An Affective Appraisal Approach to Shared Decision-Making: Theory, Evidence and Interventions for Parents and Carers of Children with Mental Health Problems

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Declaration

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

Signature:

Date: 25/05/2020

Abstract

Background: Policy guidelines recommend service user involvement in care and treatment decision-making as a person-centred approach to improving health outcomes. However, most shared decision-making (SDM) models are perceived as a rational process. There is a need for research exploring the role of emotions in children and young people's mental health (CYPMH) decisions. This thesis aimed to develop an affective appraisal approach to SDM based on theory and evidence and to develop and pilot an intervention to support parents/carers and promote SDM.

Methods: Several study designs were adopted. (1) Qualitative synthesis to understand the emotional experiences of parents. (2) Logistic regression analysis of parental help-seeking. (3) Multilevel modelling to investigate SDM in CYPMH services. (4) Interviews and focus groups with parents/carers and healthcare professionals to further explore the effect of emotions on SDM. (5) Scoping review to identify and examine existing decision support interventions. (6) Feasibility and acceptability randomised controlled trial of a novel intervention.

Findings: (1) Seven categories describing parents' emotions emerged as influencing factors to CYPMH care and treatment decisions. (2) A negative association between parental worry and help-seeking was found. (3) Almost 70% of parents reported experiencing SDM in CYPMH, and findings justified a multilevel approach to studying SDM. (4) A framework for an affective appraisal model of SDM emerged. (5) Twenty-three existing interventions were identified, incorporating an average of 4.57 elements of SDM. Time, accessibility and

appropriateness emerged as factors influencing usage and implementation. (6)
The novel intervention (Power Up for Parents) was found to be acceptable and
feasible to upgrade to a full trial.

Conclusion: This thesis provides a theoretical understanding that parents are
'expected to, but not always able to' be actively involved in care and treatment
decisions. Integrating this concept in CYPMH may help to inform policy and
practice for the implementation of SDM. These findings also provide insight for
researchers to establish a foundation for developing future interventions using
the affective appraisal approach.

Impact Statement

SDM is increasingly considered the gold-standard approach to promote collaboration between service providers and service users. Despite significant improvements in health outcomes as a direct impact of SDM, existing studies highlight many barriers to the SDM process. This thesis explored the concept of parents' emotions as a possible influencing factor to effective SDM in CYPMH, to extend the literature on emotions and health decision-making. By linking these areas of research to CYPMH, this research contributes to addressing a critical gap in the literature opening exciting new challenges and opportunities for academic enquiry.

The preliminary findings of this thesis have highlighted a range of emotions experienced by parents of children with mental health (MH) problems unfolding a theory that 'parents are expected to, but not always able to' be actively involved in effective decision-making. This work has already begun impacting children and young people mental health services by increasing the understanding around these issues and triggering new strategies that will capitalise on the findings. The findings could therefore play a key role in developing policy and informing practice on how organisations support families with children experiencing MH problems.

Knowledge translation activities involved in this thesis have also resulted in positive outcomes highlighting the potential interest in and appetite for this area of research. The project was awarded a £1000 public engagement grant from University College London (UCL) to develop an SDM resource. A webpage was developed in collaboration with parents and young people to

promote SDM in CYPMH and received over 4000 views within 2 weeks after being launched. Dissemination of the findings within this thesis through presentations and blog writing locally, regionally, and internationally has received constructive feedback that is useful to extend knowledge, contribute towards future directions in the field and encourage others to consider this research area. Additionally, various studies within this thesis (Chapters 7 and 9) have been through a rigorous peer-review process in high impact journals and consequently accepted for publication.

Lastly, the use of Power Up for Parents, a digital SDM support intervention for parents of children with MH problems, was acceptable by parents and healthcare professionals. Therefore, this evidenced-based, theoretically-informed intervention could now be considered for further evaluation in a full scale randomised controlled trial (RCT).

Dedication

This thesis is dedicated to the memory of my mother (1949 – 2019). She was my inspiration and motivation for pursuing this PhD, and her light has guided me to the end.

For my mother, may I inherit her perseverance and goodwill.

Acknowledgements

Foremost, I thank Dr Julian Edbrooke-Childs for provision of high-quality supervision throughout this PhD project. I truly admire the work ethic and dedication you modelled. You provided a space where I felt encouraged and comfortable enough to admit moments of uncertainty. My sincerest thanks to Prof Miranda Wolpert who guided and supported me through the early stages of this research to help shape my jumbled ideas, and to Prof Peter Fonagy for willingly offering mentorship and advice throughout. My gratitude is extended to the Technology Enabled Mental Health for Children and Youth Innovative Training Network (TEAM-ITN), supported by the Marie Skłodowska-Curie grant, for generously supporting this research.

An enormous thanks to the clinicians, parents and young people who volunteered their time to be involved in this research as advisors, co-producers, or research participants. A special thanks to the Family Research Advisory Group, Parent Champions, Young Champions, Helen, and the parents who served on the steering committee. Your valuable insight has richly shaped this thesis. Similarly, thanks to the technical team at Create Health, for developing the intervention and finding ways to incorporate feedback from multiple stakeholders.

A special thanks to the research and development teams, principal investigators, site collaborators and research assistants at the National Health Service (NHS) CYPMH sites that participated in the feasibility study. Thank you for showing interest in the study and offering advice on ethics that contributed

to my development as a researcher. Without your assistance, the recruitment of parents at CYPMH sites may not have been possible.

Special thanks to my family and friends, near and far, who called, visited, and insisted I took frequent breaks to refuel. Your heartfelt love, well-wishes and encouragement provided the much-needed motivation to keep going. My greatest appreciation for Miles, Brent, Dan, and Jamal for offering assistance in reviewing and editing research arising from this thesis. Also, to Maurhys, Jivaan, and Denissa, thanks for making the dark days brighter with your energetic presence.

Finally, I acknowledge the source of my own strength for the courage and diligence to embark on this PhD journey.

