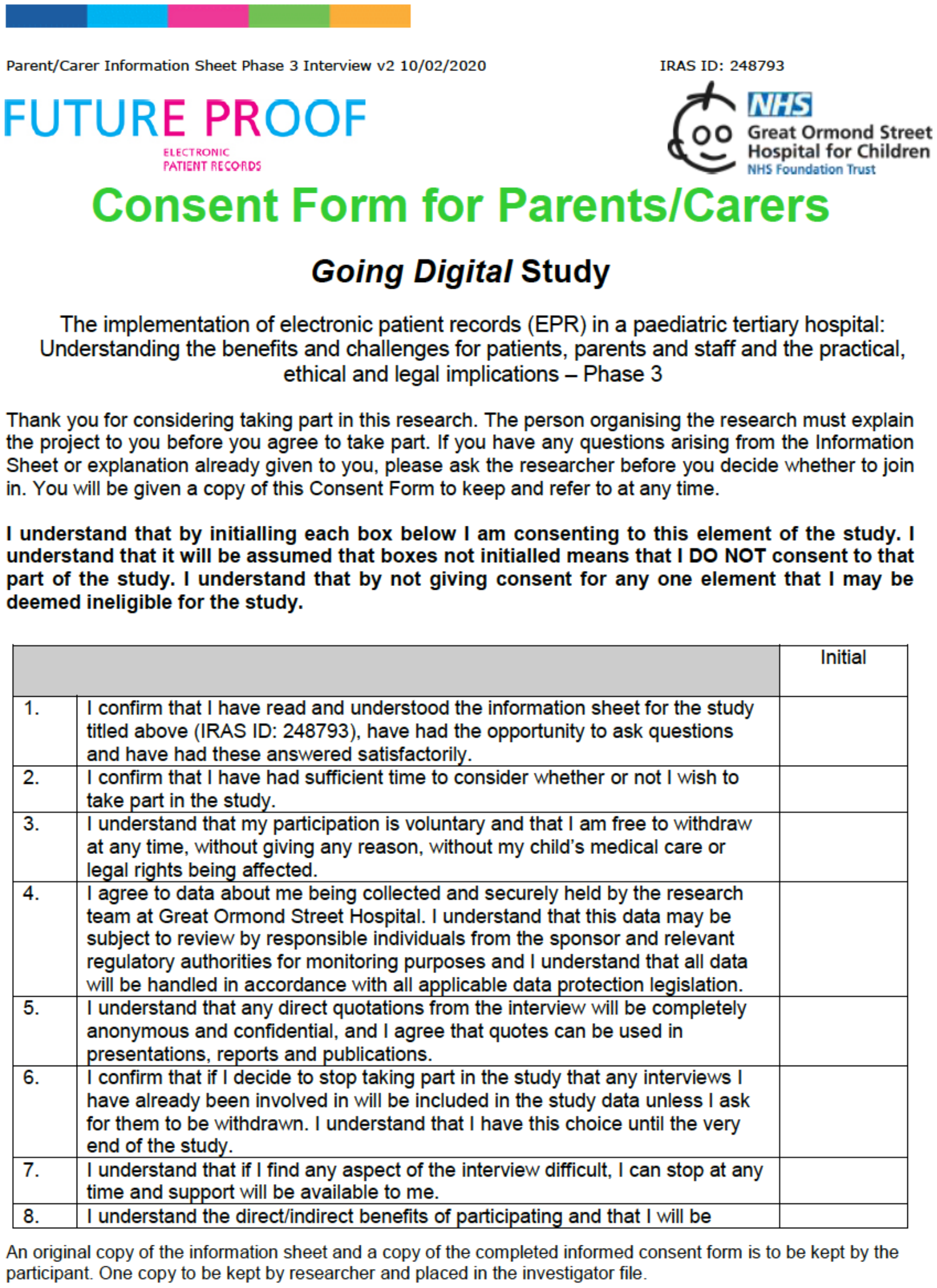
Who should I contact if I have any questions?

[redacted]

Thank you for taking the time to read this leaflet

This study is being funded by Great Ormond Street Hospital for Children

Appendix 41 – Phase 3 informed consent form



Parent/Carer Information Sheet Phase 3 Interview v2 10/02/2020

IRAS ID: 248793

FUTURE PROOF
ELECTRONIC PATIENT RECORDS

NHS
Great Ormond Street Hospital for Children
NHS Foundation Trust

Consent Form for Parents/Carers

Going Digital Study

The implementation of electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications – Phase 3

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that boxes not initialled means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Initial
1.	I confirm that I have read and understood the information sheet for the study titled above (IRAS ID: 248793), have had the opportunity to ask questions and have had these answered satisfactorily.	
2.	I confirm that I have had sufficient time to consider whether or not I wish to take part in the study.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my child's medical care or legal rights being affected.	
4.	I agree to data about me being collected and securely held by the research team at Great Ormond Street Hospital. I understand that this data may be subject to review by responsible individuals from the sponsor and relevant regulatory authorities for monitoring purposes and I understand that all data will be handled in accordance with all applicable data protection legislation.	
5.	I understand that any direct quotations from the interview will be completely anonymous and confidential, and I agree that quotes can be used in presentations, reports and publications.	
6.	I confirm that if I decide to stop taking part in the study that any interviews I have already been involved in will be included in the study data unless I ask for them to be withdrawn. I understand that I have this choice until the very end of the study.	
7.	I understand that if I find any aspect of the interview difficult, I can stop at any time and support will be available to me.	
8.	I understand the direct/indirect benefits of participating and that I will be	

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file.

	reimbursed for my travel, where relevant (travelling in only for the purposes of participating in this study e.g. interview)	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	
10.	I agree to the interview being audio-recorded.	
11.	I agree to take part in the above study.	

Full name of Parent Date Signature

Parent's e-mail address Telephone number

Full name of Person Obtaining Consent Date Signature

Who should I contact if I have any questions?

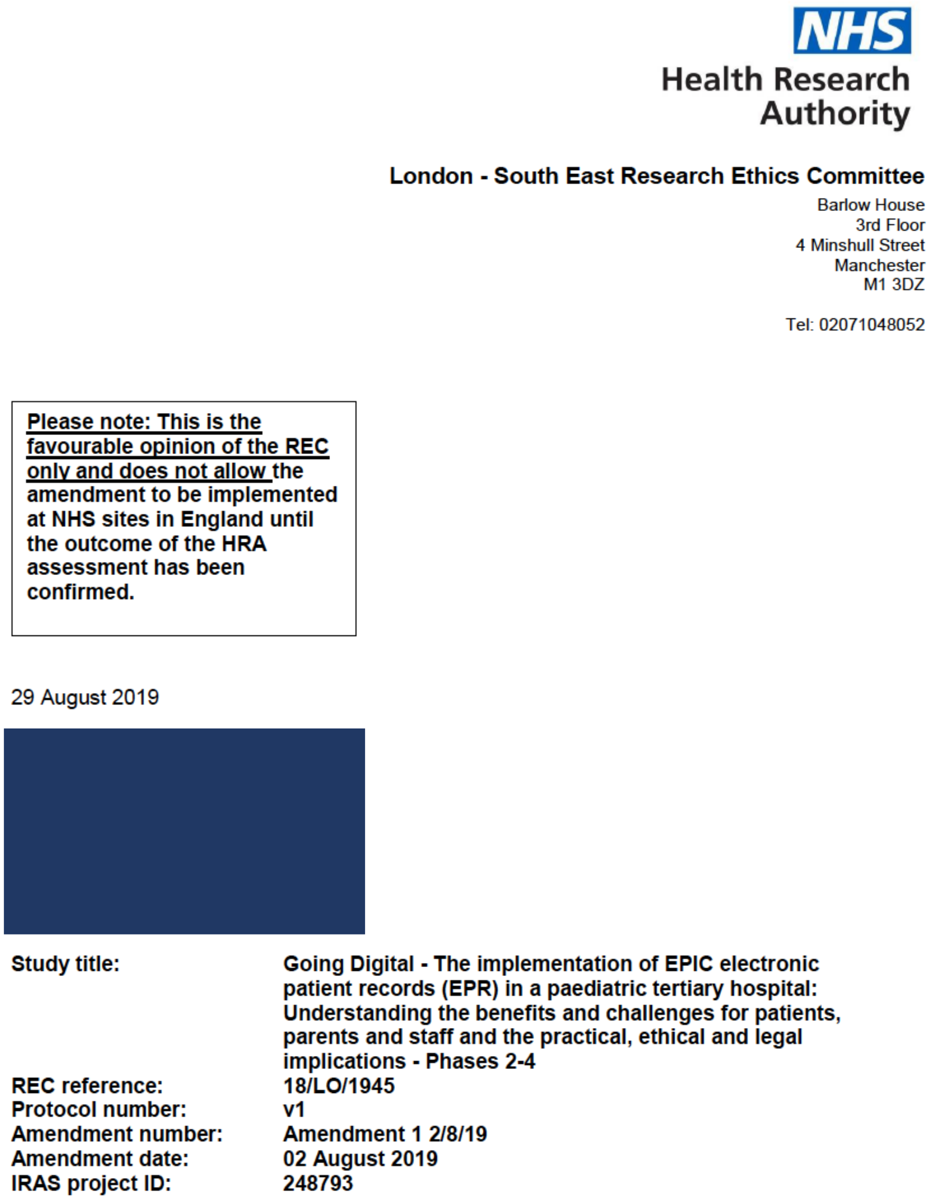
[redacted]

Thank you for taking the time to read this leaflet

This study is being funded by Great Ormond Street Hospital for Children

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file.

Appendix 42 – Substantial amendment – focus group



Health Research
Authority

London - South East Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

Tel: 02071048052

Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.

29 August 2019

[redacted]

Study title:	**Going Digital - The implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications - Phases 2-4**
REC reference:	**18/LO/1945**
Protocol number:	**v1**
Amendment number:	**Amendment 1 2/8/19**
Amendment date:	**02 August 2019**
IRAS project ID:	**248793**

Ethical opinion

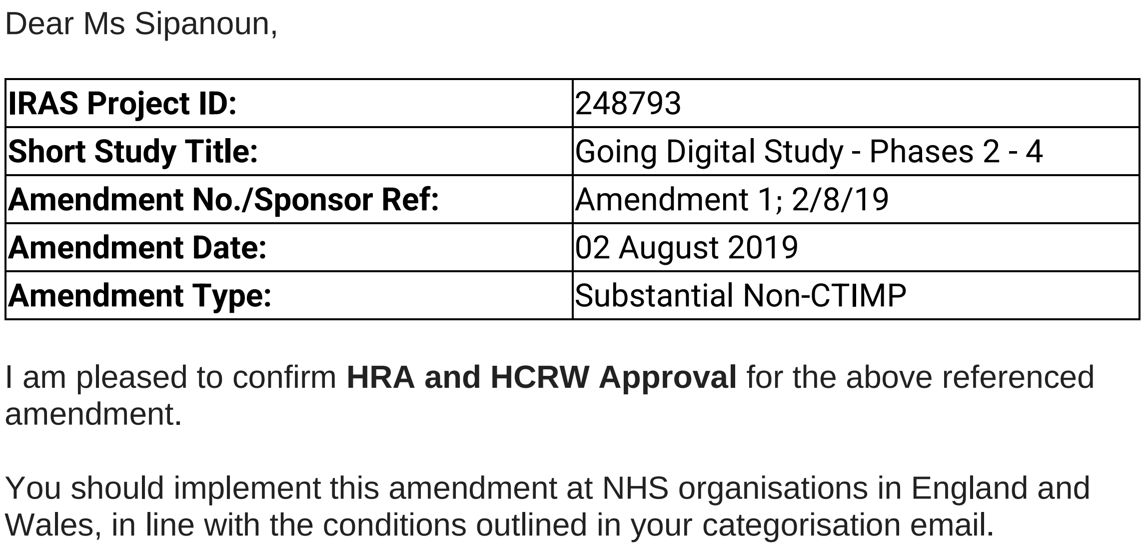
The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

The members of the Sub Committee raised no Ethical Issues with this amendment.

Approved documents

The documents reviewed and approved at the meeting were:

Document	*Version*	*Date*
Covering letter on headed paper [Cover letter]		05 August 2019
Notice of Substantial Amendment (non-CTIMP) [Amendment 1 2/8/19]	Amendment 1 2/8/19	02 August 2019
Other [Going Digital Study Mixed Methods Plan]	2	18 July 2019
Other [Going Digital Study CYP Follow Up Survey]	1	31 July 2019
Other [Going Digital Study Parent Follow Up Survey]	1	31 July 2019
Other [Going Digital Study Staff Follow Up Survey]	1	31 July 2019
Other [Phase 3 CEC Focus Group topic guide]	1	18 July 2019
Other [Phase 3 EPR CEC Consent focus group]	1	18 July 2019
Other [Phase 3 Parent Survey Invitation E-mail]	1	18 July 2019
Participant information sheet (PIS) [Phase 3 EPR CEC PIS focus group]	1	18 July 2019
Research protocol or project proposal [Going Digital Study Protocol Phases 2-4]	2	20 December 2018
Research protocol or project proposal [Going Digital Protocol Phases 2-4]	3	18 July 2019



Dear Ms Sipanoun,

IRAS Project ID:	248793
Short Study Title:	Going Digital Study - Phases 2 - 4
Amendment No./Sponsor Ref:	Amendment 1; 2/8/19
Amendment Date:	02 August 2019
Amendment Type:	Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the conditions outlined in your categorisation email.

Appendix 43 – Focus group topic guide

Facilitator's welcome, introduction and instructions to participants

Welcome and thank you for volunteering to take part in this focus group. Your participation in is of great value to the Going Digital Study and we appreciate any opinions you wish to share today.

Introduction: Introduction from researchers and participants. This focus group discussion is held with you, the members of the GOSH Paediatric Bioethics Centre (PBC), to explore the ethical and legal considerations related to MyGOSH patient portal. The focus group discussion will take no more than one and a half hours and is within your regular PBC meeting. May I tape the discussion to facilitate its recollection? (If yes, switch on the recorder)

Anonymity: Despite being recorded, I would like to assure you that the discussion will be anonymous. The transcribed notes of the focus group will contain no information that would allow individual subjects to be linked to specific statements. I and the other focus group participants would appreciate it if you would refrain from discussing the comments of other group members outside the focus group. If there are any questions or discussions that you do not wish to answer or participate in, you do not have to do so; however please try to answer and be as involved as possible.

Ground rules

- The most important rule is that only one person speaks at a time. There may be a temptation to jump in when someone is talking but please wait until they have finished.
- There are no right or wrong answers
- You do not have to speak in any particular order
- When you do have something to say, please do so. There are many of you in the group and it is important that I obtain the views of each of you
- You do not have to agree with the views of other people in the group
- Does anyone have any questions? (answers).
- OK, let's begin

Background

As you know, GOSH is no longer be using paper patient records after the implementation of EPR and a patient portal called MyGOSH in April 2019. Children and young people from the age of 12 years old (who are deemed competent by their clinician) can be granted access MyGOSH, with their parents' consent. Parents can have 'proxy' access to their child's MyGOSH account. Patients from 16 years and above can have sole access to MyGOSH (unless they are deemed not to have the capacity to do so). Their parents will then need to be granted permission to access MyGOSH by the young person. Appointments can be viewed via MyGOSH (parents and young people from 16-year-old will be able to change appointments), some test results will be released onto the portal, a limited amount of the children and young people's (CYP's) health data will be visible, and the end-user will be able to message their/their child's care team. There will also be information sheets available on MyGOSH e.g. pre-op/post-op information, information such as physio exercises for parents and CYP.

Thus, it is expected that there will be improved access for patients, improved communication between staff, patients and families, operational efficiencies, development of new models of care and treatments, in addition to enhanced innovative research analytics encompassing the whole electronic patient record system. Although this transition ought to bring many benefits, as described, it may also pose challenges for all stakeholders and raises ethical and legal dilemmas which were explored in workshops with each stakeholder group who will be using or affected by EPR/MyGOSH during phase one of the study. This included:

- Staff members from around the Trust, across specialities and across job titles/professions
- CYP who are patients or siblings of patients at GOSH (Members of the Young People's Forum)
- Parents of CYP who are patients at GOSH
- Topics raised for discussion in today's focus group include worries surrounding parent/patient use of social media, assessing capacity, parental non-disclosure of diagnosis/prognosis to the child/young person,

inequitable access, burdens on clinicians, concerns regarding keeping data safe, concerns around supporting CYP when accessing their digital health data, and what CYP themselves worry about.

Topics to cover:

Social media

- Concerns exist about parents and patients being able to share health data more easily on social media e.g. screen shots from MyGOSH – results, conversations with members of the care team – What are your thoughts on this?
- What other concerns do you have around CYP having access to their digital health data?
  Prompts: worries around the possibility of peer pressure, cyber-harassment, or cyber-bullying amongst CYP who share their health data online
- How can MyGOSH access benefit CYP?

Assessing capacity

- What do you think the ethical and legal considerations are around the issues of capacity?
- Issues surrounding assessing Gillick competence related to the use of MyGOSH
- Cases of fluctuating capacity will influence the young person’s ability to access MyGOSH, assessment of capacity is decision specific – the onus is on clinician to determine frequency of assessment (a practice no different from now but will be complicated by this determining whether the CYP has access to or doesn’t have access to MyGOSH).

Non-disclosure of diagnosis/prognosis to CYP

- Some families choose not to disclose the diagnosis to the CYP. Do you think this affect their engagement in MyGOSH?
- Will this lead to disengagement of the family from services, inequity of access and lack of opportunities that those who are engaging with MyGOSH have e.g. being able to view/change their appointments easily, being able to message their care team easily, and no access to additional patient/health promotion information on the portal?

- What will the impact be on a YP if they turn 16, gain sole access to MyGOSH and then find out their diagnosis? (Especially pertinent of they have a life-limiting condition. Onus on clinicians to identify such patients and work with the families to prevent this from happening).

Inequitable access

Initial implementation in English only (but with the possibility to translate the ‘After Visit Summary into Arabic) so MyGOSH may be inaccessible for those who English is not their first language. What implications does this have for the patient population at GOSH? What are the ethical dilemmas regarding inequitable access?

- YP worry that they will be the ones translating the medical information for their parents. There are other situations where equitable access will not be possible e.g.
    - Low literacy levels
    - Those who are not confident at using a computer/electronic device
    - Lack of regular access to the internet
    - Those who have a sensory impairment (sight/hearing)
    - Those with a physical impairment or too ill to use it
    - Those who have a learning difficulty or disability (patient or parent)

Burdens on clinicians

- Concerns raised by staff members about additional burdens placed on them whilst managing the messaging function within MyGOSH including possible parental/patient anxiety from the results released online (theoretically conversations will have been had prior to release). Expectation is that messages will be answered within 3 days, but CNSs feel overwhelmingly that the burden will fall mainly on them. What is the impact of this?

Concerns about data being kept safe

- Unwillingness to engage with MyGOSH due to not trusting online systems or fear of security of personal data
- Concerns surrounding GDPR and possible data breach
- Dilemmas surrounding confidentiality and ownership of results released onto the patient portal (linking to social media concerns)

Concerns around supporting CYP and their parents when accessing their health data

- Who is going to support CYP and their parents when accessing information via the portal?
- How will we know they understand the information?
- Will parents/patients will be more inclined to self-treat?
- Will be harder to identify safeguarding concerns e.g. less face-to-face contact, how do we know the person who says they are on the end of the message are who they say they are?
- At what point will access be restricted in cases where there are safeguarding concerns? Will this trigger further issues? Who is going to ‘police’ this?

What CYP worry about:

- CYP want to know who is looking at their health data
- They worry they will not get answers to their questions quickly enough
- They do not want to be reminded of their condition(s) all of the time
- They worry that people will write the wrong patient’s information in their online record
- They worry if everything is paperless there is the potential for all of their health data to be lost
- CYP want to know that there will be support available to them when they need it, and they worry they will read something they did not want to read or do not understand – how can we support them?

Concluding question

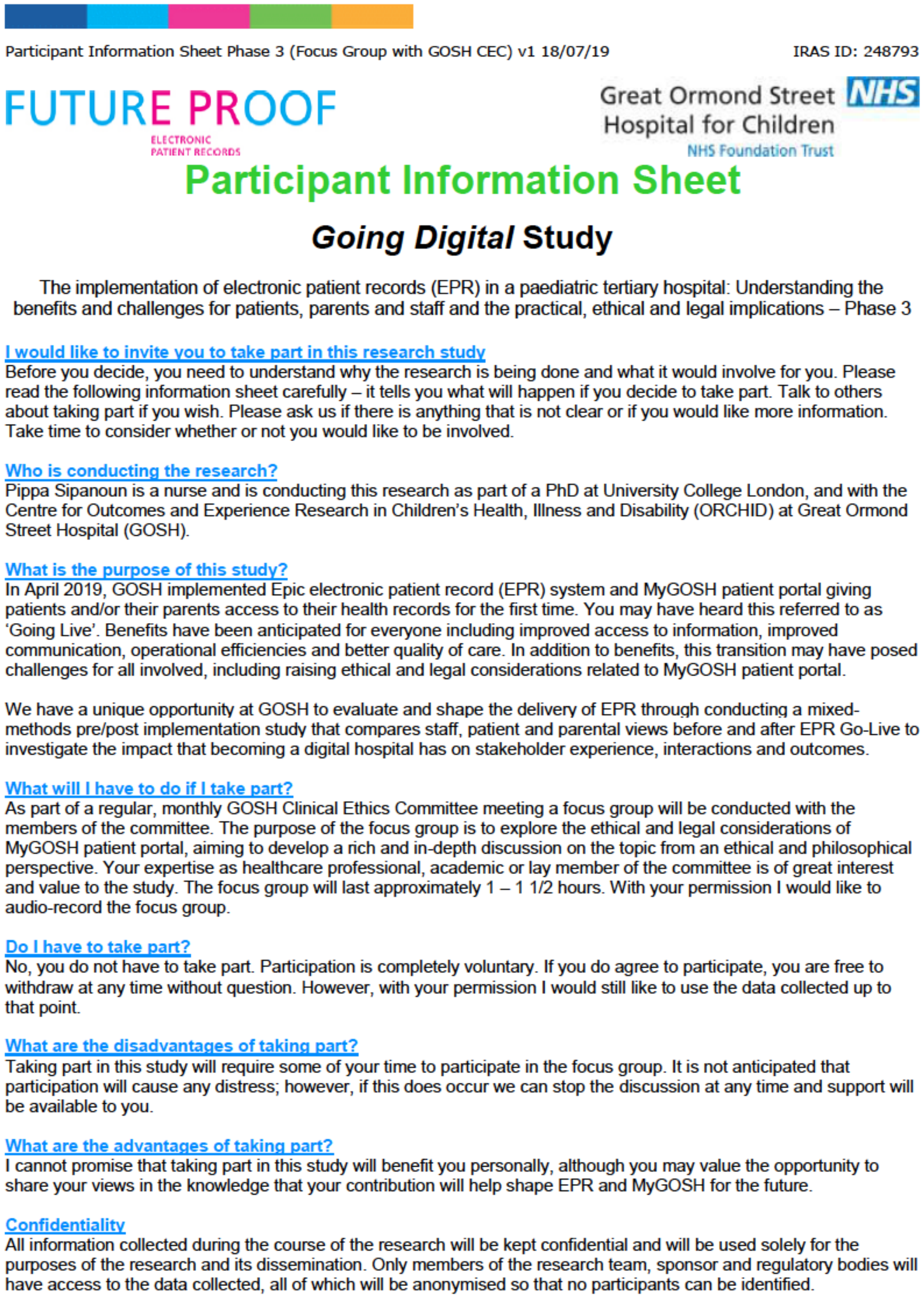
- Of all the things we’ve discussed today, what would you say are the most important issues?

Conclusion

- Thank you for participating. This has been a very successful discussion
- Your opinions are a valuable asset to the study
- We hope you have found the discussion interesting
- I would like to remind you that any comments featuring in this report will be anonymous

Thank you (close)

Appendix 44 – Phase 3 focus group participant information sheet



Participant Information Sheet Phase 3 (Focus Group with GOSH CEC) v1 18/07/19 IRAS ID: 248793

Participant Information Sheet

Going Digital Study

The implementation of electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications – Phase 3

I would like to invite you to take part in this research study

Before you decide, you need to understand why the research is being done and what it would involve for you. Please read the following information sheet carefully – it tells you what will happen if you decide to take part. Talk to others about taking part if you wish. Please ask us if there is anything that is not clear or if you would like more information. Take time to consider whether or not you would like to be involved.

Who is conducting the research?

Pippa Sipanoun is a nurse and is conducting this research as part of a PhD at University College London, and with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability (ORCHID) at Great Ormond Street Hospital (GOSH).

What is the purpose of this study?

In April 2019, GOSH implemented Epic electronic patient record (EPR) system and MyGOSH patient portal giving patients and/or their parents access to their health records for the first time. You may have heard this referred to as 'Going Live'. Benefits have been anticipated for everyone including improved access to information, improved communication, operational efficiencies and better quality of care. In addition to benefits, this transition may have posed challenges for all involved, including raising ethical and legal considerations related to MyGOSH patient portal.

We have a unique opportunity at GOSH to evaluate and shape the delivery of EPR through conducting a mixed-methods pre/post implementation study that compares staff, patient and parental views before and after EPR Go-Live to investigate the impact that becoming a digital hospital has on stakeholder experience, interactions and outcomes.

What will I have to do if I take part?

As part of a regular, monthly GOSH Clinical Ethics Committee meeting a focus group will be conducted with the members of the committee. The purpose of the focus group is to explore the ethical and legal considerations of MyGOSH patient portal, aiming to develop a rich and in-depth discussion on the topic from an ethical and philosophical perspective. Your expertise as healthcare professional, academic or lay member of the committee is of great interest and value to the study. The focus group will last approximately 1 – 1 1/2 hours. With your permission I would like to audio-record the focus group.

Do I have to take part?

No, you do not have to take part. Participation is completely voluntary. If you do agree to participate, you are free to withdraw at any time without question. However, with your permission I would still like to use the data collected up to that point.

What are the disadvantages of taking part?

Taking part in this study will require some of your time to participate in the focus group. It is not anticipated that participation will cause any distress; however, if this does occur we can stop the discussion at any time and support will be available to you.

What are the advantages of taking part?

I cannot promise that taking part in this study will benefit you personally, although you may value the opportunity to share your views in the knowledge that your contribution will help shape EPR and MyGOSH for the future.

Confidentiality

All information collected during the course of the research will be kept confidential and will be used solely for the purposes of the research and its dissemination. Only members of the research team, sponsor and regulatory bodies will have access to the data collected, all of which will be anonymised so that no participants can be identified.

How will the data be kept secure and what happens to the data at the end of the study?

All paper data will be stored in a locked filing cabinet, which is located in a research office at GOSH only accessible by a swipe card. Personal identifiable data and consent forms will be stored separately to research data. Electronic data is stored on password protected servers accessed by Trust computers and encrypted laptops. Personal data will only be stored and accessed for up to 6 months after the end of the full 3 year study. Research data will be stored in accordance with GOSH Trust policy. An end of study thesis will be submitted to UCL upon completion. The thesis will not contain any identifying information.

What will happen to the results of the study?

The results will be published and presented so they can be shared with other healthcare professionals and researchers. We will also seek opportunities to present at meetings with young people and parents, to share any new learning early. All data that is shared will be anonymised so that children and young people, parents, staff members and committee members cannot be identified. A report of the study findings will be available upon request.

Data Protection Privacy Notice

UCL Great Ormond Street Institute of Child Health (UCL GOS ICH) is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Great Ormond Street will keep identifiable information about you for 3-6 months after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

The research team from Great Ormond Street Hospital will keep your name and contact details confidential and will not pass this information to UCL GOS ICH. The research team will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from UCL GOS ICH and regulatory organisations may look at your research records to check the accuracy of the research study. UCL GOS ICH will only receive information without any identifying information. The people who analyse the information will not be able to find out your name or contact details.

You can find out more about how we use your information by contacting Lee Shailer, the Data Protection Officer, at data-protection@ucl.ac.uk.

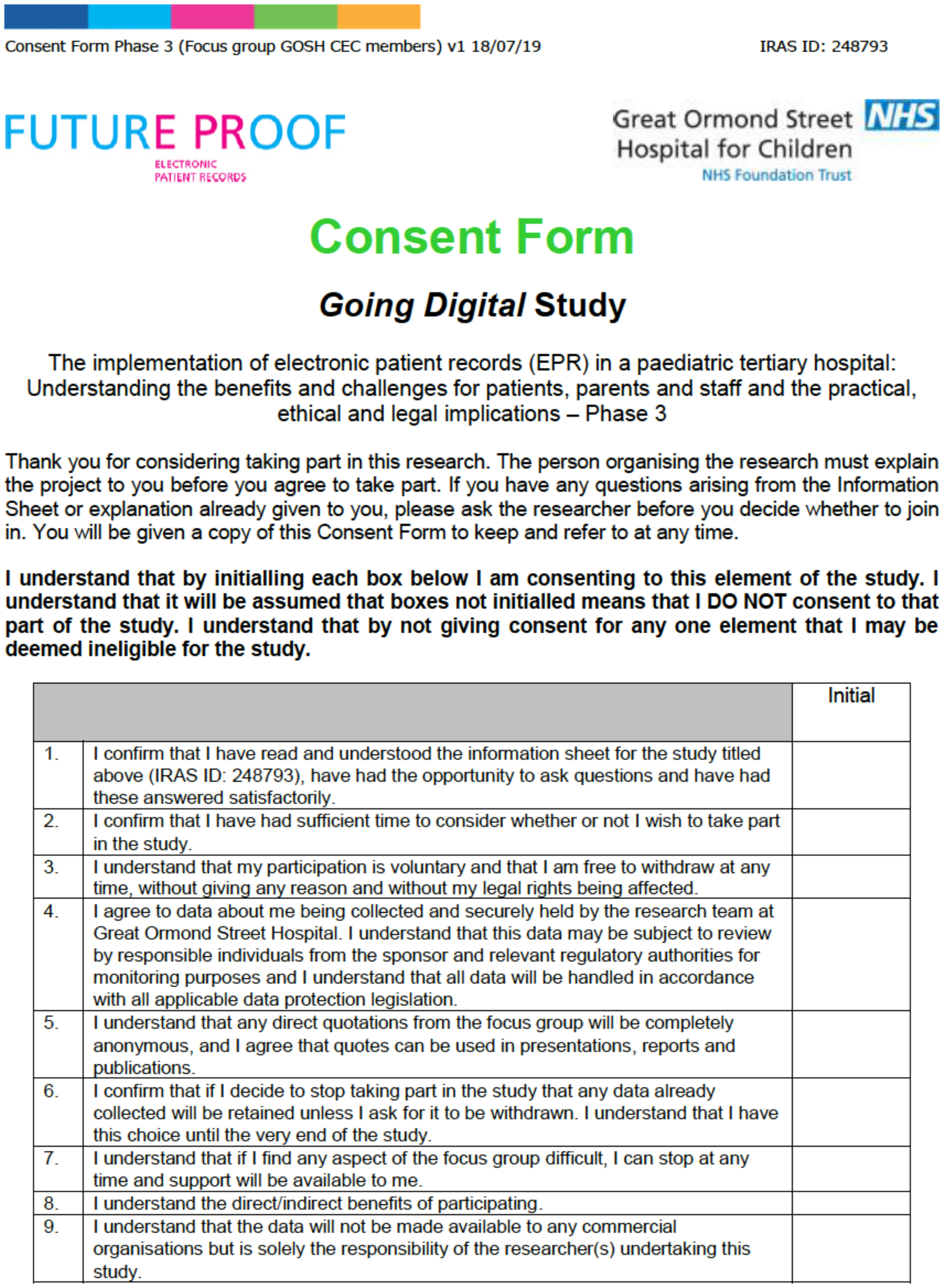
Who should I contact if I have any questions?

[redacted]

Thank you for taking the time to read this leaflet

This study is being funded by Great Ormond Street Hospital

Appendix 45 – Phase 3 focus group informed consent form



Consent Form Phase 3 (Focus group GOSH CEC members) v1 18/07/19 IRAS ID: 248793

FUTURE PROOF
ELECTRONIC PATIENT RECORDS

Great Ormond Street Hospital for Children NHS
NHS Foundation Trust

Consent Form

Going Digital Study

The implementation of electronic patient records (EPR) in a paediatric tertiary hospital: Understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications – Phase 3

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I understand that by initialling each box below I am consenting to this element of the study. I understand that it will be assumed that boxes not initialled means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Initial
1.	I confirm that I have read and understood the information sheet for the study titled above (IRAS ID: 248793), have had the opportunity to ask questions and have had these answered satisfactorily.	
2.	I confirm that I have had sufficient time to consider whether or not I wish to take part in the study.	
3.	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my legal rights being affected.	
4.	I agree to data about me being collected and securely held by the research team at Great Ormond Street Hospital. I understand that this data may be subject to review by responsible individuals from the sponsor and relevant regulatory authorities for monitoring purposes and I understand that all data will be handled in accordance with all applicable data protection legislation.	
5.	I understand that any direct quotations from the focus group will be completely anonymous, and I agree that quotes can be used in presentations, reports and publications.	
6.	I confirm that if I decide to stop taking part in the study that any data already collected will be retained unless I ask for it to be withdrawn. I understand that I have this choice until the very end of the study.	
7.	I understand that if I find any aspect of the focus group difficult, I can stop at any time and support will be available to me.	
8.	I understand the direct/indirect benefits of participating.	
9.	I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.	

10.	I agree to the focus group being audio-recorded.	
11.	I agree to take part in the above study.	

Full name of Committee Member Date Signature

Committee Member’s e-mail address Telephone number

Full name of Person Obtaining Consent Date Signature

Who should I contact if I have any questions?

[redacted]

Thank you for taking the time to read this leaflet

This study is being funded by Great Ormond Street Hospital for Children

An original copy of the information sheet and a copy of the completed informed consent form is to be kept by the participant. One copy to be kept by researcher and placed in the investigator file.

Appendix 46 – 2018 GOSH conference digital poster

UCL
GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH

Great Ormond Street Hospital for Children
NHS
NHS Foundation Trust

The Going Digital Study

The implementation of Epic electronic patient records in a paediatric tertiary hospital:

Understanding the benefits and challenges for patients, parents and staff, and the practical, ethical and legal implications

Pippa Sipanoun[1,2], Faith Gibson[1,2], Deborah Ridout[2], Jo Wray[1,2] and Kate Oulton[1,2]

[1]Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital for Children NHS Foundation Trust, London, UK

[2]UCL GOS Institute of Child Health, London, UK

Background

EPR deployment is critical and core to Great Ormond Street (GOSH) being a digital hospital. It is expected that, following implementation in April 2019, there will be improved access for patients, improved communication between staff, patients and families, operational efficiencies, development of new models of care and treatments, in addition to enhanced innovative research analytics.[1-4] Although this transition ought to bring many benefits, as described, it may also pose challenges for all stakeholders, particularly those associated with children and young people (CYP) and their parents accessing medical and nursing/clinical notes for the first time through MyGOSH patient portal (hereafter MyGOSH).

A concurrent mixed methods design will be utilised with quantitative (survey) data collection and qualitative (interviews/'A day in the life of' studies participant observation).