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List of Abbreviations

ADHD	Attention deficit and hyperactivity disorder
AFNCCF	Anna Freud National Centre for Children and Families
AIC	Akaike information criterion
ASD	Autism spectrum disorder
AUC	Area under the receiver operating characteristic curve
CASP	Critical appraisal skills programme
CI	Confidence Interval
CORC	Child Outcomes Research Consortium
CPS	Control preference scale
CPS-P	Control preference scale for paediatrics
CVT	Current View Tool
CYP	Children and young people
CYP IAPT	Children and Young People's Improving Access to Psychological Therapies
CYPMH	Children and young people's mental health
CAMHS	Children and Adolescent Mental Health Services
DCS	Decisional Conflict Scale
EBD	Emotional and behavioural disorders
EBPU	Evidence Based Practice Unit
ESQ	Experience of Service Questionnaire
FGD	Focus group discussion
GDPR	General Data Protection Regulation
GP	General practitioner
HCI	Human-Computer Interaction
HCP	Healthcare professional
ICC	Intraclass correlation coefficient
IPDAS	International Patient Decision Aids Standards
MH	Mental health
MRC	Medical Research Council
NCB	National Children's Bureau
NHS	National Health Service
OCD	Obsessive-compulsive disorder

ODSF	Ottawa decision support framework
OR	Odds ratio
PCC	Person centred care
PhD	Doctor of Philosophy
PPI	Patient and public involvement
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analyses
PSDM-Q-9	9-item Paediatric Shared Decision-Making Questionnaire
PSSUQ	Post-Study Usability Questionnaire
PUfP	Power Up for Parents
QPL	Question prompt list
RCT	Randomised controlled trial
REC	Research Ethics Committee
SDM	Shared decision-making
SDQ	Strengths and Difficulties Questionnaire
SPSS	Statistical Package for Social Sciences
STAI-AD	State-Trait Anxiety Inventory- Adult
TAMHS	Targeted Mental Health in Schools
TEAM-ITN	Technology Enabled MH for Young People - Innovative Training Network
UCL	University College London
UK	United Kingdom
USA	United States of America
WHO	World Health Organization

Publications and conference presentations associated with this thesis

Journal articles

Liverpool, S., Pereira, B., Hayes, D., Wolpert, M., Edbrooke-Childs, J. (2020). A scoping review and assessment of essential elements of shared decision-making of parent-involved interventions in child and adolescent mental health. *European Child and Adolescent Psychiatry*. https://doi.org/.10.1007/s00787-020-01530-7

Liverpool, S., Pinheiro Mota, C., Sales, C., Čuš, A., Carletto, S., Hancheva C., … Edbrooke-Childs J. (2020) Engaging children and young people in digital mental health interventions: A systematic review of modes of delivery, facilitators, and barriers. *Journal of Medical Internet Research*. https://doi.org/.10.2196/16317

Liverpool, S., Webber, H., Matthews, R., Wolpert, M., Edbrooke-Childs, J. (2019). A Mobile App to Support Parents Making Child Mental Health Decisions: Protocol for a Feasibility Cluster Randomized Controlled Trial. *JMIR Research Protocols* ;8(8), https:// doi.org/ 10.2196/14571.

Conference presentations

Liverpool, S., Edbrooke-Childs, J., Wolpert, M. (2017, July) Power Up for Parents: A comparative RCT to promote Shared Decision-Making. Poster session presented at the International Shared Decision-Making conference, Lyon.

Liverpool, S., Edbrooke-Childs, J., Wolpert, M. (2018, May) Involving parents in the development of a web application for child mental health. Oral presentation at the Digital Child Mental Health conference, London.

Liverpool, S., Edbrooke-Childs, J. (2018, August) Design and development of a parent app to promote shared decision-making. Oral presentation at the EU midterm review and TEAM summer school, Glasgow

Liverpool, S., Edbrooke-Childs, J. (2019, July) The emotional experiences of parents of children with mental health challenges: A synthesis of qualitative evidence. Poster session presented at the European Society for Child and Adolescent Psychiatry Congress, Vienna

Liverpool, S., Edbrooke-Childs, J. (2019, July) Development of a digital intervention to support parents of children with mental health problems. In Fitzpatrick, G (Chair) & Akkaya-Kalayci, T (Co-chair) Technology for youth mental health: Involving users, opportunities and ethical implications. Symposia conducted at the European Society for Child and Adolescent Psychiatry Congress, Vienna

Liverpool, S., Edbrooke-Childs, J. (2019, July) Shared decision-making in child and adolescent mental health: a scoping review and quality assessment of available parent-involved interventions. Oral presentation at the 10th International Shared Decision-Making Conference, Quebec City

Liverpool, S., Edbrooke-Childs, J. (2020, January) Supporting parents making

child mental health decisions: Learnings from a feasibility and acceptability trial.

Oral presentation at the Digital Child Mental Health Conference, Barcelona

Declaration of the candidate's role in each of the studies

All research activity included in this thesis was guided and supported by Dr Julian Edbrooke-Childs and informed by input from Prof Miranda Wolpert and Prof Peter Fonagy.

Chapter 1. General Introduction

All work is the PhD candidate's own.

Chapter 2. Overview of the Literature

All work is the PhD candidate's own.

Chapter 3. The Emotional Experiences of Parents Making Child Mental Health Decisions: A Synthesis of Qualitative Evidence (Study 1)

The review was conceptualised and conducted by the PhD candidate. The search strategy was guided by recent reviews in CYPMH (Cheng, Hayes, Edbrooke-Childs, et al., 2017; Gondek et al., 2017), recommendations for qualitative literature searching (Shaw et al., 2004) and input from the subject librarian at UCL, Institute of Child Health. A second reviewer (JP) independently screened the articles for inclusion. Another reviewer (BP) independently conducted appraisals and data extraction on 20% of the included articles. Similarly, another reviewer (ME), coded 20% of the articles and assisted in grouping and categorising the codes to develop themes. All other work, including analysis and interpretation, is the PhD candidate's own work.