This single site, single arm pre-post study with data being collected from a sample of all relevant stakeholders pre and post implementation of EPR and MyGOSH aims to:

1) To understand from the perspective of patients, parents and staff;
- Their expectations regarding EPR and MyGOSH and whether these are met
- The benefits and challenges of transitioning to an EPR system and the use of MyGOSH
- Their information and support needs when accessing EPR and MyGOSH
- The impact of EPR and MyGOSH on interactions during in-patient and out-patient consultations

2) To identify the ethical dilemmas and legal implications associated with EPR and MyGOSH implementation

Primary Outcomes:

- The proportion of CYP who report being involved in decisions about their care after the introduction of EPR[5]
- The proportion of parents who are given a choice of admission date/time after the introduction of EPR[6]

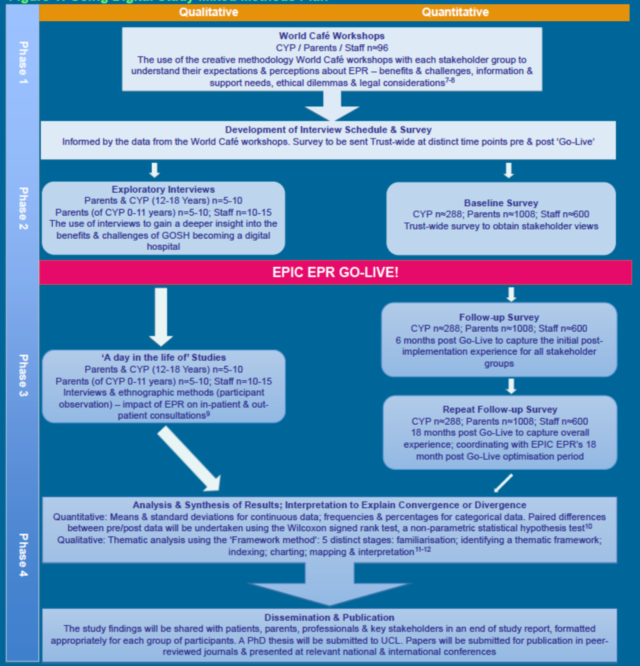
Secondary Outcomes:

- Comparison of primary outcomes between patients under a single speciality with those under multiple specialities
- Proportion of staff who identify potential ethical dilemmas and legal implications associated with the implementation of EPR/MyGOSH
- Identification of the benefits and challenges for patients, parents and staff when implementing an EPR system
- Identification of the practical, ethical and legal implications for all stakeholders involved when implementing an EPR system

Pippa Sipanoun is PhD Student at UCL GOSH ICH (previous NIHR GOSH BRC Intern); Professor Faith Gibson is Professor of Child Health and Cancer Care at Surrey University and Deputy Chief Nurse for Research, ORCHID at GOSH; Deborah Ridout is a Senior Research Fellow, Population, Policy and Practice Programme, ICH; Dr Jo Wray is a Senior Research Fellow at ORCHID, GOSH; Dr Kate Oulton is a Senior Research Fellow and Lead for Clinical Academic Careers at ORCHID, GOSH.

This study provides a unique opportunity to shape and evaluate the delivery of EPIC Electronic Patient Records (EPR) and MyGOSH patient portal at GOSH for the benefit of all stakeholders involved. The aim is also to provide an exemplar model for utilisation by other institutions implementing EPR.

Figure 1: Going Digital Study Mixed Methods Plan



World Café Workshops
CYP / Parents / Staff n≈96
The use of the creative methodology World Café workshops with each stakeholder group to understand their expectations & perceptions about EPR – benefits & challenges, information & support needs, ethical dilemmas & legal considerations[7-8]

Development of Interview Schedule & Survey
Informed by the data from the World Café workshops. Survey to be sent Trust-wide at distinct time points pre & post 'Go-Live'

Exploratory Interviews
Parents & CYP (12-18 Years) n=5-10
Parents (of CYP 0-11 years) n=5-10; Staff n=10-15
The use of interviews to gain a deeper insight into the benefits & challenges of GOSH becoming a digital hospital

Baseline Survey
CYP n≈288; Parents n≈1008; Staff n≈600
Trust-wide survey to obtain stakeholder views

EPIC EPR GO-LIVE!

'A day in the life of' Studies
Parents & CYP (12-18 Years) n=5-10
Parents (of CYP 0-11 years) n=5-10; Staff n=10-15
Interviews & ethnographic methods (participant observation) – impact of EPR on in-patient & out-patient consultations[9]

Follow-up Survey
CYP n≈288; Parents n≈1008; Staff n≈600
6 months post Go-Live to capture the initial post-implementation experience for all stakeholder groups

Repeat Follow-up Survey
CYP n≈288; Parents n≈1008; Staff n≈600
18 months post Go-Live to capture overall experience; coordinating with EPIC EPR's 18 month post Go-Live optimisation period

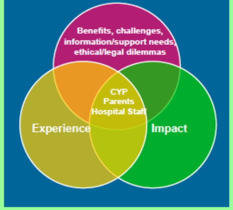
Analysis & Synthesis of Results; Interpretation to Explain Convergence or Divergence
Quantitative: Means & standard deviations for continuous data; frequencies & percentages for categorical data. Paired differences between pre/post data will be undertaken using the Wilcoxon signed rank test, a non-parametric statistical hypothesis test[10]
Qualitative: Thematic analysis using the 'Framework method': 5 distinct stages: familiarisation; identifying a thematic framework; indexing; charting; mapping & interpretation[11-12]

Dissemination & Publication
The study findings will be shared with patients, parents, professionals & key stakeholders in an end of study report, formatted appropriately for each group of participants. A PhD thesis will be submitted to UCL. Papers will be submitted for publication in peer-reviewed journals & presented at relevant national & international conferences

Potential ethical and legal dilemmas to be considered pre EPR Go-Live (April 2019)

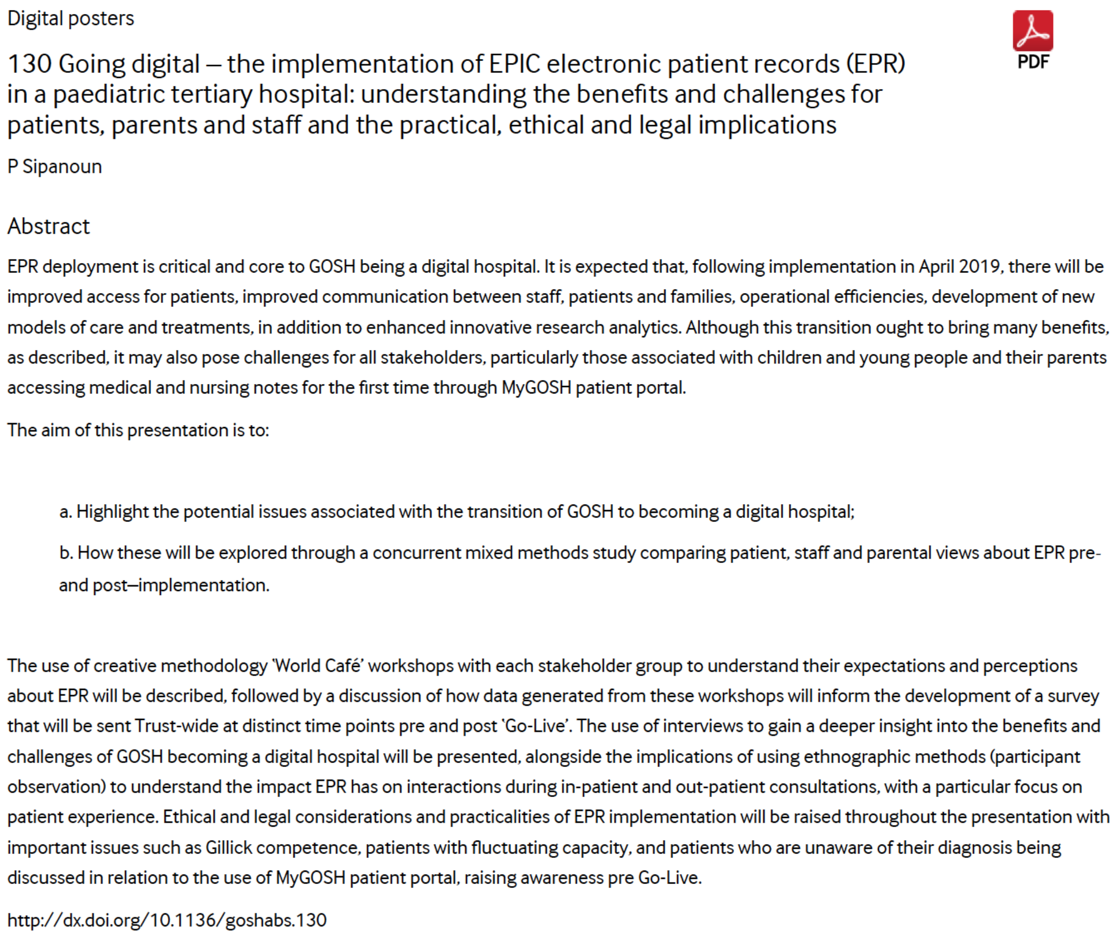
- Cases of fluctuating capacity will influence the young person's ability to access MyGOSH[13]
- Issues surrounding assessing Gillick competence related to the use of MyGOSH[14]
- Some families choose not to disclose the diagnosis to the child or young person. Will this lead to disengagement of the family from services and lead to the possibility of the patient not gaining the treatment or support they need?
- Possible conflict between family members/professionals when a young person turns 16 and has the option to have sole access to MyGOSH/their electronic health records. This is particularly relevant to those CYP who have not been told their diagnosis, raising additional dilemmas
- Possible causes of inequitable access
  - Initial implementation in English only, low literacy levels, lack of regular access to the internet, those who are visually impaired
  - How do you ensure those that choose not to sign up receive equitable access to appointments, treatment and care? How will this be managed?
  - Unwillingness to engage with MyGOSH due to not trusting online systems or fear of security of personal data
- Concerns surrounding GDPR and possible data breach
- Dilemmas surrounding confidentiality and ownership of results released onto the patient portal
  - Who do the results belong to?
  - Will CYP share their results on social media? Will this potentially lead to issues with peer pressure, cyberharassment or cyberbullying?
  - How will practitioners or clinicians manage the additional demands placed on them of possible parental/patient anxiety if all patient results are released onto the portal at the same time?
  - Will those with access or proxy access be able to download content? Concerns exist about parents posting information about patients, staff members or institutions on social media[15]. Can this be prevented?
- Who is going to support CYP and their parents when accessing information via the portal?
  - How will we know they understand the information?
  - Will people be more inclined to self-treat?
- Will EPR/MyGOSH make it easier or harder to identify cases of fabricated and induced illness and other serious safeguarding issues? How will these be managed?
  - At what point will access be restricted in cases where there are safeguarding concerns? Will this trigger further issues? Who is going to 'police' this?

**Figure 2:
Diagrammatical representation of significant aspects of the study, the interrelatedness of components identified in the aims, and the impact on and experience of children and young people, parents and hospital staff**



References: 1. McGinn, C.A., Grenier, S. & Duplantie, J. (2011) Comparison of user groups' perspectives of barriers & facilitators to implementing electronic health records: a systematic review, *BMC Medicine* 9 (1); **2. Delpierre, C., Cuzin, L., Fillaux, J., Alvarez, M., Massip, P. & Lang, T.** (2004) A systematic review of computer-based patient record systems & quality of care: more randomized clinical trials or a broader approach? *International Journal for Quality in Health Care* 16 (5), 407-416; **3. Ueckert, F., Goerz, M., Ataian, M., Tessmann, S. & Prokosch, H.U.** (2003) Empowerment of patients & communication with health care professionals through an electronic health record, *International Journal of Medical Informatics* 70 (2-3), 99-108; **4. GOSH** (2017) Full Business Case for an Electronic Patient Record System (EPR) & Research & Innovation Platform (unpublished); **5. Care Quality Commission** (2017) GOSH, Parent & Children & Young People Surveys <https://www.cqc.org.uk/provider/RP4/survey/14#undefined>; **6. Ibid.**, 5; **7. Brown, J., Isaacs, D. & The World Café Community** (2001) The World Café: Living knowledge through conversations that matter, *Systems Thinker* 12 (5) 1-5; **8. Brown, J., Isaacs, D. & The World Café Community** (2005) *The World Cafe Book: Shaping Our Futures Through Conversations that Matter*, San Francisco: Berrett-Koehler Publishers, Inc.; **9. O'Reilly, K.** (2011) *Ethnographic Methods* (2nd ed.) Oxon: Routledge; **10. Wilcoxon, F.** (1945) Individual Comparisons by Ranking Methods, *Biometrics Bulletin* 1 (6) 80-83; **11. Braun, V. & Clarke, V.** (2006) Using thematic analysis in psychology, *Qualitative Research in Psychology* 3 (2) 77-101; **12. Fereday, J. & Muir-Cochrane, E.** (2008) Demonstrating rigor using thematic analysis: A hybrid approach of inductive & deductive coding & theme development, *International Journal of Qualitative Methods* 5 (1) 80-92; **13. Mental Capacity Act** 2005, 1, 1 (2); **14. Gillick v West Norfolk & Wisbech AHA** [1985] UKHL 7; **15. Das, R.** (2018) Populist discourse on a British social media patient-support community: The case of the Charlie Gard support campaign on Facebook *Discourse, Context & Media* <https://doi.org/10.1016/j.dcm.2017.11.005>

Appendix 47 – Published abstract



Digital posters

130 Going digital – the implementation of EPIC electronic patient records (EPR) in a paediatric tertiary hospital: understanding the benefits and challenges for patients, parents and staff and the practical, ethical and legal implications

P Sipanoun

Abstract

EPR deployment is critical and core to GOSH being a digital hospital. It is expected that, following implementation in April 2019, there will be improved access for patients, improved communication between staff, patients and families, operational efficiencies, development of new models of care and treatments, in addition to enhanced innovative research analytics. Although this transition ought to bring many benefits, as described, it may also pose challenges for all stakeholders, particularly those associated with children and young people and their parents accessing medical and nursing notes for the first time through MyGOSH patient portal.

The aim of this presentation is to:

a. Highlight the potential issues associated with the transition of GOSH to becoming a digital hospital;

b. How these will be explored through a concurrent mixed methods study comparing patient, staff and parental views about EPR pre- and post–implementation.

The use of creative methodology 'World Café' workshops with each stakeholder group to understand their expectations and perceptions about EPR will be described, followed by a discussion of how data generated from these workshops will inform the development of a survey that will be sent Trust-wide at distinct time points pre and post 'Go-Live'. The use of interviews to gain a deeper insight into the benefits and challenges of GOSH becoming a digital hospital will be presented, alongside the implications of using ethnographic methods (participant observation) to understand the impact EPR has on interactions during in-patient and out-patient consultations, with a particular focus on patient experience. Ethical and legal considerations and practicalities of EPR implementation will be raised throughout the presentation with important issues such as Gillick competence, patients with fluctuating capacity, and patients who are unaware of their diagnosis being discussed in relation to the use of MyGOSH patient portal, raising awareness pre Go-Live.

http://dx.doi.org/10.1136/goshabs.130

Appendix 48 – ‘Roundabout’ entry

Going Digital Study

This research study explores the benefits, challenges and practical implications of GOSH transitioning to a digital hospital.

We’re asking children and young people, parents and staff about their expectations and perceptions of the EPR system before and after implementation.

All stakeholder groups were involved in workshops to develop surveys that will be sent Trust-wide before and after go-live. We’re also talking to children and young people, parents and staff members to gain a deeper insight into the hospital ‘going digital’.

The study findings will be shared with patients, parents, professionals and key stakeholders at the end of the study.

Get involved

- Share your views during an interview
- Look out for the survey in clinical areas before and after go-live
- Contact study chief investigator

[redacted]

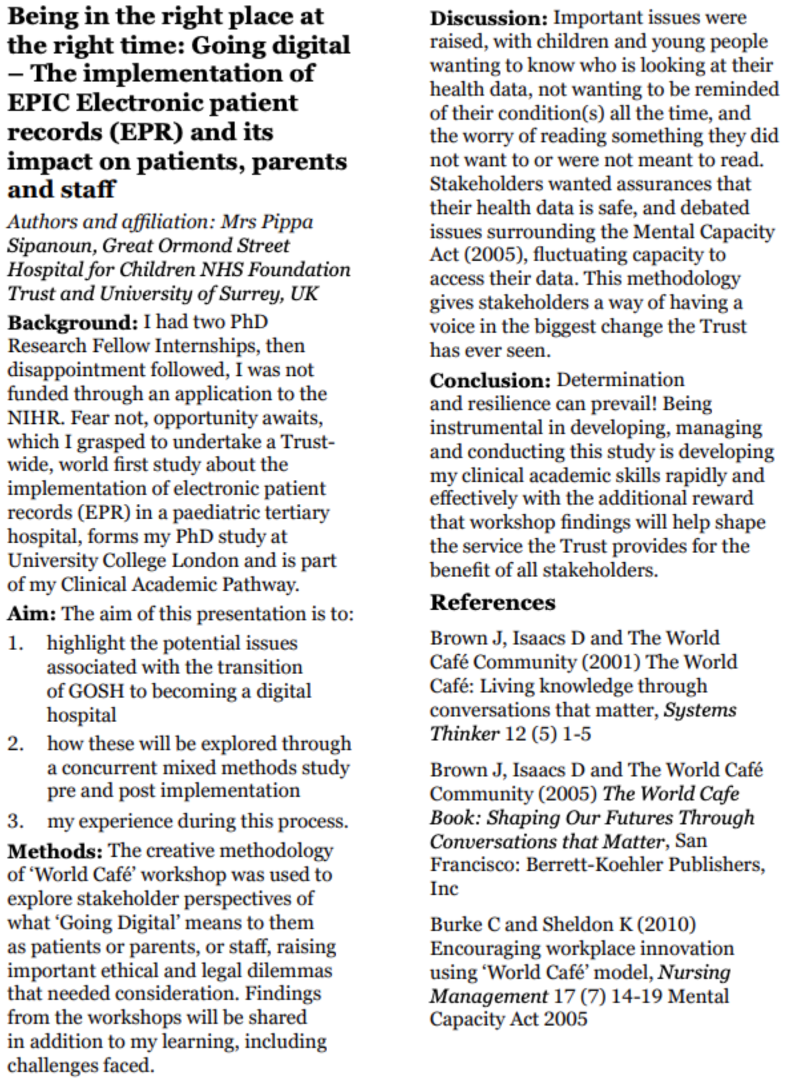
Pippa (pictured), a nurse who has worked at GOSH for many years, is a member of the Clinical Academic Faculty within the Centre for Outcomes and Experience Research in Children’s Health, Illness and Disability (ORCHID). Clinical Academic Careers within ORCHID are supported by the NIHR Biomedical Research Centre. The Going Digital Study forms part of Pippa’s PhD training supported through a GOSH Fellowship.

orchid

UCL
GREAT ORMOND STREET
INSTITUTE OF CHILD HEALTH

NIHR | National Institute for Health Research

Appendix 49 – 2019 RCN International Research Conference



Being in the right place at the right time: Going digital – The implementation of EPIC Electronic patient records (EPR) and its impact on patients, parents and staff

Authors and affiliation: Mrs Pippa Sipanoun, Great Ormond Street Hospital for Children NHS Foundation Trust and University of Surrey, UK

Background: I had two PhD Research Fellow Internships, then disappointment followed, I was not funded through an application to the NIHR. Fear not, opportunity awaits, which I grasped to undertake a Trust-wide, world first study about the implementation of electronic patient records (EPR) in a paediatric tertiary hospital, forms my PhD study at University College London and is part of my Clinical Academic Pathway.