Chapter 4. Associations between Help-seeking, Child Psychosocial Impairment and Parent State of Worry (Study 2)

The PhD candidate conceptualised the study and applied for permission to access the Targeted Mental Health in Schools (TaMHS) dataset held by the UCL Evidence-Based Practice Unit (EBPU). The data utilised in this study were collected between 2008 and 2011 and collated and cleaned by researchers at EBPU. All other work, including analysis and interpretation, is the PhD candidate's own work.

Chapter 5. Associations between Clinical Characteristics and Parental Experience of Shared Decision-Making using Administrative Data from Children and Adolescent Mental Health Services (Study 3)

The PhD candidate conceptualised the study and applied for permission to access the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT) dataset held by the Child Outcomes Research Consortium (CORC). The data utilised in this study were collected between 2011 and 2015 and collated and cleaned by researchers at CORC. All other work, including analysis and interpretation, is the PhD candidate's own work.

Chapter 6. Views and Experiences of Parents and Healthcare Professionals on Shared Decision-Making in Children and Adolescent Mental Health Services (Study 4)

The PhD candidate conceptualised the study and obtained UCL and NHS research ethical approvals. Except for two focus group discussions (FGDs) and

two parent interviews, conducted by an NHS site's research assistant, all other interviews and FGDs were conducted by the PhD candidate. The PhD candidate transcribed an initial four audio recordings and the remaining were transcribed by a transcription company approved by UCL and Anna Freud National Centre for Children and Families (AFNCCF). Another researcher (JP), independently reviewed three random transcripts and generated codes for cross-validation. All other work, including analysis and interpretation, is the PhD candidate's own work.

Chapter 7. A Scoping Review and Assessment of Essential Elements of Shared Decision-Making of Parent-Involved Interventions in Children and Adolescent Mental Health Services (Study 5)

The study was conceptualised by the PhD candidate and discussed during supervision meetings with the PhD candidate's supervisors. A second reviewer (BP) collaborated to pilot the eligibility criteria, crosschecked the included records and verified the data extracted. The PhD candidate's primary supervisor (JEC) participated in assessing the interventions for essential elements of SDM. Another reviewer (DH) suggested studies/interventions for inclusion. All other work, including screening, quality checks, data extraction, analysis and interpretation, is the PhD candidate's own work.

Chapter 8. Development of Power Up for Parents

The development process of Power Up for Parents was guided by the Medical Research Council (MRC) Framework for the Development and Evaluation of Complex Interventions (Craig et al., 2011) and the Workbook for Developing

and Evaluating Decision Aids (O'Connor & Jacobsen, 2003). The content was developed based on stakeholders' input and Create Health was responsible for the technical development of Power Up for Parents. All other work is the PhD candidate's own.

Chapter 9. Acceptability and Feasibility Pilot Study of a Digital Intervention to Support Parents and Carers of Children with Mental Health Problems (Study 6)

The PhD candidate conceptualised and designed the study and obtained UCL and NHS research ethical approvals. Site collaborators and research assistants at NHS sites identified research participants and collected data where applicable. All other work, including coordination and management of the recruitment process, data collection, data cleaning, analysis and interpretation, was conducted by the PhD candidate.

Chapter 10. General Discussion and Conclusions of the Thesis

All work is the PhD candidate's own.

Chapter 1 General Introduction

The current chapter provides a general introduction to the thesis. First the problem statement is presented followed by the aims and organisation of the thesis. Additionally, the researcher's perspective, highlighting the importance of patient and public involvement (PPI), and the epistemological and ontological position that underpins the research process is discussed.

Problem Statement

Children and young people mental health problems have high prevalence, tend to co-occur, potentially predict further health problems, and impact different areas of the children and young people's life (Jensen & Steinhausen, 2015; Kieling et al., 2011; Perou et al., 2013; Polanczyk et al., 2015). Once MH symptoms are suspected, the families experience many decisions, such as, (1) how, when, and from where to seek help (Wolpert et al., 2015); (2) agreeing on the diagnostic tests (Berger et al., 2017); (3) agreeing on the goals of treatment (Bradley et al., 2013; Law & Jacob, 2015); and (4) agreeing on treatment options when more than one treatment option is available (Ahmed, McCaffery, et al., 2017; Hayes, Town, Lemoniatis, et al., 2018). Although scholarly works commonly focus on these decisions, other decisions are also made daily, with some being more complex than others (Frensch & Cameron, 2002).

Many key decision-making actors are usually involved in the care and treatment of children and young people (CYP) accessing health care (Canadian Paediatric Society, 2004). As such, parents (inclusive of non-biological

caregivers) are recognised by the literature and by the law as important members of the CYPMH decision-making process (Allan, 2004; Benson & Pinnaro, 2015; Féat et al., 2005; Haine-Schlagel & Walsh, 2015). However, it is often difficult for them to engage efficiently (Gondek et al., 2017). Additionally, the need to participate in decision-making in child health has been associated with added stressors for the parents involved (Adams & Levy, 2017). Nonetheless, significant benefits to involvement have been identified (Edbrooke-Childs et al., 2015).Yet, healthcare professionals (HCPs) report low participation from parents (Baker-Ericzén et al., 2013; Boland et al., 2017), parents report feeling isolated and excluded by services (Andershed et al., 2017), and there are treatment disagreements between parents, clinicians and children (Simmons, Hetrick & Jorm, 2013).

Despite a range of interventions and service delivery models to support the involvement of parents, the implementation of decision-making strategies, such as SDM, in CYPMH settings continues to be a challenge (Wolpert et al., 2012). Barriers to implementation include professional, relational, service user/ parent, service-level and context-level factors (Gondek et al., 2017). Further, research in general paediatric care highlighted that the parent's emotional states were the most commonly reported barrier to adopting SDM measures (Boland et al., 2019). Several studies have further explored the emotional experiences of parents of a children with MH problems (Boshoff et al., 2018; Corcoran et al., 2015; Hayes & Watson, 2013), but fewer studies have explored how specific emotional experiences of parents affect involvement in care and treatment decisions (Brinkman et al., 2009; Coletti et al., 2012). As a result, a

closer examination is needed to fully understand the influence of emotions on decision making in CYPMH context.

Due to existing challenges impacting the decision-making process, it is clear that there is a need to provide additional support for parents. An exploration of this phenomenon, how it can be addressed (e.g. identification of potential interventions), and scope for the development of feasible and acceptable interventions is yet to be thoroughly investigated. Therefore, a gap in research indicates the necessity for understanding the role of parents' emotional experiences in CYPMH decisions, exploring possible associations, and developing and piloting an intervention that is acceptable and feasible to support parents and promote involvement in care and treatment decisions.

Relevance of this topic

Shared decision making (SDM) has been broadly defined as a cognitive, emotional, and relational process where service providers and service users collaborate to derive care and treatment decisions (Charles et al., 1999). Service user involvement in healthcare decisions is highly recommended, linked to better health outcomes and promotes satisfaction with services (Edbrooke-Childs et al., 2015; National Institute for Health and Care Excellence, 2019; Wolpert et al., 2012). In CYPMH, service users include children and young people as primary service users and parents as secondary service users (Gabe et al., 2004). However, previous studies have mainly focused on the dyad relationships between service providers and primary

service users (Bomhof-Roordink et al., 2019). Therefore, the areas where triad relationships exist have been less understood (further discussed in Chapter 2).

The literature highlights that cognitively competent children and young people should be encouraged to be involved in their care and treatment (Adams et al., 2017). This is further strengthened by the development of policies and guidelines such as the "no decision about me without me" movement which support the inclusion of younger services users in the health decision making process (Department of Health, 2012). Generally, when children and young people are experiencing good health they appreciate being included in SDM (Boland et al., 2019). However, researchers highlight that when children and young people experience emotional ehanced states or feeling unwell they are less likely to be involved in SDM (Boland et al., 2019; Hayes et al., 2019). Similarly, Boland and colleagues (2019) highlighted that children and young people preferred to be involved in lower stake decisions. Researchers agree that these factors influence SDM in pediatric clinical practice with implications for strategies such as developing and agreeing therapeutic goals. As a result children and young people welcome the support of their parents, sometimes as advocates, to facilitate care and treatment decisions (Gondek et al., 2017).

The inclusion of parents in the SDM process as the patient's surrogate is challenging (Opel, 2018). Opel highlights that unlike competent adult patients, who are deciding for themselves, this approach has limitations on decision-making authority. For example, he indicated that the essential role of the surrogate in paediatric decision-making can complicate SDM's iconic features,

such as taking steps to build consensus; therefore, challenging person centred care strategies such as agreeing on treatment goals. In addition, researchers suggest that emotions may impact service users' involvement in SDM (Légaré & Thompson-Leduc, 2014) and threaten parents' assumed role in the decision-making process (Jackson et al., 2008). Interviews with clinicians, parents and young people corroborated those findings, highlighting that strong emotional states affected the SDM process (Brinkman et al., 2009; Hayes et al., 2019, 2020). Therefore, researchers suggest that emotions act as important social information influencing SDM (Treffers & Putora, 2019) with implications for intervention use (further discussed in Chapter 7). Many studies report heightened emotions in parents of children with mental health problems (Corcoran et al., 2015, 2017) implicating a need for further research in this area.

Previous research suggest that clinicians' ability to listen, respect and validate service users' values may promote SDM (Hayes et al., 2019). However, this could be complicated with the inclusion of parents and children with different treatment goals. As a result some clinicians suggest the involvement of parents in the SDM process could be optional (Simmons et al., 2012). This approach is yet to be fully understood, as other researchers report that if the child or parent only is included, the process is not regarded as SDM (Park and Cho, 2018). Although some clinicians viewed SDM as time consuming, they worried that not including parents could result in drop out from care (Hayes et al., 2019). These factors further complicated the SDM process and sometimes left clinicians feeling overwhelmed. One important step forward may be to understand the role of affect on SDM (Chapters 3 and 5).

Thesis aims and organisation

      The overarching aim of this research was to address the above gap in the literature on SDM for parents and carers of children with mental health problems through the exploration of theory, evidence, and interventions, including testing the feasibility and acceptability of an intervention (Power Up for Parents) underpinned by an affective appraisal approach to SDM. To achieve this aim, the following steps were undertaken:

Chapter 1: The current chapter describes and outlines the problem and presents the structure of the thesis.

Chapter 2: Provides an overview of the literature introducing the topics of interest for this research (i.e. the prevalence of CYPMH, decision-making in CYPMH, influencing factors, and the role of emotions in health decisions).

 Chapter 3: Study 1. Systematically reviews the qualitative literature on parents' emotions as a potential influencing factor of involvement in CYPMH care and treatment decisions.

Chapter 4: Study 2. Tests the emerging concepts from Study 1 to explore the role of parents' emotion on their decision to seek CYPMH support, and in so doing, identifies factors that are independently associated with help-seeking in a cross-sectional analysis.

Chapter 5: Study 3. Explores parents' experiences of involvement in SDM in child and adolescent mental health services (CAMHS) using administrative data. This study also sought to highlight additional problems and contextual

factors that are associated with participation in SDM, to further identify specific groups of parents requiring additional support.

Chapter 6: Study 4. Examines the views and experiences of parents and healthcare professionals (HCPs) on SDM in CAMHS and further explores the influence of emotions and perceived support systems. In so doing, a framework describing an affective appraisal approach model to SDM emerged highlighting the interaction between key decision-makers and the role parents' emotions, support systems, and attitudes, beliefs and experiences play in shaping the SDM process and outcome.

Chapter 7: Study 5. Identifies existing parent decision support interventions and assesses the elements of SDM included. Additionally, the review explores potential influencing factors to usage and implementation, with the overall aim of informing the development of new interventions.

Chapter 8: Describes the development of a novel intervention, called Power Up for Parents, identifying the evidence base and underpinning theories, guided by the MRC framework for developing and evaluating complex interventions.

Chapter 9: Study 6. Determines the acceptability of an intervention to support parents and promote involvement in CYPMH decisions and examines the feasibility of upscaling to a future randomised controlled trial (RCT) to test its effectiveness.