Aim: The aim of this presentation is to:

1. highlight the potential issues associated with the transition of GOSH to becoming a digital hospital
2. how these will be explored through a concurrent mixed methods study pre and post implementation
3. my experience during this process.

Methods: The creative methodology of 'World Café' workshop was used to explore stakeholder perspectives of what 'Going Digital' means to them as patients or parents, or staff, raising important ethical and legal dilemmas that needed consideration. Findings from the workshops will be shared in addition to my learning, including challenges faced.

Discussion: Important issues were raised, with children and young people wanting to know who is looking at their health data, not wanting to be reminded of their condition(s) all the time, and the worry of reading something they did not want to or were not meant to read. Stakeholders wanted assurances that their health data is safe, and debated issues surrounding the Mental Capacity Act (2005), fluctuating capacity to access their data. This methodology gives stakeholders a way of having a voice in the biggest change the Trust has ever seen.

Conclusion: Determination and resilience can prevail! Being instrumental in developing, managing and conducting this study is developing my clinical academic skills rapidly and effectively with the additional reward that workshop findings will help shape the service the Trust provides for the benefit of all stakeholders.

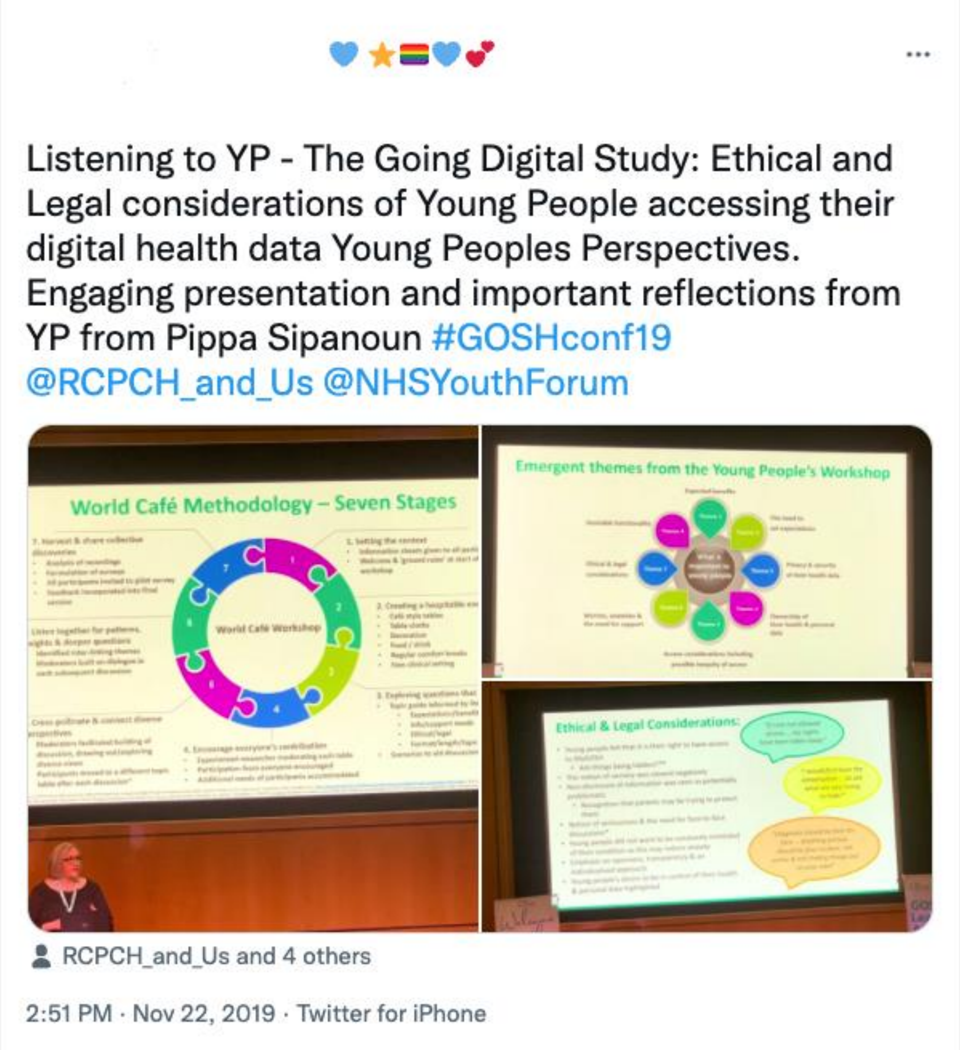
References

Brown J, Isaacs D and The World Café Community (2001) The World Café: Living knowledge through conversations that matter, *Systems Thinker* 12 (5) 1-5

Brown J, Isaacs D and The World Café Community (2005) *The World Cafe Book: Shaping Our Futures Through Conversations that Matter*, San Francisco: Berrett-Koehler Publishers, Inc

Burke C and Sheldon K (2010) Encouraging workplace innovation using 'World Café' model, *Nursing Management* 17 (7) 14-19 Mental Capacity Act 2005

Appendix 50 – Tweet from GOSH Conference oral presentation



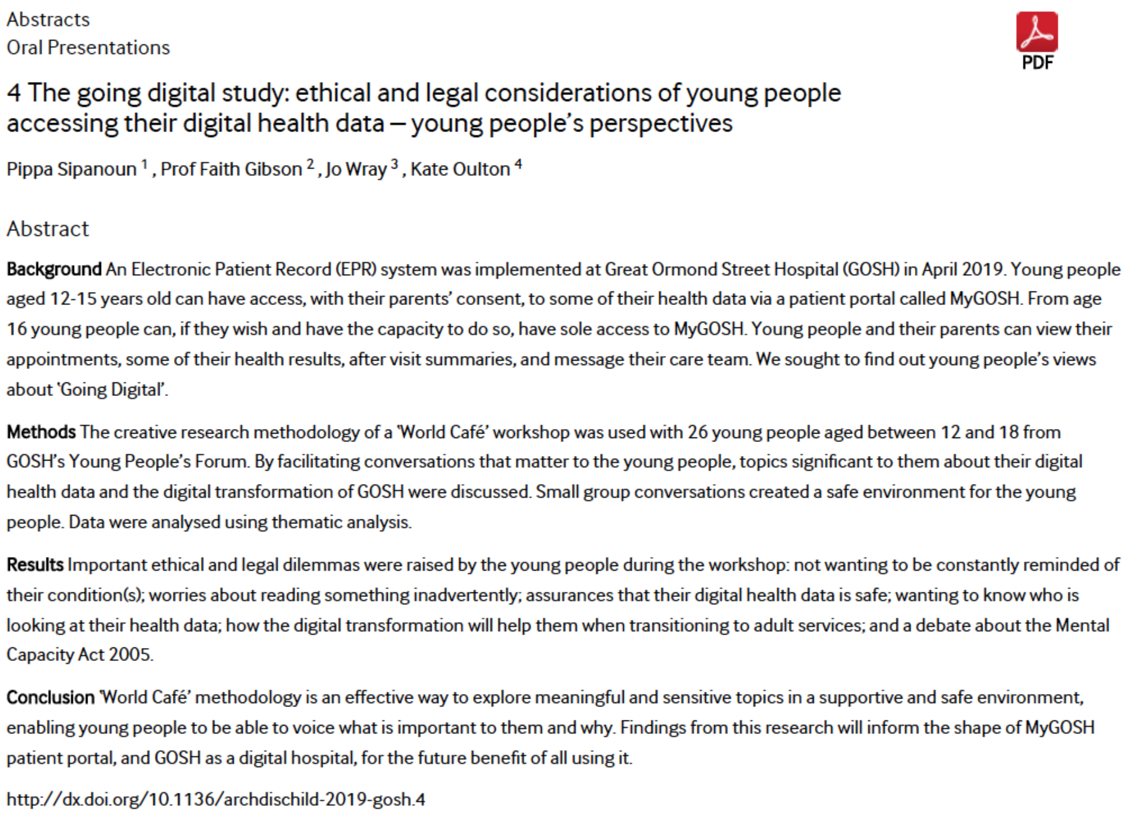
💙⭐🏳️‍🌈💙💕

Listening to YP - The Going Digital Study: Ethical and Legal considerations of Young People accessing their digital health data Young Peoples Perspectives. Engaging presentation and important reflections from YP from Pippa Sipanoun #GOSHconf19 @RCPCH_and_Us @NHSYouthForum

RCPCH_and_Us and 4 others

2:51 PM · Nov 22, 2019 · Twitter for iPhone

Appendix 51 – Published abstract



Abstracts
Oral Presentations

4 The going digital study: ethical and legal considerations of young people accessing their digital health data – young people's perspectives

Pippa Sipanoun [1] , Prof Faith Gibson [2] , Jo Wray [3] , Kate Oulton [4]

Abstract

Background An Electronic Patient Record (EPR) system was implemented at Great Ormond Street Hospital (GOSH) in April 2019. Young people aged 12-15 years old can have access, with their parents' consent, to some of their health data via a patient portal called MyGOSH. From age 16 young people can, if they wish and have the capacity to do so, have sole access to MyGOSH. Young people and their parents can view their appointments, some of their health results, after visit summaries, and message their care team. We sought to find out young people's views about 'Going Digital'.

Methods The creative research methodology of a 'World Café' workshop was used with 26 young people aged between 12 and 18 from GOSH's Young People's Forum. By facilitating conversations that matter to the young people, topics significant to them about their digital health data and the digital transformation of GOSH were discussed. Small group conversations created a safe environment for the young people. Data were analysed using thematic analysis.

Results Important ethical and legal dilemmas were raised by the young people during the workshop: not wanting to be constantly reminded of their condition(s); worries about reading something inadvertently; assurances that their digital health data is safe; wanting to know who is looking at their health data; how the digital transformation will help them when transitioning to adult services; and a debate about the Mental Capacity Act 2005.

Conclusion 'World Café' methodology is an effective way to explore meaningful and sensitive topics in a supportive and safe environment, enabling young people to be able to voice what is important to them and why. Findings from this research will inform the shape of MyGOSH patient portal, and GOSH as a digital hospital, for the future benefit of all using it.

http://dx.doi.org/10.1136/archdischild-2019-gosh.4

Appendix 52 – Institute of Medical Ethics Postgraduate Bioethics conference abstract

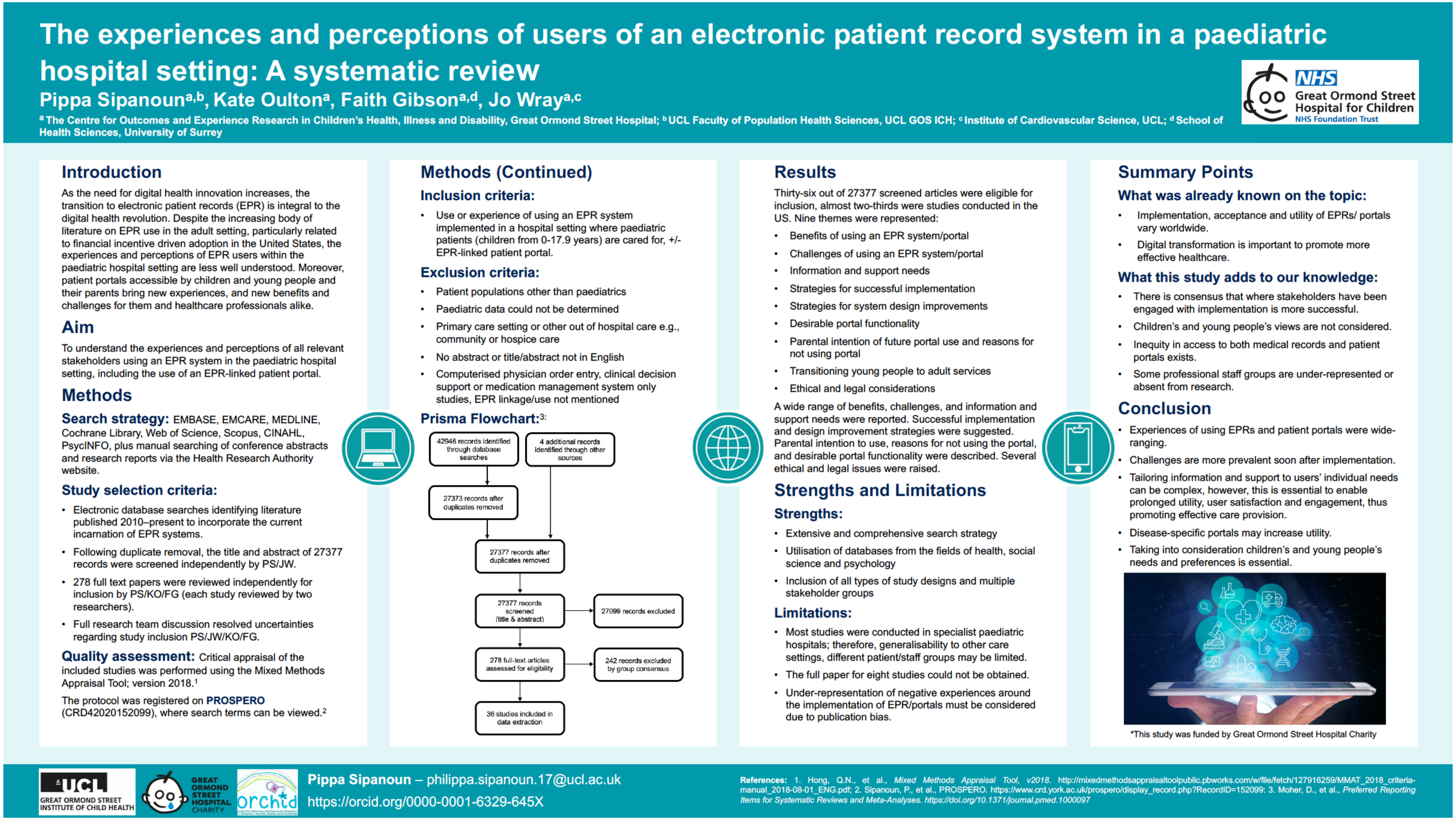
Ethical and Legal considerations of Children and Young People's Digital Health Data – The Children and Young People's Perspective

An Electronic Patient Record (EPR) system is imminently being implemented in a paediatric tertiary centre in the UK. Children and young people (CYP) aged 12 -15 years will have access, with their parents' consent, to some of their health data for the first time via a patient portal. They will be able to view their appointments, their results and will be able to message their doctor, nurse, or therapist. From the age of 16 years old young people can, if they so wish and are competent to do so, be the only person to access the portal. The young person can also give their parents permission portal access.

The creative methodology of 'World Café' workshop was used to explore CYP perspectives of what 'Going Digital' means to them as patients at the hospital, raising important ethical and legal dilemmas that need consideration. This presentation will highlight what is important to the CYP from their perspective, what they want to know and why. This includes issues such as wanting to know who is looking at their health data, not wanting to be reminded of their condition(s) all the time, the worry of reading something they did not want to or were not meant to read, assurances that their health data is safe, and a debate surrounding the Mental Capacity Act (2005), fluctuating capacity and times when they are too unwell to use the portal.

This project formed phase one of a PhD study at University College London and informed survey development for phases two and three of the study.

Appendix 53 – 2021 RCN International Research Conference poster and UCL Doctoral School poster competition



The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: A systematic review

Pippa Sipanoun[a,b], Kate Oulton[a], Faith Gibson[a,d], Jo Wray[a,c]

[a] The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital; [b] UCL Faculty of Population Health Sciences, UCL GOS ICH; [c] Institute of Cardiovascular Science, UCL; [d] School of Health Sciences, University of Surrey

Introduction

As the need for digital health innovation increases, the transition to electronic patient records (EPR) is integral to the digital health revolution. Despite the increasing body of literature on EPR use in the adult setting, particularly related to financial incentive driven adoption in the United States, the experiences and perceptions of EPR users within the paediatric hospital setting are less well understood. Moreover, patient portals accessible by children and young people and their parents bring new experiences, and new benefits and challenges for them and healthcare professionals alike.

Aim

To understand the experiences and perceptions of all relevant stakeholders using an EPR system in the paediatric hospital setting, including the use of an EPR-linked patient portal.

Methods

Search strategy: EMBASE, EMCARE, MEDLINE, Cochrane Library, Web of Science, Scopus, CINAHL, PsycINFO, plus manual searching of conference abstracts and research reports via the Health Research Authority website.

Study selection criteria:

- Electronic database searches identifying literature published 2010–present to incorporate the current incarnation of EPR systems.
- Following duplicate removal, the title and abstract of 27377 records were screened independently by PS/JW.
- 278 full text papers were reviewed independently for inclusion by PS/KO/FG (each study reviewed by two researchers).
- Full research team discussion resolved uncertainties regarding study inclusion PS/JW/KO/FG.

Quality assessment: Critical appraisal of the included studies was performed using the Mixed Methods Appraisal Tool; version 2018.[1]

The protocol was registered on **PROSPERO** (CRD42020152099), where search terms can be viewed.[2]

Methods (Continued)

Inclusion criteria:

- Use or experience of using an EPR system implemented in a hospital setting where paediatric patients (children from 0-17.9 years) are cared for, +/- EPR-linked patient portal.

Exclusion criteria:

- Patient populations other than paediatrics
- Paediatric data could not be determined
- Primary care setting or other out of hospital care e.g., community or hospice care
- No abstract or title/abstract not in English
- Computerised physician order entry, clinical decision support or medication management system only studies, EPR linkage/use not mentioned

Prisma Flowchart:[3]:

42946 records identified through database searches

4 additional records identified through other sources

27373 records after duplicates removed

27377 records after duplicates removed

27377 records screened (title & abstract)

27099 records excluded

278 full-text articles assessed for eligibility

242 records excluded by group consensus

36 studies included in data extraction

Results

Thirty-six out of 27377 screened articles were eligible for inclusion, almost two-thirds were studies conducted in the US. Nine themes were represented:

- Benefits of using an EPR system/portal
- Challenges of using an EPR system/portal
- Information and support needs
- Strategies for successful implementation
- Strategies for system design improvements
- Desirable portal functionality
- Parental intention of future portal use and reasons for not using portal
- Transitioning young people to adult services
- Ethical and legal considerations

A wide range of benefits, challenges, and information and support needs were reported. Successful implementation and design improvement strategies were suggested. Parental intention to use, reasons for not using the portal, and desirable portal functionality were described. Several ethical and legal issues were raised.

Strengths and Limitations

Strengths:

- Extensive and comprehensive search strategy
- Utilisation of databases from the fields of health, social science and psychology
- Inclusion of all types of study designs and multiple stakeholder groups

Limitations:

- Most studies were conducted in specialist paediatric hospitals; therefore, generalisability to other care settings, different patient/staff groups may be limited.
- The full paper for eight studies could not be obtained.
- Under-representation of negative experiences around the implementation of EPR/portals must be considered due to publication bias.

Summary Points

What was already known on the topic:

- Implementation, acceptance and utility of EPRs/ portals vary worldwide.
- Digital transformation is important to promote more effective healthcare.

What this study adds to our knowledge:

- There is consensus that where stakeholders have been engaged with implementation is more successful.
- Children's and young people's views are not considered.
- Inequity in access to both medical records and patient portals exists.
- Some professional staff groups are under-represented or absent from research.

Conclusion

- Experiences of using EPRs and patient portals were wide-ranging.
- Challenges are more prevalent soon after implementation.
- Tailoring information and support to users' individual needs can be complex, however, this is essential to enable prolonged utility, user satisfaction and engagement, thus promoting effective care provision.
- Disease-specific portals may increase utility.
- Taking into consideration children's and young people's needs and preferences is essential.

*This study was funded by Great Ormond Street Hospital Charity

Pippa Sipanoun – philippa.sipanoun.17@ucl.ac.uk
https://orcid.org/0000-0001-6329-645X

References: 1. Hong, Q.N., et al., *Mixed Methods Appraisal Tool, v2018.* http://mixedmethodsappraisaltoolpublic.pbworks.com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf; 2. Sipanoun, P., et al., PROSPERO. https://www.crd.york.ac.uk/prospero/display_record.php?RecordID=152099: 3. Moher, D., et al., *Preferred Reporting Items for Systematic Reviews and Meta-Analyses. https://doi.org/10.1371/journal.pmed.1000097*

Appendix 54 – 2021 RCN International Research Conference

4.2 Theme: Children and young people

Session no: 4.2.1 Abstract no: 0378

The Going Digital Study: the ethical and legal considerations of children and young people using a patient portal

Presenter: Pippa Sipanoun, RN Adult, RN Child, BSc (Hons), MA, Great Ormond Street Hospital, UK

Co-author(s): Jo Wray, UK; Kate Oulton, UK; Faith Gibson, UK

Abstract

Background: In April 2019, Great Ormond Street Hospital (GOSH) transitioned to an electronic patient record (EPR) system, including a patient portal (MyGOSH), which enables patients aged 12 years or older (and their parents) to access their digital health data. This includes access to results, documentation, appointments, and facilitates communication with their care team.

Aims: As part of the Going Digital Study, a longitudinal project conducted from 2018-2021 on stakeholder experiences during EPR implementation in a paediatric tertiary hospital, a focus group was conducted to explore ethical and legal considerations of children and young people using MyGOSH.

Methods: Recruited participants were members of the GOSH Paediatric Bioethics Service. Written informed consent was provided by all participants (n=7). The focus group was recorded, transcribed verbatim, and analysed using thematic analysis.

Results: Six themes were identified: burden, uncertainty and responding to change - managing expectations; access, competence and capacity - granting access to the system; inequalities in access resulting in inequities; documenting, risks and data safety; engagement, empowerment and understanding – how to use and manage personal information; legal considerations and obligations.

Discussion: Giving young people patient portal access to their digital health data can increase engagement, and empower them to be more involved in their care, yet poses challenges for all involved. Complexities exist in assessing capacity or competence when granting system access, disclosing sensitive information, maintaining confidentiality, managing the burden on clinicians, managing user expectations whilst providing an equitable service, and data management that meets professional and legal requirements.

Conclusion: Ongoing support is required for all relevant stakeholders following patient portal implementation to navigate the ethical and legal complexities, promote equity and portal utility for patient benefit.

The Going Digital Study: The ethical & legal considerations of children & young people using a patient portal

Pippa Sipanoun
Research Associate/PhD Student
Great Ormond Street Hospital
UCL GOS ICH

RCN International Nursing Research Conference 7-9th September 2021

Appendix 55 – UCL Doctoral School poster competition

The Going Digital Study: The views and perceptions of children and young people, parents and staff before and after electronic patient record implementation – Trust-wide survey findings

Pippa Sipanoun[a,b], Kate Oulton[a], Faith Gibson[a,c], Jo Wray[a,d]

[a] The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital; [b] UCL Faculty of Population Health Sciences, UCL GOS ICH; [c] School of Health Sciences, University of Surrey; [d] Institute of Cardiovascular Science, UCL

Introduction

In April 2019, Great Ormond Street Hospital (GOSH) transitioned to an electronic patient record (EPR) system, including a patient portal (MyGOSH), which enables patients aged 12 years or older and their parents to access some of their digital health data. This includes access to results, documentation, appointments, and facilitates communication with their care team.

Aim

To explore the views and experiences of children and young people (CYP), parents, and staff related to EPR and MyGOSH implementation and the effect this had on care provision in a paediatric tertiary hospital, comparing pre and post implementation findings.

Methods

Surveys were developed from workshops with each stakeholder group, piloted, and distributed Trust-wide to all participant groups before and after EPR implementation. Anonymised responses were collected in REDCap; data were analysed using SPSS.

Inclusion criteria:

- CYP aged 12-25 who were patients at GOSH
- Parents of children of all ages who were patients at GOSH
- Staff at GOSH

Exclusion criteria:

- Intellectual disability or language barriers that precluded understanding of survey content
- Private patients (permission to include not granted)

Results

Pre/post-implementation views were captured from *n*=6137 survey respondents (Table 1).

Table 1: Stakeholder responses at each time point

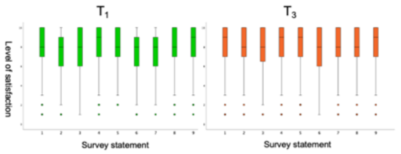
	Pre (T_1) *n*=	6 months post (T_2) *n*=	18 months post (T_3) *n*=
CYP	288	X	174
Parents	1040	X	2905
Staff	650	512	568

- CYP and parents overwhelmingly agreed access to MyGOSH at 12 years of age was appropriate (CYP: T_1=74.6%; T_3=85%; parents: T_1=72.8%; T_3=73.8%)
- Concerns about EPR/MyGOSH use were greater for CYP and parents prior to use, with anticipation worse than reality.
- Information/support needs of CYP and parents were not always met post-implementation, with CYP not always understanding health information via MyGOSH.
- Parents advocated against their children sharing health data via social media (SM), staff worried MyGOSH made it easier for CYP to do this, but findings demonstrate CYP do not use SM this way.
- Barriers existed for some families to access and use MyGOSH including digital poverty, English not being their first language, or having a physical or intellectual impairment or disability.
- Staff found meeting families' needs and expectations whilst managing a new EPR system more difficult at six months post-transition than at 18 months.

Results (continued)

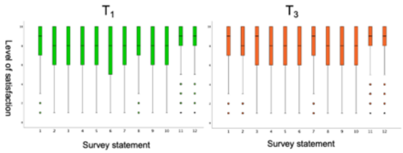
Overall satisfaction with care remained high for both CYP (Figure 1) and parents (Figure 2) at both time points.

Figure 1: Overall satisfaction with care - CYP



Survey statements: 1) Co-ordination of appointments; 2) Convenience of appt; 3) Ease of speaking to member of care team; 4) Overall communication from care team; 5) Ease of getting questions answered; 6) Time to receiving test results; 7) Mode of receiving test results; 8) Involvement in decisions about your care; 9) Informed about your care.

Figure 2: Overall satisfaction with care – Parents



1) Appointment booking; 2) Changing appointments; 3) Co-ordination of appointments; 4) Convenience of appt; 5) Time to receiving after visit summary (AVS); 6) Ease of speaking to member of care team; 7) Overall communication from care team; 8) Ease of getting questions answered; 9) Time to receiving test results; 10) Mode of receiving test results; 11) Involvement in decisions about child's care; 12) Informed about child's care.

- CYP: statistically significant improvements seen in convenience/coordination of appointments, ease of receiving results and getting questions answered*
- Parents: statistically significant improvements seen in convenience/coordination of appointments, time to receiving AVS, ease of speaking to member of care team, and overall communication with care team*

*COVID-19 recognised as confounding factor

Strengths and Limitations

Strengths:

- Trust-wide inclusion of all stakeholder groups enabling everyone to share their views
- Rigorous research processes were followed, with robust methodology applied, strengthening survey findings

Limitations:

- Cross-sectional analysis only - linkage via a unique identifier was not possible due to the anonymous and confidential nature of the surveys.
- Baseline data collection was hampered by staff reluctance to engage in survey distribution to families.

Conclusion

- Great Ormond Street Hospital has successfully transitioned to EPR, embracing the challenges around CYP accessing their digital health data via MyGOSH.
- However, the initial post-implementation phase necessitates the most support for staff, and all stakeholder groups require ongoing support for an extended period (>18 months) to meet families' expectations and promote system utility.
- Ongoing commitment is required to meet the individual needs of families, bridging the digital divide, and overcoming barriers to accessing or using MyGOSH.
- To promote inclusion, further research is required to include those who were unable to participate in the study. Findings demonstrate that these groups are also at risk of exclusion from digital health.

This study was funded by Great Ormond Street Hospital and Great Ormond Street Hospital Charity

Pippa Sipanoun – philippa.sipanoun.17@ucl.ac.uk
https://orcid.org/0000-0001-6329-645X

Appendix 56 – Published abstract

Young People and Their Parents Accessing Their Digital Health Data Via a Patient Portal: The Ethical and Legal Implications

Pippa Sipanoun, Jo Wray, Kate Oulton, Faith Gibson

Abstract—
Background: With rapidly evolving digital health innovation, there is a need for digital health transformation that is accessible and sustainable, that demonstrates utility for all stakeholders while maintaining data safety. Great Ormond Street Hospital for Children aimed to future-proof the hospital by transitioning to an electronic patient record (EPR) system with a tethered patient portal (MyGOSH) in April 2019. MyGOSH patient portal enables patients 12 years or older (with their parent's consent) to access their digital health data. This includes access to results, documentation, and appointments that facilitate communication with their care team. As part of the Going Digital Study conducted between 2018-2021, data were collected from a sample of all relevant stakeholders before and after EPR and MyGOSH implementation. Data collection reach was wide and included the hospital legal and ethics teams. **Aims**: This study aims to understand the ethical and legal implications of young people and their parents accessing their digital health data. **Methods**: A focus group was conducted. Recruited participants were members of the Great Ormond Street Hospital Paediatric Bioethics Centre. Participants included expert and lay members from the Committee from a variety of professional or academic disciplines. Written informed consent was provided by all participants (n=7). The focus group was recorded, transcribed verbatim, and analysed using thematic analysis. **Results**: Six themes were identified: access, competence and capacity - granting access to the system; inequalities in access resulting in inequities; burden, uncertainty and responding to change - managing expectations; documenting, risks and data safety; engagement, empowerment and understanding – how to use and manage personal information; legal considerations and obligations. **Discussion**: If healthcare professionals are to empower young people to be more engaged in their care, the importance of including them in decisions about their health is paramount, especially when they are approaching the age of becoming the consenter for treatment. Complexities exist in assessing competence or capacity when granting system access, when disclosing sensitive information, and maintaining confidentiality. Difficulties are also present in managing clinician burden, managing user expectations whilst providing an equitable service, and data management that meets professional and legal requirements. **Conclusion**: EPR and tethered-portal implementation at Great Ormond Street Hospital for Children was not only timely, due to the need for a rapid transition to remote consultations during the COVID-19 pandemic, which would not have been possible had EPR/MyGOSH not been implemented, but also integral to the digital health revolution required in healthcare today. This study is highly relevant in understanding the complexities around young people and their parents accessing their digital health data and, although the focus of this research related to portal use and access, the findings translate to young people in the wider digital health context. Ongoing support is required for all relevant stakeholders following MyGOSH patient portal implementation to navigate the ethical and legal complexities. Continued commitment is needed to balance the benefits and burdens, promote inclusion and equity, and ensure portal utility for patient benefit, whilst maintaining an individualized approach to care.

Keywords—Patient portal, young people, parents, ethical, legal.

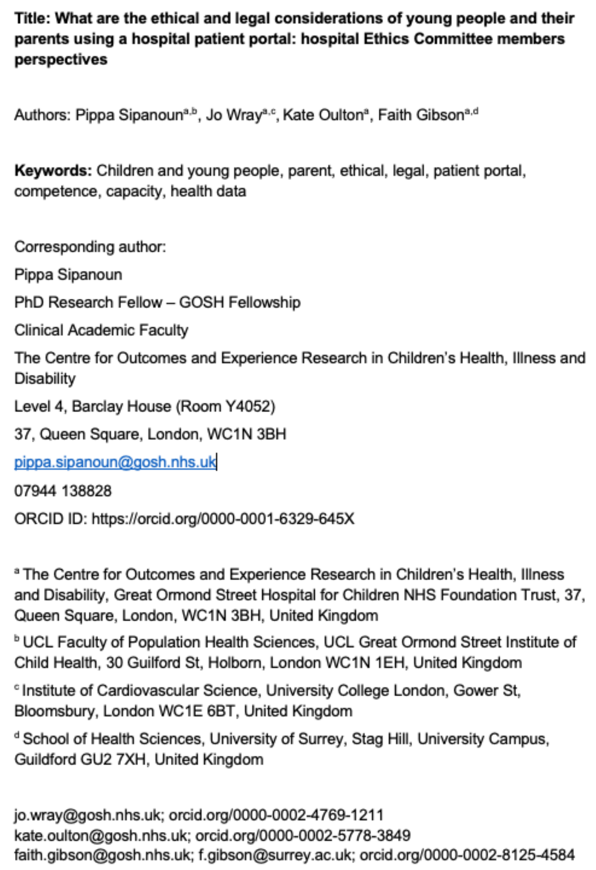
P. Sipanoun is with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability at Great Ormond Street Hospital for Children, London, UK and the UCL Faculty of Population Health Sciences, UCL Great Ormond Street Institute of Child Health, London, UK (phone: 07944138828; e-mail: pippa.sipanoun@gosh.nhs.uk).

J. Wray is with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability at Great Ormond Street Hospital for Children, London, UK and the Institute of Cardiovascular Health at University College London, UK (e-mail: jo.wray@gosh.nhs.uk).

K. Oulton is with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability at Great Ormond Street Hospital for Children, London, UK (k.oulton@gosh.nhs.uk).

F. Gibson is with the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability at Great Ormond Street Hospital for Children, London, UK and the University of Surrey, UK (e-mail: f.gibson@surrey.ac.uk).

Appendix 57 – Submitted manuscript – focus group



Title: What are the ethical and legal considerations of young people and their parents using a hospital patient portal: hospital Ethics Committee members perspectives

Authors: Pippa Sipanoun[a,b], Jo Wray[a,c], Kate Oulton[a], Faith Gibson[a,d]

Keywords: Children and young people, parent, ethical, legal, patient portal, competence, capacity, health data

Corresponding author:

Pippa Sipanoun

PhD Research Fellow – GOSH Fellowship

Clinical Academic Faculty

The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability

Level 4, Barclay House (Room Y4052)

37, Queen Square, London, WC1N 3BH

pippa.sipanoun@gosh.nhs.uk

07944 138828

ORCID ID: https://orcid.org/0000-0001-6329-645X

[a] The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital for Children NHS Foundation Trust, 37, Queen Square, London, WC1N 3BH, United Kingdom

[b] UCL Faculty of Population Health Sciences, UCL Great Ormond Street Institute of Child Health, 30 Guilford St, Holborn, London WC1N 1EH, United Kingdom

[c] Institute of Cardiovascular Science, University College London, Gower St, Bloomsbury, London WC1E 6BT, United Kingdom

[d] School of Health Sciences, University of Surrey, Stag Hill, University Campus, Guildford GU2 7XH, United Kingdom

jo.wray@gosh.nhs.uk; orcid.org/0000-0002-4769-1211
kate.oulton@gosh.nhs.uk; orcid.org/0000-0002-5778-3849
faith.gibson@gosh.nhs.uk; f.gibson@surrey.ac.uk; orcid.org/0000-0002-8125-4584

Title: What are the ethical and legal considerations of young people and their parents using a hospital patient portal: hospital Ethics Committee members perspectives

ABSTRACT

Background: In April 2019, our hospital transitioned to an electronic patient record system and patient portal (MyGOSH). MyGOSH enables young people aged 12 years or older and parents to access results, documentation, appointments, and communicate with their care team.