Chapter 10: Discusses the overall findings of the thesis and the potential implications for policy, practice, and future research.

Researcher's Perspective

Prior knowledge

The PhD candidate began this research with an educational background in Health Psychology and employment experience in child development and policy research. Knowledge and skills in this area were further developed through familiarisation with the decision-making literature and workshops with Parent Champions and the Family Research Advisory Group. Discussions with parents of CYP with MH problems provided a better understanding of their personal experiences, which helped inform the project's research process.

Epistemological and Ontological position

Fundamental to the discussions on the use of mixed methods in social and behavioural research, researchers proposed a move from "paradigmatic foundations" to "conceptual stances". This move supports a more practical orientation that emphasizes individual components of philosophy and theory that guides research activities (Tashakkori & Teddlie, 2015). Epistemology refers to a branch of philosophy that studies the origins, methods and limits of human knowledge and informs the underlying assumptions and basic ideas about how research is conducted (Dancy et al., 2010). Philosophers agree that it is related to ontology, the study of being (Lawson, 2004) or the nature of reality (Lawrenz, 2010). These two concepts complement each other in that an epistemological stance implies a particular ontology and vice versa (Crotty, 1998).

The chosen conceptual stance or paradigm guides the researcher as decisions are made throughout the research process (Clarke & Hollway, 2018).

These paradigms exist on a continuum such that interpretivism provides a subjective meaning of the social phenomena so the researcher can focus on the details of the situation and the subjective, relative and transactional meanings ascribed to the situation. The other extreme is positivism which states that only observable data can provide credible information to explain a phenomenon (Dancy et al., 2010).

To achieve a middle ground, pragmatism acknowledges that either or both observable and subjective meanings can provide acceptable knowledge dependent on the research question (Tashakkori, Teddlie, & Biesta, 2015). Advocates for the pragmatic approach suggest that the research question should drive all study decisions. However, critics of this approach suggest that pragmatism is incompatible with interpretivist research (Biesta, 2010; Cronenberg, 2020). Therefore, the PhD candidate adopts a dialectic stance for this thesis which allows for the mixing and integration at various levels of research, including the paradigmatic level in a mixed-method study. The Dialectic stance has been described as a "respectful conversation between differing perspectives" (Cronenberg, 2020, p. 93) and is focused on the learning and deeper understanding of the viewpoints that emerge.

Although there exist similarities between the pragmatic and dialectic stances, the pragmatic understanding of knowledge is embedded in Dewey's transactional constructivism which is able to offer philosophical support for explanatory research but not so much for interpretive research (Biesta, 2010). However, it was necessary to rely on an interpretivist stance in order to obtain a deeper understanding of the participants' experience and therefore the dialectic

stance was selected as more suitable for the current mixed methods research project. Additionally, methods and perspectives vary throughout this research and the dialectic stance allows for the equal status of mixed methods designs because one phase of the study did not take precedence over the other.

There are four key characteristics to consider in order to engage in the dialectic stance: 1) sustaining a data dialogue, 2) giving equal voice, 3) preserving data integrity and 4) value consonance and dissonance (Cronenberg, 2020). Table 1.1 denotes how various parts of this thesis map onto the four key characteristics of the dialectic stance.

Table 1.1 Characteristics and evidence of the dialectic epistemological stance

Characteristics	Meaning	Current research
Sustain a data dialogue	The researcher sustains an ongoing dialogue between different forms of data and the knowledge and understandings of the paradigmatic perspectives within which the data were collected.	During the process of conducting this research, it was important to maintain a research diary with information about the data collection process, including any assumptions made, and detail reflections of the overall study which was then routinely explored in supervision.

Characteristics	Meaning	Current research
Give an equal voice	All paradigms used in the study are given an equal voice or equal priority in the dialogue.	Study 1 of this thesis was underpinned by the interpretivism stance utilising a social constructivist approach to understand the experience of the population to be studied. Quantitative studies included in this thesis are nearer to the positivist side of the spectrum utilising the realism paradigm perspective to describe the "reality" of the CYPMH decision-making phenomenon. However, studies are connected in that the results of the qualitative studies informed the quantitative studies while both remained independent with its own valid input.

Characteristics	Meaning	Current research
Preserve data integrity	Researchers preserve the integrity of quantitative and qualitative data forms in the dialectic stance because data transformation prioritises one paradigmatic approach over another	Both qualitative and quantitative data forms were preserved with the main aim to address the research questions. No one data form was superior to the next. For studies where both forms of data were collected, equal voices were given.
Value consonance and dissonance	When integrating qualitative and quantitative data, the researcher must seek convergent data (triangulation) and divergent data because both offer important perspectives on the phenomenon under investigation	Qualitative and quantitative data were used to address the research questions throughout this thesis. Although each form of data produced unique findings, they were also used for triangulation and to inform each other.

Patient and Public Involvement

The research in this thesis was developed and conducted with input from the Family Research Advisory Group at the National Children's Bureau, and the Parent Champions at the Anna Freud National Centre for Children and Families (AFNCCF). These groups consist of biological parents, adoptive parents, foster and sibling carers. They provided expert opinions on various aspects of the development and feasibility testing of the intervention (Chapters 8 and 9) and are referred to as parent partners throughout this thesis.

It was necessary to include the involvement of parents in the research process to ensure the research was carried out "with" and not "about" the subject population. PPI has been advocated across various types of health research (Bagley et al., 2016) and is often the requirement of many funding bodies (INVOLVE, 2017). Additionally, there is some evidence to suggest that PPI improves the quality of research (Blackburn et al., 2018). However, researchers agree there are also some challenges such as low levels of engagement and input, when involving the public in research (Staniszewska et al., 2011). Therefore, researchers have presented guidelines and recommendations for effective collaboration, such as efficient planning and management of the process (Staniszewska et al., 2017). By following these guidelines, commonly reported challenges were not experienced in the current research project. Additionally, the parent partners were trained, and had a wealth of experience in research advisory.