Aims: A focus group was conducted to explore the ethical and legal considerations of young people/parents using a patient portal from the perspective of hospital Ethics Committee members.

Participants and research context: Members of the hospital Paediatric Bioethics Centre were recruited (n=7). Written informed consent was provided by all participants.

Research design: The focus group discussion was recorded, transcribed verbatim, and analysed using thematic analysis.

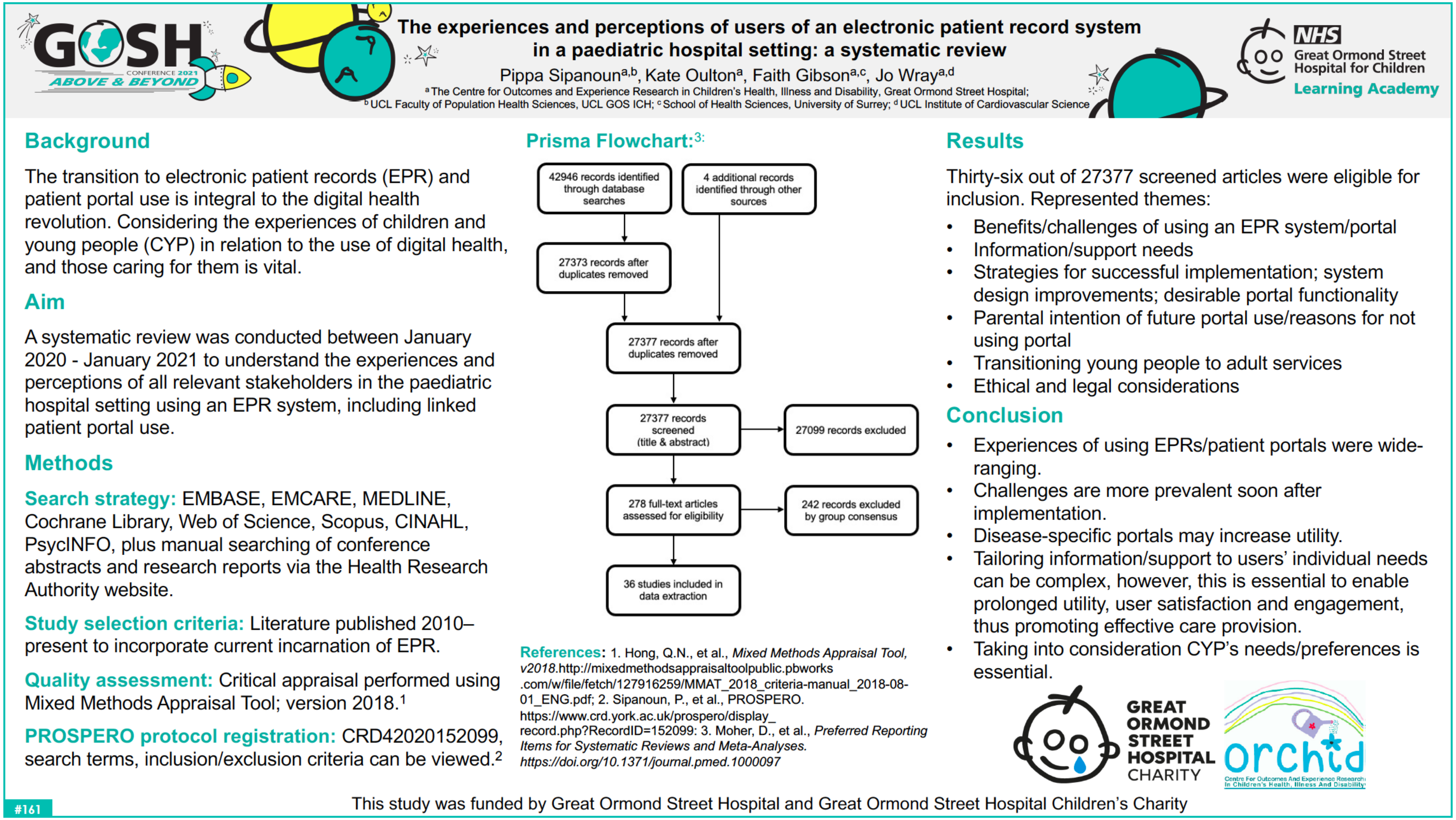
Ethical considerations: HRA Research Ethics Approval was granted by London Southeast REC (IRAS Project ID: 248793; REC Reference: 18/LO/1945)

Results: Four themes, and sub-themes, were identified: 1) granting access – complexities of assessing competence/capacity, exclusion from MyGOSH due to non-disclosure of diagnosis, and truth-telling; 2) inequalities resulting in inequities – complexities of inequity in access; 3) responding to change – providing support and managing expectations; 4) engagement, empowerment and understanding – data safety, empowering young people to take ownership of their health data, a one-size fits all system may not meet the needs of all families, and early engagement with young people/parents.

Discussion: Giving families portal access can increase engagement, empowering them to be more involved in care, yet poses challenges. Complexities exist in assessment for portal access and supporting and managing user expectations whilst providing an equitable service.

Conclusions: Ongoing support is required for all stakeholders following portal implementation to navigate ethical and legal complexities, promote equity and portal utility for patient benefit.

Appendix 58 – 2021 GOSH conference poster



GOSH CONFERENCE 2021 ABOVE & BEYOND

The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: a systematic review

Pippa Sipanoun[a,b], Kate Oulton[a], Faith Gibson[a,c], Jo Wray[a,d]

[a] The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital;
[b] UCL Faculty of Population Health Sciences, UCL GOS ICH; [c] School of Health Sciences, University of Surrey; [d] UCL Institute of Cardiovascular Science

NHS Great Ormond Street Hospital for Children Learning Academy

Background

The transition to electronic patient records (EPR) and patient portal use is integral to the digital health revolution. Considering the experiences of children and young people (CYP) in relation to the use of digital health, and those caring for them is vital.

Aim

A systematic review was conducted between January 2020 - January 2021 to understand the experiences and perceptions of all relevant stakeholders in the paediatric hospital setting using an EPR system, including linked patient portal use.

Methods

Search strategy: EMBASE, EMCARE, MEDLINE, Cochrane Library, Web of Science, Scopus, CINAHL, PsycINFO, plus manual searching of conference abstracts and research reports via the Health Research Authority website.

Study selection criteria: Literature published 2010–present to incorporate current incarnation of EPR.

Quality assessment: Critical appraisal performed using Mixed Methods Appraisal Tool; version 2018.[1]

PROSPERO protocol registration: CRD42020152099, search terms, inclusion/exclusion criteria can be viewed.[2]

Prisma Flowchart:[3]:

42946 records identified through database searches

4 additional records identified through other sources

27373 records after duplicates removed

27377 records after duplicates removed

27377 records screened (title & abstract)

27099 records excluded

278 full-text articles assessed for eligibility

242 records excluded by group consensus

36 studies included in data extraction

References: 1. Hong, Q.N., et al., *Mixed Methods Appraisal Tool, v2018.*http://mixedmethodsappraisaltoolpublic.pbworks .com/w/file/fetch/127916259/MMAT_2018_criteria-manual_2018-08-01_ENG.pdf; 2. Sipanoun, P., et al., PROSPERO. https://www.crd.york.ac.uk/prospero/display_ record.php?RecordID=152099: 3. Moher, D., et al., *Preferred Reporting Items for Systematic Reviews and Meta-Analyses. https://doi.org/10.1371/journal.pmed.1000097*

Results

Thirty-six out of 27377 screened articles were eligible for inclusion. Represented themes:

- Benefits/challenges of using an EPR system/portal
- Information/support needs
- Strategies for successful implementation; system design improvements; desirable portal functionality
- Parental intention of future portal use/reasons for not using portal
- Transitioning young people to adult services
- Ethical and legal considerations

Conclusion

- Experiences of using EPRs/patient portals were wide-ranging.
- Challenges are more prevalent soon after implementation.
- Disease-specific portals may increase utility.
- Tailoring information/support to users' individual needs can be complex, however, this is essential to enable prolonged utility, user satisfaction and engagement, thus promoting effective care provision.
- Taking into consideration CYP's needs/preferences is essential.

GREAT ORMOND STREET HOSPITAL CHARITY

orchid Centre For Outcomes And Experience Research In Children's Health, Illness And Disability

#161

This study was funded by Great Ormond Street Hospital and Great Ormond Street Hospital Children's Charity

Appendix 59 – Published abstract

Digital posters

97 The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: a systematic review

Pippa Sipanoun [1] , Kate Oulton [2] , Faith Gibson [3] , Jo Wray [4]

Abstract

Background The transition to electronic patient records (EPR) and patient portal use is integral to the digital health revolution. Considering the experiences of children and young people (CYP) in relation to the use of digital health, and those caring for them is vital.

Aims A systematic review was conducted between January 2020 – January 2021 to understand the experiences and perceptions of all relevant stakeholders using an EPR system in the paediatric hospital setting, including EPR-linked patient portal use. This formed part of the Going Digital Study, longitudinal research on stakeholder experiences before/after EPR implementation in a paediatric tertiary hospital.

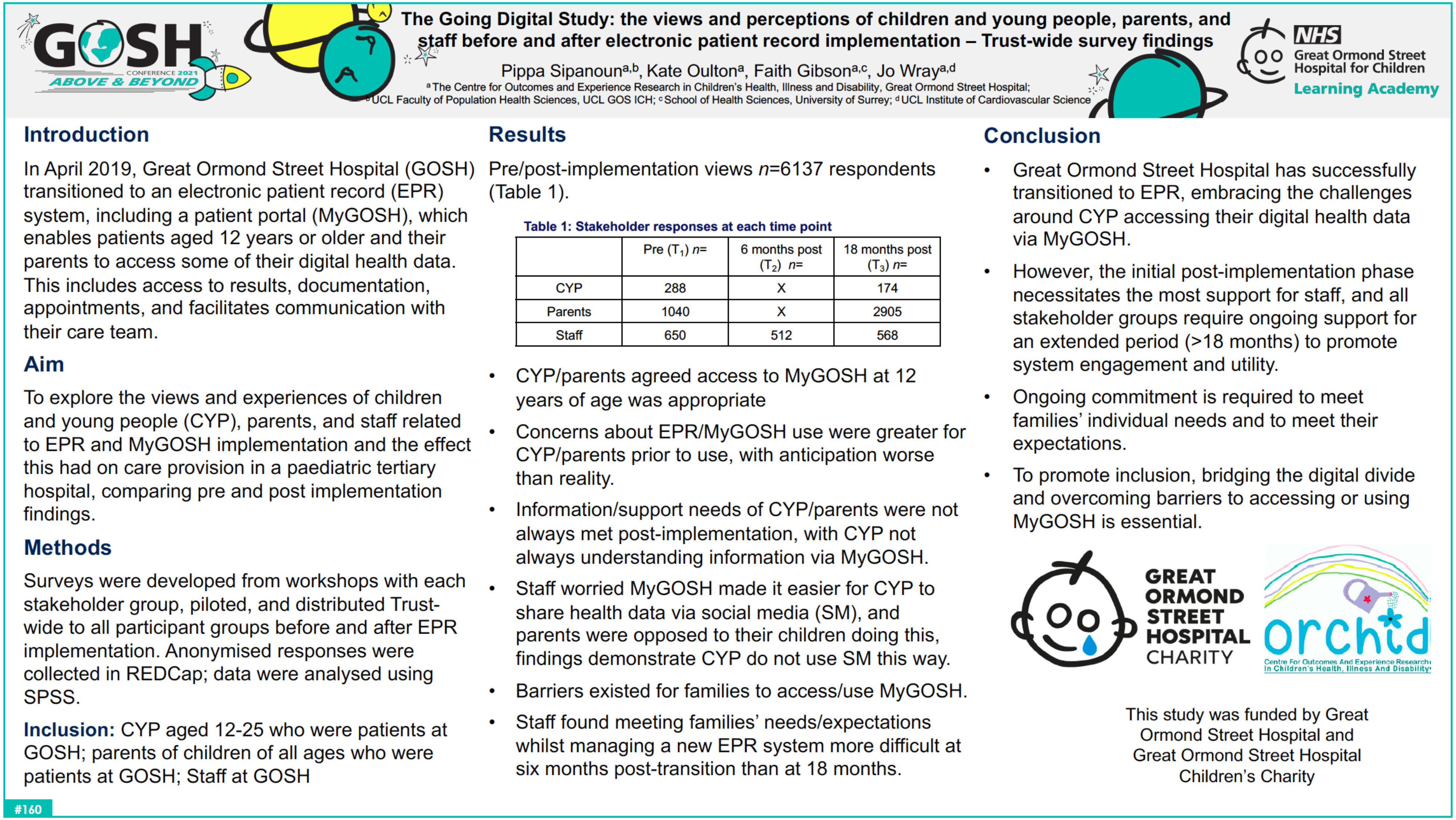
Methods Studies were identified through electronic database and citation searching, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. A systematic search was conducted in EMBASE, EMCARE, MEDLINE, Cochrane Library, Web of Science, Scopus, CINAHL, and PsycINFO electronic databases identifying literature published from 2010. Furthermore, manual searching of conference abstracts and research reports via the Health Research Authority website was conducted. Inclusion criteria were studies reporting on an EPR system in use in hospital settings where child patients (0–17.9 years) were cared for, with/without an EPR-linked patient portal.

Results Thirty-six out of 27377 screened articles were eligible for inclusion. A wide range of benefits, challenges, and information and support needs were identified. Strategies for successful implementation, design improvements, and desirable portal functionality were suggested, together with parental intention to use (or not the portal). Several ethical and legal issues were raised.

Conclusions Experiences of using EPRs and patient portals were wide-ranging with challenges more prevalent soon after implementation. Tailoring information and support to users' individual needs is complex but is essential to enable prolonged utility, user satisfaction, and engagement, thus promoting effective care provision. Disease-specific portals may increase utility. Taking into consideration CYP's needs and preferences is essential.

http://dx.doi.org/10.1136/archdischild-2021-gosh.97

Appendix 60 – 2021 GOSH conference poster



The Going Digital Study: the views and perceptions of children and young people, parents, and staff before and after electronic patient record implementation – Trust-wide survey findings

Pippa Sipanoun[a,b], Kate Oulton[a], Faith Gibson[a,c], Jo Wray[a,d]

[a] The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital; [b] UCL Faculty of Population Health Sciences, UCL GOS ICH; [c] School of Health Sciences, University of Surrey; [d] UCL Institute of Cardiovascular Science

Introduction

In April 2019, Great Ormond Street Hospital (GOSH) transitioned to an electronic patient record (EPR) system, including a patient portal (MyGOSH), which enables patients aged 12 years or older and their parents to access some of their digital health data. This includes access to results, documentation, appointments, and facilitates communication with their care team.

Aim

To explore the views and experiences of children and young people (CYP), parents, and staff related to EPR and MyGOSH implementation and the effect this had on care provision in a paediatric tertiary hospital, comparing pre and post implementation findings.

Methods

Surveys were developed from workshops with each stakeholder group, piloted, and distributed Trust-wide to all participant groups before and after EPR implementation. Anonymised responses were collected in REDCap; data were analysed using SPSS.

Inclusion: CYP aged 12-25 who were patients at GOSH; parents of children of all ages who were patients at GOSH; Staff at GOSH

Results

Pre/post-implementation views *n*=6137 respondents (Table 1).

Table 1: Stakeholder responses at each time point

	Pre (T_1) *n*=	6 months post (T_2) *n*=	18 months post (T_3) *n*=
CYP	288	X	174
Parents	1040	X	2905
Staff	650	512	568

- CYP/parents agreed access to MyGOSH at 12 years of age was appropriate
- Concerns about EPR/MyGOSH use were greater for CYP/parents prior to use, with anticipation worse than reality.
- Information/support needs of CYP/parents were not always met post-implementation, with CYP not always understanding information via MyGOSH.
- Staff worried MyGOSH made it easier for CYP to share health data via social media (SM), and parents were opposed to their children doing this, findings demonstrate CYP do not use SM this way.
- Barriers existed for families to access/use MyGOSH.
- Staff found meeting families' needs/expectations whilst managing a new EPR system more difficult at six months post-transition than at 18 months.

Conclusion

- Great Ormond Street Hospital has successfully transitioned to EPR, embracing the challenges around CYP accessing their digital health data via MyGOSH.
- However, the initial post-implementation phase necessitates the most support for staff, and all stakeholder groups require ongoing support for an extended period (>18 months) to promote system engagement and utility.
- Ongoing commitment is required to meet families' individual needs and to meet their expectations.
- To promote inclusion, bridging the digital divide and overcoming barriers to accessing or using MyGOSH is essential.

This study was funded by Great Ormond Street Hospital and Great Ormond Street Hospital Children's Charity

#160

Appendix 61 – Published abstract

Digital posters

96 The going digital study: the views and perceptions of children and young people, parents, and staff before and after electronic patient record implementation – trust-wide survey findings

Pippa Sipanoun [1] , Kate Oulton [2] , Faith Gibson [3] , Jo Wray [4]

Abstract

Background In April 2019, Great Ormond Street Hospital (GOSH) transitioned to an electronic patient record (EPR) system, including a patient portal (MyGOSH), which enables patients aged 12 years or older and their parents to access digital health data. This includes access to results, documentation, appointments, and facilitates communication with their care team.

Aims To explore, as part of a longitudinal study, the views and experiences of children and young people (CYP), parents, and staff related to EPR implementation in a paediatric tertiary hospital, comparing pre and post findings.

Methods Surveys were developed from workshops with each stakeholder group, piloted, and distributed Trust-wide to all participant groups before and after EPR implementation. Anonymised responses were collected in REDCap; data were analysed using SPSS.

Results Pre/post-implementation views were captured from n=6137 survey respondents. Concerns about the implications of using MyGOSH were greater for both CYP and parents before compared to after implementation, with anticipation worse than reality. However, their information and support needs were not always met post-implementation, with CYP not always understanding health information on MyGOSH. Barriers existed for some families in accessing and using MyGOSH for a variety of reasons including digital poverty, English not being their first language, or having a physical or intellectual impairment or disability. Staff found meeting the needs and expectations of families whilst managing a new EPR system more difficult at six months post-transition than at 18 months, with most response scores returning to baseline at this point.

Conclusion Ongoing commitment is required to meeting the individual needs of families; bridging the digital divide and overcoming barriers to accessing or using MyGOSH. The initial post-implementation phase demands the most support for staff, and all stakeholder groups require ongoing support for an extended period (>18 months) after transitioning to EPR for successful implementation and system utility.

http://dx.doi.org/10.1136/archdischild-2021-gosh.96

Appendix 62 – Systematic review publication

International Journal of Medical Informatics 160 (2022) 104691

Contents lists available at ScienceDirect

International Journal of Medical Informatics

journal homepage: www.elsevier.com/locate/ijmedinf

The experiences and perceptions of users of an electronic patient record system in a pediatric hospital setting: a systematic review

Pippa Sipanoun [a,b,*], Kate Oulton [a], Faith Gibson [a,d], Jo Wray [a,c]

[a] The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital for Children NHS Foundation Trust, 37, Queen Square, London WC1N 3BH, United Kingdom
[b] UCL Faculty of Population Health Sciences, UCL Great Ormond Street Institute of Child Health, 30 Guilford St, Holborn, London WC1N 1EH, United Kingdom
[c] Institute of Cardiovascular Science, University College London, Gower St, Bloomsbury, London WC1E 6BT, United Kingdom
[d] School of Health Sciences, University of Surrey, Stag Hill, University Campus, Guildford GU2 7XH, United Kingdom

ARTICLE INFO

Keywords:
Electronic patient record
Pediatric
Hospital
Experience
Perception
Implementation

ABSTRACT

Context: With the ever-increasing need for digital health innovations, the transition to electronic patient records (EPR) is an integral part of the digital health revolution. There is an increasing body of literature on EPR use in the adult hospital setting, particularly related to adoption as a result of financial incentives in the United States (US). The experiences and perceptions of EPR users within the pediatric hospital setting are less well understood, despite the advent of patient portals accessible by children and young people (CYP) and their parents, which bring new benefits and challenges for them and healthcare professionals alike.

Objectives: The aim of this review was to understand the experiences and perceptions of all relevant stakeholders using an EPR system in the pediatric hospital setting, including the use of an EPR-linked patient portal.

Methods: Studies were identified through electronic database and citation searching, following Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines. A systematic search was conducted in EMBASE, EMCARE, MEDLINE, Cochrane Library, Web of Science, Scopus, CINAHL, and PsycINFO electronic databases to identify literature published 2010–present, in addition to manual searching of conference abstracts, and research reports searched via the Health Research Authority website. Inclusion criteria were studies reporting on an EPR system in use in hospital setting where child patients (from 0 to 17.9 years) are cared for, with or without an EPR-linked patient portal.

Results: Thirty-six out of 42,946 articles were eligible for inclusion, almost two-thirds were studies conducted in the US. A wide range of benefits, challenges, and information and support needs were reported. Strategies for successful implementation and design improvements were suggested, as was desirable portal functionality and parental intention to use, or reasons for not using the portal. Several ethical and legal issues were raised.

Conclusions: Experiences of using EPRs and patient portals were wide-ranging with challenges more prevalent soon after implementation. Although tailoring information and support to users' individual needs and practice context can be complex, this is essential to enable prolonged utility, user satisfaction and engagement, which, in turn, will promote effective care provision. Disease-specific portals may increase utility, and taking into consideration children's and young people's needs and preferences is essential.

1. Introduction

Having a first class, well-funded healthcare system is a fundamental premise to health. Integral to this is the worldwide transition to digital health, including utilization of EPR.[1] There is an increasing body of literature on EPR use in the adult setting, especially adoption related to

---

* Corresponding author at: Clinical Academic Faculty, The Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Level 4, Barclay House (Room 4052), 37, Queen Square, London WC1N 3BH, United Kingdom.

E-mail addresses: pippa.sipanoun@gosh.nhs.uk (P. Sipanoun), kate.oulton@gosh.nhs.uk (K. Oulton), faith.gibson@gosh.nhs.uk (F. Gibson), jo.wray@gosh.nhs.uk (J. Wray).

[1] Electronic patient records may also be termed electronic health records or electronic medical records but for the purposes of this review the term electronic patient records will be used.

https://doi.org/10.1016/j.ijmedinf.2022.104691
Received 4 March 2021; Received in revised form 12 January 2022; Accepted 14 January 2022
Available online 19 January 2022

Appendix 63 – Showcase for research impact

Centre For Outcomes And Experience Research In Children's Health, Illness And Disability

A series of snippets to showcase research impact for patients and families, from healthcare professionals outside medicine, doing their own research studies – brought to you by **ORCHID**
Orchid@gosh.nhs.uk

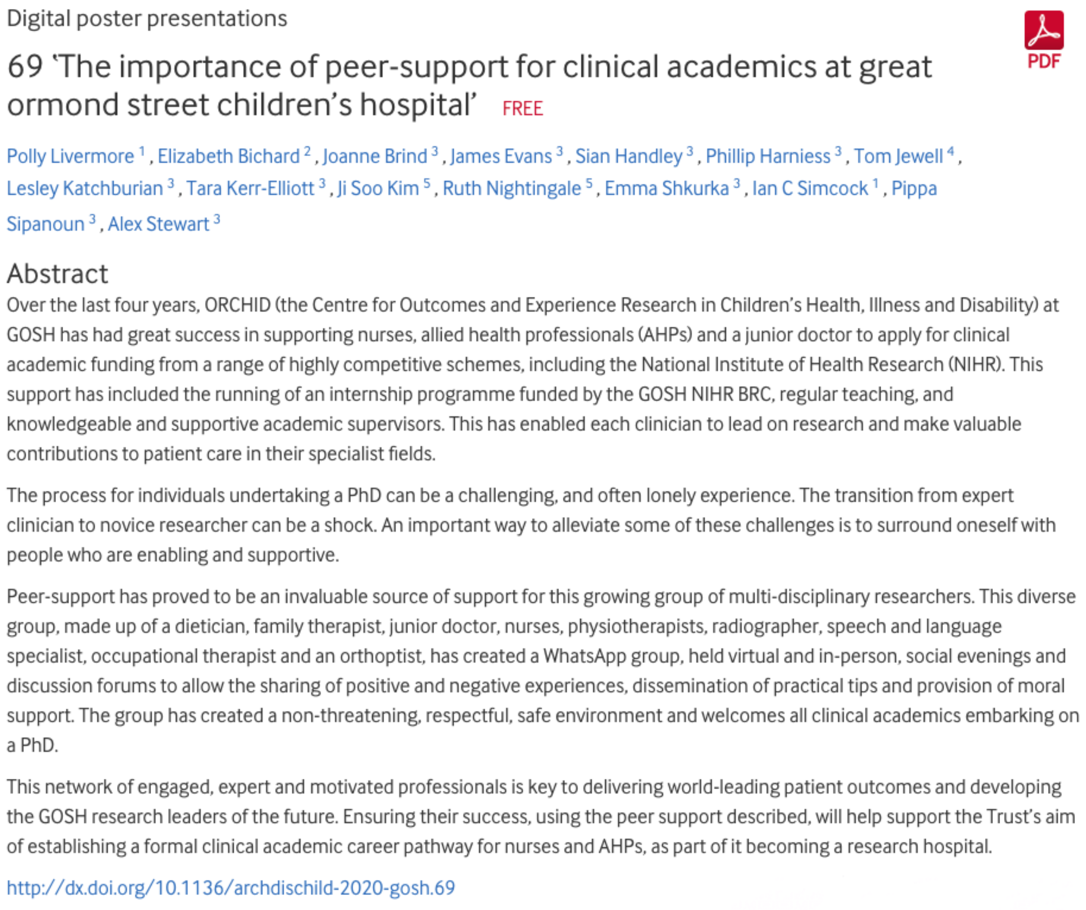
Up next : Pippa Sipanoun
- An Ethicist and ICU Nurse

My research study investigated the practical, ethical and legal considerations of implementing an electronic patient record system at Great Ormond Street Hospital. The study focused on the experiences and perceptions of children and young people, parents and staff before and after system implementation.

The study findings will be used to help shape the provision of digital health services for children and young people.

NIHR | Great Ormond Street Hospital Biomedical Research Centre

Appendix 64 – Published abstract



Digital poster presentations

69 'The importance of peer-support for clinical academics at great ormond street children's hospital' FREE

Polly Livermore [1], Elizabeth Bichard [2], Joanne Brind [3], James Evans [3], Sian Handley [3], Phillip Harniess [3], Tom Jewell [4], Lesley Katchburian [3], Tara Kerr-Elliott [3], Ji Soo Kim [5], Ruth Nightingale [5], Emma Shkurka [3], Ian C Simcock [1], Pippa Sipanoun [3], Alex Stewart [3]

Abstract

Over the last four years, ORCHID (the Centre for Outcomes and Experience Research in Children's Health, Illness and Disability) at GOSH has had great success in supporting nurses, allied health professionals (AHPs) and a junior doctor to apply for clinical academic funding from a range of highly competitive schemes, including the National Institute of Health Research (NIHR). This support has included the running of an internship programme funded by the GOSH NIHR BRC, regular teaching, and knowledgeable and supportive academic supervisors. This has enabled each clinician to lead on research and make valuable contributions to patient care in their specialist fields.

The process for individuals undertaking a PhD can be a challenging, and often lonely experience. The transition from expert clinician to novice researcher can be a shock. An important way to alleviate some of these challenges is to surround oneself with people who are enabling and supportive.

Peer-support has proved to be an invaluable source of support for this growing group of multi-disciplinary researchers. This diverse group, made up of a dietician, family therapist, junior doctor, nurses, physiotherapists, radiographer, speech and language specialist, occupational therapist and an orthoptist, has created a WhatsApp group, held virtual and in-person, social evenings and discussion forums to allow the sharing of positive and negative experiences, dissemination of practical tips and provision of moral support. The group has created a non-threatening, respectful, safe environment and welcomes all clinical academics embarking on a PhD.

This network of engaged, expert and motivated professionals is key to delivering world-leading patient outcomes and developing the GOSH research leaders of the future. Ensuring their success, using the peer support described, will help support the Trust's aim of establishing a formal clinical academic career pathway for nurses and AHPs, as part of it becoming a research hospital.

http://dx.doi.org/10.1136/archdischild-2020-gosh.69

Appendix 65 – Formal Doctoral training and additional development activities

My training and development plan is built on the Vitae's Researcher Development Framework (RDF) and is focused on the personal and professional development I need to become a Clinical Academic and Clinical Leader specialising in Clinical Ethics: Ethical decision-making in paediatric child health and rare diseases. All aspects of my training plan have been incorporated into my research timetable.

1) Formal study

UCL's Doctoral Skills Development Programme is comprehensive, and it is expected that I will accrue a minimum of 20 points per year or 60 points over 3 years, as indicated below.

I have linked each area of study to Vitae's Researcher Development Framework (RDF) Domain – A = Knowledge and intellectual abilities; B = Personal effectiveness; C= Research organisation and governance; D = Communication, influence, and impact.

Pre-PhD	**RDF Domain**	**Points**
Basic Statistics for Research – e-learning Course	A1/A2	5
Ethics 1: Good Research Ethics – Moodle Research Skills Module	C1	1
Ethics 2: Working with Human Subjects – Moodle Research Module	C1	1
		7

Year 1	**RDF Domain**	**Points**
Your PhD Part 1 – Reading for a PhD – The first important steps: • Efficient reading • Literature review	A1/C2	2
Your PhD Part 2 – Management skills for researchers • Managing your PhD • Personal effectiveness	A1/B1/B2/C2	2
Introduction to qualitative thematic analysis	A1	2
Introduction to public engagement	D2/D3	1
PhD Leadership Skills	B3/D1	1
PhD Survival Online Training	B3/D1	1
Introduction to qualitative research: in-depth interviewing	A1	1
Introduction to search strategies for systematic reviews of interventions	A1/C2	1
Public Engagement 1: Introduction to Public Engagement	D2/D3	1
Hugh Kearns: Time for research – taking control of your time	B2/C2	1
Hugh Kearns: Turbo charge your writing	A2/D2	1
Academic Writing	A1/D2	2
Bibliographic referencing (EndNote X7)	A1	1
Mixed methods approach in social sciences	A1	2
Emotional intelligence	B1/D1	2
Action Learning Set for Doctoral Students	B3/D1	5
CASC Introduction to Research Methods and Statistics. This 5-day course included: • Introduction to Study Design • Types, Storage, and Graphical Displays of Data • Summarising Data • Quantifying Differences and Associations • Making Inferences • Significance Testing • Paired Data • Non-parametric tests • Bootstrapping • Beyond t-tests • Displaying Results • Revision/Evaluation of course	A1/A2	10
		36

Year 2	**RDF Domain**	**Points**
Professional behaviour and research integrity	C1/C2	1
Research methods for quantitative data	A1	6
CASC Introduction to SPSS – uses, functions of statistical software SPSS including data entry, basic analyses, and graphs	A1/D2	2
Critical thinking & the researcher: an exploration	A2	2
Fundamentals of giving a poster presentation	A2/A3/D2	1
How to write your methodology chapter	D2/D3	2
The Writing Series: Format your thesis	A1/D2	1
		15

Year 3	**RDF Domain**	**Points**
Your PhD Part 3 – Managing/producing your thesis/reports	A1/B2/C2/D2	2
UCL Arena One Gateway Workshop	A1/D1/D3	1
UCL Arena One Teaching Associate Programme (leading to Associate Fellow of the Higher Education Academy)	A1/D1/D3	6
Postgraduate funding: Considering the alternatives	B3/C3	1
Preparing for your Viva	B2/D2/C1	2
Effective Academic Interviews	B3	1
Effective Academic Applications	B3	1
The Writing Series: Impact statements (advanced)	D2/D3	1
The Writing Series: Abstracts	A3/D2	1
The Writing Series: Healthy Writing Habits	B2/C2	1
The Writing Series: Literature Review	C2/D2	1
How to create your own luck	B1/B2	1
Networking naturally	B3/D3	1
Influencing and Negotiating	B3/D1	2
Researchers Prepare for a Career Beyond Academia – CV's/ Applications Employer Q&A	B3	1
Academic Career Planning for PhD Students	B3	1
Applying for an Early Career Research Fellowship	B3	1
Researchers Careers in Public Health Panel	B3	1
Generating Grant Funding	B3/C3	2
CASC Introduction to Dealing with Missing Data	A1/D2	4
		32

2) Specialist academic training and development in addition to formal study:

I. Conducting Focus Groups (Social Research Association)
II. Ethnographic Methods (Participant Observation) (Social Research Association)
III. Ethics in Practice in Innovative Methods Summer Training Event (Social Research Association)
IV. UCL's MyeXtend – Systematic Reviews in Health and Disease
V. Mediation Training (as member of the GOSH Clinical Ethics Service)
VI. Bioethics Educational Forum
    - Age Discrimination - Using age as a determinant of rationing in the pandemic
    - Miracles in Medicine
    - Creating a Future – reproduction from the deceased? The ethics of posthumous gamete use
    - Ethics of crowdfunding for the sick child
    - Dignity in children: human rights, healthcare, and social media
    - Moral distress
    - Children's Rights and Interests in Healthcare
    - Transgender ethics and law
VII. Inspire Session – to critically analyse a research paper
VIII. Academic Inquiring Minds
    - Poetry in Research
    - Open Research
    - Research Ethics (Presented by me)
    - Research in a C19 world – Data Management for Online Research; Video-conferencing with young children
    - Research Viva's from the perspective of the student and the examiner
    - Undertaking Peer Review
    - Single Case Study methodology
    - Delphi studies
    - Questionnaire Development (Joint presentation with Jo Wray)
    - Mixed Methods Research

- Longitudinal Research
- Interpretative Phenomenological Analysis
- Dissemination
- Academic Writing Skills
- Funding Opportunities
- Qualitative Interviewing
- Literature Reviews: Methodology and Practical Tips
- Applying for Research Grant funding - what are reviewers looking for?