Parent partners were directly involved in the design of the intervention (Chapter 8), as well as the reviewing of documents used in the pilot and

feasibility study (Chapter 9). Parent partners also provided guidance on how to approach the qualitative interviews (Chapters 6 and 9). Furthermore, they were very vocal about their views on digital interventions which helped the PhD candidate to approach this research with an open mind.

Brief Summary

The current chapter provided a general introduction to the thesis, presenting the problem statement, aims and organisation of the thesis. Then the researcher's perspective, including epistemological and ontological position, and the importance of PPI in the current research was discussed. The next chapter will build on this by reviewing the literature underpinning the main topics of this thesis.

Chapter 2 Overview of the Literature

The current chapter provides an overall introduction and integrated review of the key background information for the thesis. First the prevalence of CYPMH problems is reported. A review of the health decision-making literature with reference to help-seeking and shared decision-making is discussed. Consequently, a critical review of the literature is conducted. In undertaking the literature review, a broad search strategy was adopted utilising key concepts, "children and young people" and "health decision making" in the Cochrane Library, MEDLINE, PsycINFO and gray literature sources to identify relevant published and unpublished literature.

Prevalence of children and young people's mental health problems

Researchers suggest that MH problems are common among children and young (CYP) (Grist et al., 2017). According to the World Health Organization (WHO) up to 20% of CYP suffer from a disabling mental illness (WHO, 2013). As stressed by the WHO, health is not merely the absence of diseases but a state of complete well-being. Therefore, for this thesis, CYPMH is referred to as the mental, emotional, psychological, behavioural and social well-being of children (below the age of 14) and young people (15-24), using age definitions from the United Nations Secretariat (United Nations, 1985). However, services offering support for CYPMH are referred to as child and adolescent mental health services (CAMHS) provided by NHS trusts and independent health providers. The term CAMHS is used for consistency throughout the thesis due to the wide age range for CYP which encompasses

transition services and mental health services provided for young people over age 18.

There exist considerable differences in prevalence estimates of CYP living with MH problems between countries (Kieling et al., 2011), ranging from 9.5% in the United Kingdom (Ford et al., 2003) to 22% in the Netherlands (Verhulst & van der Ende, 1997). Differences are often attributed to heterogeniety in methods use to collect data (e.g. definition of mental health problems) which may be influenced by the cultural context (Kieling et al., 2011). These researchers agree that culture defines and creates specific sources of distress (e.g. anxiety and depression) and impairment, and affects how symptoms are intepreted. However, an international study conducted in 27 countries estimated the worldwide-pooled prevalence of MH problems to be 13.4% among CYP (Polanczyk et al., 2015). Specifically, the results of that study showed anxiety disorders were the most common conditions with a prevalence of 6.5%, followed by disruptive behaviour disorder with a prevalence of 5.7%. Oppositional defiance disorder (3.6%), attention-deficit-hyperactivity-disorder (ADHD) (3.4%), depressive disorders (2.6%) and conduct disorder (2.1%) were also reported.

Research also suggest that about half of the CYPMH problems begin before age 14 years (Kessler et al., 2005), and are associated with recurrent or chronic adversity (Merikangas et al., 2009). A national survey conducted in the UK reported that 12.8% of 5 to 19-year-olds are diagnosed with a MH condition (Campion, 2019). Also, suicide appears to be one of the three most common causes of death in young people in many European countries, with suicide

rates of 15 to 29 year-olds ranging from 8 per 100,000 in West and South

Europe to 25 per 100,000 in North and East Europe (World Health

Organization, 2018). Non-fatal self-harm is even more common, and Public

Health England estimates 22% of 15-year-olds report self-harm (Brooks et al.,

2017).

Further to this, research has shown that MH problems in CYP tend to co-

occur with other mental or physical health problems (Munir, 2016). An

American national comorbidity survey reported approximately 50% of all lifetime

cases to start by age 14, and 75% by age 24 years, with 27.7% of the sample

reporting two or more lifetime disorders and 17.3% three or more (Kessler et

al., 2005). A recent systematic review and meta-analysis corroborates these

findings, reporting that autism spectrum disorders (ASD) co-occur 28% of the

time with ADHD; 20% for anxiety disorders; 13% for sleep-wake disorders; 12%

for disruptive, impulse-control, and conduct disorders; 11% for depressive

disorders; 9% for obsessive-compulsive disorder (OCD); 5% for bipolar

disorders; and 4% for schizophrenia spectrum disorders (Lai et al., 2019).

Researchers have also highlighted the potential global burden of MH

problems, reporting MH disorders to be among the top 20 most costly disorders

(Baranne & Falissard, 2018). Similarly, researchers frequently report the

adverse outcomes of childhood MH problems in adulthood (Leitner, 2014).

These outcomes generally include negative impacts on (mental) health, quality

of life, public sector services, employment status and income, which has further

economic implications (Beecham, 2014). Although the prevalence of CYPMH

problems is alarming, there is accumulating evidence that researchers,

practitioners and policymakers are actively investigating and implementing strategies to support CYP (NHS, 2019; WHO, 2013).

Types of decisions in children and young people's mental health

A conceptual framework has been proposed, conceptualising five needs-based groupings for CYP with MH problems and their families (Wolpert et al., 2016). The THRIVE care framework illustrates an integrated needs-led approach to delivering CYPMH services in the UK. The overarching theme of the THRIVE model represents a person-centred approach to care and treatment highlighting five components: (1) thriving, (2) getting advice and signposting, (3) getting help, (4) getting more help, and (5) getting risk support. The authors of this framework encourage the active involvement of CYP and their families in decisions throughout the help-seeking process through SDM. For this thesis, the PhD candidate proposes that based on the needs of CYP with MH problems, and their families, a variety of different decisions such as how, when, and where to seek help (Wolpert et al., 2015); agreeing on the diagnostic tests (Berger et al., 2017); agreeing on the goals of treatment (Bradley et al., 2013; Law & Jacob, 2015); and agreeing on treatment options (Ahmed, McCaffery, et al., 2017; Hayes, Town, Lemoniatis, et al., 2018) will emerge. Therefore, parents may experience SDM opportunities at various stages of the CYPMH care and treatment process.