IX. Arena One Gateway workshop

X. Arena One Teaching Associate Programme with Higher Education Authority Fellowship submission

XI. UCL GOS ICH/BRC Intuition to Statistics

- The scary thing called ‘Statistics’ –Introduction to statistics as a ‘tool’
- A look from above – *p*-values
- Sherlock’s gamble – The concept of probability
- The power of sample size – Introduction to sample size calculations

3) Clinical training and development plan

Leadership

- The King’s Fund ‘Personal impact and influence’ course (May/June 2021) – Enhancement of my self-awareness, self-management, and personal integrity, developing key characteristics of NHS leadership qualities framework

Maintaining and advancing clinical practice

- Annual clinical updates and mandatory training completed to maintain clinical expertise and vicarious liability
- Increase knowledge in paediatric clinical ethics
- Continue role as an expert member of the GOSH Paediatric Bioethics Centre
- Attend ‘Genethics’ Forum meetings led by Professor Michael Parker, Director of the Ethox Centre (attended x 2 meetings in 2019)
- Advance interpersonal skills and networking:

    - Continuing to attend ethical rapid response reviews
    - Attend and present at relevant conferences

4) Additional Research Training

- MRC Good Research Practice (most recent January 2022)
- NIHR Introduction to Good Clinical Practice Online eLearning (Primary Care; June 2018)
- NIHR Informed Consent in Paediatric Research Online eLearning (June 2018)
- HRA eLearning Module – Induction for New research Ethics Committee Members (June 2018)
- HRA eLearning Module – Research Ethics Committee Induction (June 2018)
- HRA eLearning Module – Research Participants Lacking Mental Capacity (August 2018)
- HRA Induction Training for Committee Members (September 2018)
- HRA Training – Human Tissue Act; The use of human samples in research (October 2018)
- HRA eLearning Module – Reviewing the research design of a Clinical Trial of an Investigational Medicinal Product (CTIMP; November 2018)
- HRA Training – The Ethical Issues of Research Involving Children (January 2019)
- HRA Research Ethics Members' Training Day (February 2019)
- Participation in HRA Research transparency consultation for REC members of the 'Make it public. Transparency and openness in health and social care research' document.
- HRA Training – Research Involving Adults Who Lacking Capacity 2: Reviewing Projects (April 2021)
- HRA REC Member Training Day (June 2021)
- HRA Chair's Training Day (July 2021)

5) Conferences Attended

- GOSH Conference 2021 – Above and Beyond. London, UK, November 2021 (virtual conference)
- International Conference on Digital Health 2021 – London, UK, October 2021 (virtual conference)
- RCN International Nursing Research Conference 2021 - Virtual Conference, UK, September 2021
- HETT Reset 2021 – Virtual Conference, UK, February 2021
- Institute of Medical Ethics Virtual Conference: Ethics lessons from a pandemic – London, UK, January 2021
- Children and Young People Now Conferences: Safeguarding Children in the Digital Age – London, UK, January 2021 (virtual conference)
- GOSH Conference 2020 – Our People, Our Patients, Our Hospital. London, UK, November 2020 (virtual conference)
- 1st European Paediatric Bioethics Conference: COVID-19 ethical learning for child health – London, UK, November 2020 (virtual conference)
- Risky Business - Lessons from COVID-19: Making Sense of the Pandemic, London, UK, June 2020 (virtual conference)
- GOSH Paediatric Bioethics Service - Fundamentals of Paediatric Bioethics and Law Conference, London, UK, February 2020
- GOSH Conference 2019 – Care of the Complex Child - London, UK, November 2019
- RCN International Nursing Research Conference and Exhibition 2019 - Sheffield , UK, September 2019
- GOSH Conference 2018 – Continuing Care, London, UK, November 2018
- 2nd International Conference on Nursing Science and Practice. Transforming nursing science with advanced nursing and practice - London, UK, August 2018
- ERSC Research Methods Festival 2018 - Bath, UK, July 2018
- Institute of Medical Ethics Postgraduate Bioethics Conference ‘Bioethics in the Public Square’ - King’s College London, London, U, July 2018

- ORCHID Clinical Academic Careers Conference - A Showcase of Healthcare Research with Children & Young People - London, UK, June 2018

6) Mentoring/advisory roles

- Mentoring of an iBSc Medical Student, as part of the Paediatric Bioethics Service. This is a service evaluation entitled ‘Ethical review of the impact of changes to healthcare services on children during the first wave of the Coronavirus Disease (COVID-19) pandemic’
- Member of the GOSH Mentoring Service
- Clinical supervisor for a NIHR CDRF applicant
- Survey development advisor for a study conducted through the Genetics and Genomics Medicine Programme at UCL GOS Institute of Child Health

7) Review/peer review

- Peer review of a MSc research application for CRACC submission
- Peer reviewer for The European Journal of Oncology

8) Grant funding and awards

- UCL GOS ICH Travel and External Training Fund Award – £150 – June 2021
- Institute of Medical Ethics – Postgraduate Conference Grant – £200 – April 2021
- UCL PhD Carers Grant - £295.50 – March 2021
- Great Ormond Street Hospital PhD Fellowship – £175,000

9) Prizes/other achievements

- First prize in the poster competition at the RCN International Nursing Research Conference – September 2021 – **Sipanoun P,** Oulton K, Gibson F, Wray J. The experiences and perceptions of users of an electronic patient record system in a paediatric hospital setting: A systematic review
- Awarded Associate Fellowship of the Higher Education Academy – December 2021

Appendix 66 – Associate Fellowship Award

AdvanceHE

This is to certify that

Philippa Sipanoun

has achieved the status of Associate Fellow (AFHEA)

In recognition of attainment against the UK Professional Standards Framework for teaching and learning support in higher education.

Fellowship reference
PR232551

Date of Fellowship
29/11/2021

[redacted]

Alison Johns
Chief Executive
Advance HE

[redacted]

Stephen Marston
Chair of the Board of Directors
Advance HE

Appendix 67 – Legal implications for critical care publication

Anaesthesia 2020, 75, 1517–1528 doi:10.1111/anae.15147

Review Article

COVID-19: legal implications for critical care

N. Coghlan,[1,2] **D. Archard,**[3] **P. Sipanoun,**[4] **T. Hayes**[5] and **B. Baharlo**[6]

1 Barrister, Lincoln's Inn, London, UK
2 Master of Law Researcher, European University Institute, Florence, Italy
3 Emeritus Professor of Philosophy, Queen's University Belfast, Belfast, UK
4 Research Associate and PhD Student, Centre for Outcomes and Experience Research in Children's Health, Illness and Disability, Great Ormond Street Hospital for Children NHS Foundation Trust and University College London Great Ormond Street Institute of Child Health, London, UK
5 Speciality Registrar, Department of Vascular Surgery, Lister Hospital, Stevenage, UK
6 Consultant, General Intensive Care Unit, Hammersmith Hospital, Imperial College Healthcare NHS Trust, London, UK

Summary

The COVID-19 pandemic has caused an unprecedented challenge for the provision of critical care. Anticipating an unsustainable burden on the health service, the UK Government introduced numerous legislative measures culminating in the Coronavirus Act, which interfere with existing legislation and rights. However, the existing standards and legal frameworks relevant to critical care clinicians are not extinguished, but anticipated to adapt to a new context. This new context influences the standard of care that can be reasonably provided and yields many human rights considerations, for example, in the use of restraints, or the restrictions placed on patients and visitors under the Infection Prevention and Control guidance. The changing landscape has also highlighted previously unrecognised legal dilemmas. The perceived difficulties in the provision of personal protective equipment for employees pose a legal risk for Trusts and a regulatory risk for clinicians. The spectre of rationing critical care poses a number of legal issues. Notably, the flux between clinical decisions based on best interests towards decisions explicitly based on resource considerations should be underpinned by an authoritative public policy decision to preserve legitimacy and lawfulness. Such a policy should be medically coherent, legally robust and ethically justified. The current crisis poses numerous challenges for clinicians aspiring to remain faithful to medicolegal and human rights principles developed over many decades, especially when such principles could easily be dismissed. However, it is exactly at such times that these principles are needed the most and clinicians play a disproportionate role in safeguarding them for the most vulnerable.

Correspondence to: B. Baharlo
Email: behrad.baharlo@nhs.net

Accepted: 21 May 2020
Keywords: COVID-19; critical care; human rights; law; resource allocation
This article is accompanied by an editorial by Ferguson et al. *Anaesthesia* 2020; **75**: 1428–31.

Introduction

On 31 December 2019, China reported the first cases of a pneumonia of unknown aetiology in Wuhan, Hubei province [1], subsequently identified to be due to a novel Coronavirus (2019-nCov) [2]. Renamed as SARS-Cov-2 due to its potential to cause a severe acute respiratory syndrome [3], the World Health Organization (WHO) declared this virus and the disease COVID-19 a public health emergency of international concern [4]. The virus spread globally, manifesting a pandemic [5], and outside China, outbreaks in Iran and Italy further illustrated the potential for disease and associated mortality [6, 7]. Although the UK diagnosed its index case at the end of January, the events that unfolded in Lombardy three weeks later vividly demonstrated the

Appendix 68 – Published abstract

Digital posters

47 Ethical review of the impact of changes to healthcare services on children and young people during the first wave of the coronavirus disease 2019 (COVID-19) pandemic

Namithaa Sunil Kumar [1], Pippa Sipanoun [2], Mariana Dittborn [3], Mary Doyle [4], Sarah Aylett [5]

Abstract

Background Changes to paediatric services during the Coronavirus disease 2019 (COVID-19) pandemic potentially challenged children's fundamental right to health. As COVID-19 has presented with greater morbidity and mortality in adults than in children, healthcare resources including staff were diverted from paediatric services to support adult care. Infection-control measures were also implemented, including hospital visiting restrictions and reduced face-to-face paediatric care.

Objectives We investigated paediatricians' perceptions around the impact of changes to paediatric services during the first wave of the COVID-19 pandemic on children and young people (CYP), to develop recommendations for maintaining their care during subsequent pandemics.

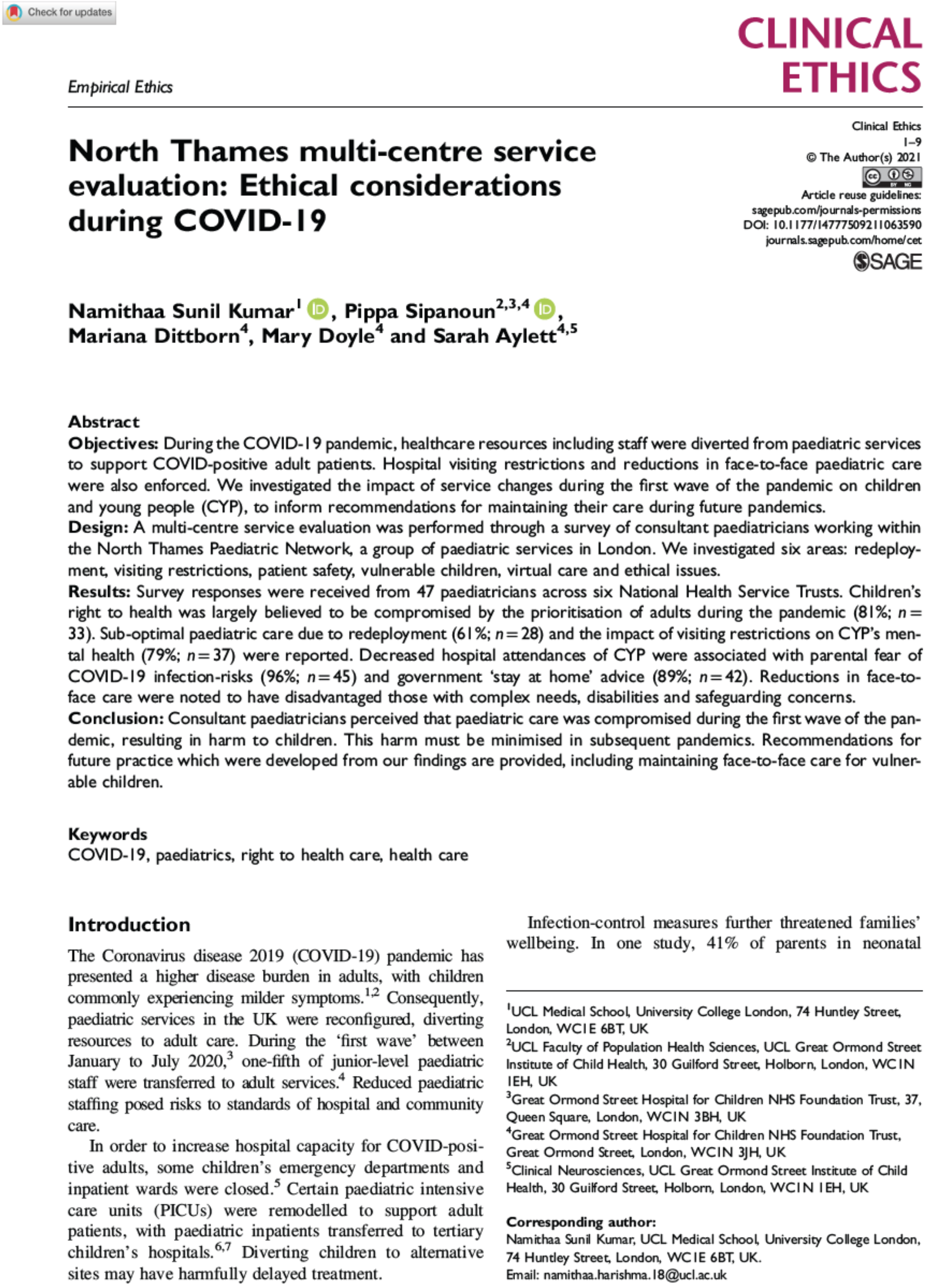
Methods A multi-centre service evaluation was conducted through surveying consultant paediatricians working within the North Thames Paediatric Network, a cohort of paediatric services in London.

Results Forty-seven consultant paediatricians across six National Health Service trusts completed the survey. Lower quality of paediatric care due to redeployment was reported (61%; *n=28*), alongside consequences of visiting restrictions for CYP's mental health (79%; *n=37*). Fewer hospital attendances of CYP were linked to caregivers' fear of COVID-19 infection-risks (96%; *n=45*) and government 'stay at home' messages (89%; *n=42*). Although 52% (*n= 24*) relayed that care accessibility had improved with virtual formats, inequities for those with reduced technological access or skills were noted (83%; *n=38*). Risk of harm to children with complex needs, disabilities and safeguarding concerns was reported due to reductions in face-to-face care. Paediatricians largely perceived that the prioritisation of adults during the pandemic had compromised children's right to health (81%; *n=33*).

Conclusion Consultant paediatricians raised concern around poorer quality and accessibility of paediatric care during the pandemic's first wave, and resulting harm occurring to children. In future pandemics, children's welfare must receive greater consideration and support. Recommendations for future practice are provided based upon our findings, including maintaining face-to-face consultations with vulnerable and disadvantaged children.

http://dx.doi.org/10.1136/archdischild-2021-gosh.47

Appendix 69 – Service evaluation publication



Check for updates

Empirical Ethics

CLINICAL ETHICS

Clinical Ethics
1–9

DOI: 10.1177/14777509211063590
journals.sagepub.com/home/cet
SAGE

North Thames multi-centre service evaluation: Ethical considerations during COVID-19

Namithaa Sunil Kumar[1], Pippa Sipanoun[2,3,4], Mariana Dittborn[4], Mary Doyle[4] and Sarah Aylett[4,5]

Abstract

Objectives: During the COVID-19 pandemic, healthcare resources including staff were diverted from paediatric services to support COVID-positive adult patients. Hospital visiting restrictions and reductions in face-to-face paediatric care were also enforced. We investigated the impact of service changes during the first wave of the pandemic on children and young people (CYP), to inform recommendations for maintaining their care during future pandemics.
Design: A multi-centre service evaluation was performed through a survey of consultant paediatricians working within the North Thames Paediatric Network, a group of paediatric services in London. We investigated six areas: redeployment, visiting restrictions, patient safety, vulnerable children, virtual care and ethical issues.
Results: Survey responses were received from 47 paediatricians across six National Health Service Trusts. Children's right to health was largely believed to be compromised by the prioritisation of adults during the pandemic (81%; $n = 33$). Sub-optimal paediatric care due to redeployment (61%; $n = 28$) and the impact of visiting restrictions on CYP's mental health (79%; $n = 37$) were reported. Decreased hospital attendances of CYP were associated with parental fear of COVID-19 infection-risks (96%; $n = 45$) and government 'stay at home' advice (89%; $n = 42$). Reductions in face-to-face care were noted to have disadvantaged those with complex needs, disabilities and safeguarding concerns.
Conclusion: Consultant paediatricians perceived that paediatric care was compromised during the first wave of the pandemic, resulting in harm to children. This harm must be minimised in subsequent pandemics. Recommendations for future practice which were developed from our findings are provided, including maintaining face-to-face care for vulnerable children.

Keywords
COVID-19, paediatrics, right to health care, health care

Introduction

The Coronavirus disease 2019 (COVID-19) pandemic has presented a higher disease burden in adults, with children commonly experiencing milder symptoms.[1,2] Consequently, paediatric services in the UK were reconfigured, diverting resources to adult care. During the 'first wave' between January to July 2020,[3] one-fifth of junior-level paediatric staff were transferred to adult services.[4] Reduced paediatric staffing posed risks to standards of hospital and community care.

In order to increase hospital capacity for COVID-positive adults, some children's emergency departments and inpatient wards were closed.[5] Certain paediatric intensive care units (PICUs) were remodelled to support adult patients, with paediatric inpatients transferred to tertiary children's hospitals.[6,7] Diverting children to alternative sites may have harmfully delayed treatment.

Infection-control measures further threatened families' wellbeing. In one study, 41% of parents in neonatal

---

[1] UCL Medical School, University College London, 74 Huntley Street, London, WC1E 6BT, UK
[2] UCL Faculty of Population Health Sciences, UCL Great Ormond Street Institute of Child Health, 30 Guilford Street, Holborn, London, WC1N 1EH, UK
[3] Great Ormond Street Hospital for Children NHS Foundation Trust, 37, Queen Square, London, WC1N 3BH, UK
[4] Great Ormond Street Hospital for Children NHS Foundation Trust, Great Ormond Street, London, WC1N 3JH, UK
[5] Clinical Neurosciences, UCL Great Ormond Street Institute of Child Health, 30 Guilford Street, Holborn, London, WC1N 1EH, UK

Corresponding author:
Namithaa Sunil Kumar, UCL Medical School, University College London, 74 Huntley Street, London, WC1E 6BT, UK.
Email: namithaa.harishma.18@ucl.ac.uk