Decision-making roles

Historically and culturally, a paternalistic approach to care and treatment decisions have been adopted (Rodriguez-Osorio & Dominguez-Cherit, 2008; Sandman & Munthe, 2010). This approach positioned the service user as a

passive actor in the decision-making process and the service provider as the authority making the decision with no input from the service user. On the other extreme is the patient-informed approach where the role of the service provider is solely to provide sufficient information about care and treatment options to enable the service user to make an informed decision. This approach placed the service user as the decision-maker with no deliberation or decision-making steps involving the service provider. A middle ground to these two approaches has been proposed and favoured as a shared decision-making model where the service user and service provider interact and share all stages of the decision-making process (Sandman & Munthe, 2010). The SDM approach to person-centred care has been widely advocated across various health settings and patient populations including CAMHS (Chief Medical Officer, 2014; Wolpert et al., 2012).

What is shared decision-making?

SDM has been broadly defined as the involvement of service users in the process of making decisions where there are important reasonable competing treatment options (Charles et al., 1997; Légaré & Thompson-Leduc, 2014). Charles, Gafni & Whelan (1999), further described SDM as a cognitive, emotional, and relational process where provider and patient collaborate. Researchers generally agree that the key features of SDM are (1) at least 2 persons are involved, (2) through collaboration, information is exchanged in both directions, (3) all parties are aware of the treatment options, and (4) value-related priorities are explored (Bomhof-Roordink et al., 2019; Elwyn et al., 2004).

Although SDM may be rooted in consumerism, it has been consistently applied in healthcare settings to encourage service user participation in treatment decision-making (Charles, Gafni & Wheelan, 1999). These researchers also suggested that SDM can be "a mechanism to decrease the informational and power asymmetry between doctors and patients by increasing patients' information, sense of autonomy and /or control over treatment decisions that affect their well-being" (p.682). In addition, SDM is embedded in patient centred care, and was developed in an attempt to reduce uncertainty about treatment options (Jordan, Ellis & Chambers, 2002). At its core, the SDM literature perceive service users as competent and having the capacity to participate in the SDM process. Another key assumption is that multiple care or treatment options exist with competing outcomes and substantial uncertainty. Together these have important ethical and practical implications, further highlighting a need for a deeper understanding in specific health contexts.

Although its application to different health setting may have resulted in varying definitions, there appears to be common themes that underpin these definitions. Researchers agree that an effective communication process between the decision-makers, exchanging relevant information (medical information and service user's values and preferences), and reaching a joint decision are essential to SDM (Jordan, Ellis & Chambers, 2002; Kon & Morrison 2018). However, definitions differ contextually (acute vs chronic care). For instance, SDM in chronic care may require patients to make and revisit decisions, with fewer decisions occurring during the clinical encounter, and several ongoing lifestyle decisions (Montori, Gafni & Charles, 2006).

Additionally, Montori and colleagues highlighted that SDM in chronic care requires more active patient participation in carrying out the decision, and offers a longer window of opportunity to make decisions and to revisit and reverse them. Conversely, SDM in acute care may require minimal patient participation to realize, and are often urgent, and may be irreversible.

Despite the appreciation for SDM, researchers in CYPMH have identified limitations of the existing definitions. In adult settings, health decisions are *usually* made between the patient and the clinician; however, in child health settings, the SDM process is unique as it involves a sometimes-complex triad relationship between clinicians, children and parents (Charles et al., 1999; Dicé et al., 2016; Wyatt et al., 2015). Previous studies have mainly focused on the dyad relationships between physicians and patients; therefore, the areas where triad relationships exist have been less understood (Bomhof-Roordink et al., 2019). Additionally, previous definitions imply two or three adult decision-makers are involved (Bomhof-Roordink et al., 2019; Makoul & Clayman, 2006). Therefore, researchers in CYPMH agree that a consensus definition of SDM is still lacking and suggests the CYPMH literature could benefit from further investigations into the SDM process (Cheng, Hayes, Edbrooke-Childs, et al., 2017; Wyatt et al., 2015). As a result, implementation researchers across health settings have attempted to identify the behaviours associated with SDM resulting in several unique and overlapping models.

This thesis was based on the principles that: (1) all members of the triad are involved in the CYPMH decision-making process as developmentally appropriate, and 2) that all members of the triad have an agreed decision in

terms of the outcome. It was anticipated that the degree to which individual members of the triad become involved might vary in different aspects of the process depending on the legal context, capacity, experience and expertise of the participants and type of problem. Taking into account existing SDM definitions and qualitative data from parents and HCPs (Chapter 6, Study 4), the following definition of SDM underpins this thesis.

SDM in CYPMH is defined as a process involving key-decision-makers (i.e. parents, healthcare professionals and CYP), as developmentally appropriate, sharing information and views, and all parties taking steps (i.e. informed or involved) to build a consensus about the preferred care and treatment option.

Theories and models of shared decision-making

Since conception, there has been an increasing interest in SDM (Makoul & Clayman, 2006). To date, researchers have proposed over 40 SDM models (Bomhof-Roordink et al., 2019). However, the majority of the available models are for specific health settings with fewer models specific to paediatric settings and MH care. Additionally, researchers highlight that models are either applicable to treatment decisions, screening, diagnostic testing, or generic to any decision (Makoul & Clayman, 2006; Bomhof-Roordink et al., 2019).

There appears to be considerable overlap between models. Describing treatment options is frequently present in SDM models; it was included in 35/40 models (88%) described by Bomhof-Roordick and colleagues (2019) and 51% of the models described by Makoul & Clayman (2006). Other common

elements present in more than half of the models were: making the decision, patient preferences, tailored information, deliberating, creating choice awareness, and learning about the patient. Fewer models include elements to reach a mutual agreement, HCP expertise and patient expertise.

Other researchers further highlight that much of the evidence for SDM thus far, derive from adult medicine (Feenstra et al., 2014; Wyatt et al., 2015; Boland et al., 2019). SDM experts also express the presence of additional complexities of the triad and fewer paediatric studies available (Lipstein et al., 2015). Taken together, further investigations are needed to broaden our knowledge of SDM and its application to CYP health settings. Therefore, existing models identifying CYP as patients, the parent, and the HCP as actors were of interest to this thesis. Other models crucial to the study of SDM in a broader context were described and discussed in various studies throughout the thesis. The identified models/theories, involving more than 2 actors and or the involvement of children and parents are reviewed below.

Interprofessional Shared Decision-Making model (IP-SDM)

The revised IP-SDM model proposes that the patient and his or her family (including significant others) are a distinct and active part of the SDM team (Légaré, Stacey, Gagnon, et al., 2011; Légaré, Stacey, Pouliot, et al., 2011). As such, they collaborate with the interprofessional team throughout the SDM process. The care team is usually composed of HCPs who care for the patient and influence the SDM process through their roles and relationships. This model highlights that the care team serves to initiate the SDM process and act as the decision coach. Therefore, to be effective, the interprofessional team

must develop a collaborative relationship with authentic, constructive and honest communication of mutual trust and respect among team members as well as between team members and the patient. To achieve this, the researchers suggested that the team must provide integrated and cohesive care and share power among its members. The authors also suggested that the team members must be able to exercise their partnership and share their knowledge regularly and without interruptions, communicating information systematically throughout the therapeutic process and using well-designed information and communication technologies. However, this approach to SDM is yet to be taken up extensively in clinical care and have been criticized for relying on the HCP to initiate the SDM process (Yu et al., 2014). Therefore, its application to paediatric care may not be fully understood.

Shared decision making in paediatrics

SDM in paediatric care is conceptually defined as "the active participation of parents, children and health professionals in reaching a compromise via collaborative partnership, with a common goal for the child's health" (Park & Cho, 2018, p. 482). The authors highlighted active participation from the three parties (parent, child, and practitioner) and noted that where children were unable to participate due to age or capacity the decision making was not regarded as SDM. Therefore, the model proposes key attributes that is required to achieve SDM in paediatrics, (1) the active participation of parents, CYP and health professional, (2) collaborative partnership, (3) reaching a compromise and (4) common goal. The authors can be praised for addressing a critical gap between theory and practice when integrating SDM into paediatric care. However, the model was developed based on findings from a biased

sample of studies included in a literature review and the authors recommended collecting primary data to further develop and revise the model.

Shared Decision-Making in Youth Mental Health Care

Another model by Langer and Jensen-Doss (2018), built on previous models and developed an SDM model specific to CYPMH care. The authors expressed that conducting SDM in youth psychotherapy may take many forms, but suggested at its core, an SDM process must, at a minimum: (1) include the youth, the caregiver, or both in a decision making process with the clinician, with the possibility of including other stakeholders as well; (2) facilitate sharing information bi-directionally, with the clinician sharing information about psychopathology and treatment options, and receiving information about the youth's symptoms, and the youth and caregivers' preferences, values, and goals; and (3) determine the course of action collaboratively, through a process of discussion, compromise, and agreement (Charles et al., 1997). Based on these core principles and the essential and ideal elements of SDM (Makoul & Clayman, 2006), Langer and Jensen-Doss (2018) developed the following sample SDM protocol.

1. Discuss preferred roles in treatment planning.
2. Specify decisions to be made.
3. Present the available options for each decision.
4. Determine pros and cons of each option.
5. Design preliminary treatment plan
6. Implement progress monitoring.

Unlike Park and Cho (2018), the model suggests that either the child or parent or both should be involved in the decision-making process to achieve SDM. The model therefore claims to adapt to the complexities of the triad

relationship in treatment planning in CYPMH settings with CYP being involved as much as they are willing and able. However, the authors admitted based on their limited review of the literature, involving CYP in the SDM may not be a straightforward process. Additionally, the authors agreed more research is needed to capture the views of HCP in CAMHS to explore the generalizability of the model. To address the inconsistencies in the two models and help fully understand the SDM process in CYPMH clinical practice further primary research is needed (discussed in Chapter 6, Study 4).

Shared decision-making: The right process, with the right partners, at the right time and place

This model proposes a broader understanding of SDM where SDM acts as an integrative process and spans across all encounters with different clinicians (Dobler et al., 2017). The model also highlights a need to ensure that patients and clinicians take part in the SDM process with the right information, using the right tools, in the right manner, in the right setting, and at the right time. The authors recommend that focus be shifted to the quality of the SDM process as opposed to the development and usage of SDM interventions. The shift advocates for SDM to be safe, effective, patient-centred, timely, efficient, and equitable as outlined by the Institute of Medicine (Institute of Medicine, 2001). The focus on quality is especially important to paediatric care as research commonly report several barriers and facilitators to SDM (Boland et al., 2019; Gondek et al., 2016). However, this theory was developed with a focus on physical health and transferability to CYPMH is yet to be established.

The patient-centred care approach

Another model explored SDM in the emergency room involving children accessing healthcare. The model stated that the important component of patient-centred care was the inclusion of the patient and their family in the treatment decisions (Dudley et al., 2015) The authors stressed that SDM goes beyond the concept of informed consent, and requires that, in addition to informing patients about treatment strategies and outcomes, respect for patient's competence and self-determination in terms of participation and ownership of such decisions is included. The authors also highlighted that families could be involved in various decisions, such as medication administration, waiting time and screening. Theorists concluded that this approach fosters a mutually beneficial patient-provider relationship in delivering optimal care. The model acknowledges that several decision-making opportunities, apart from treatment options, arise, which existing models do not sufficiently take into account.

How is shared decision-making measured?

As highlighted above, research in the area of SDM has tapped into two major constructs (i.e. process and outcome) of SDM (Bomhof-Roordink et al., 2019). The SDM models generally highlight steps to be taken in order for SDM to occur (Langer & Jensen-Doss, 2018; Makoul & Clayman, 2006). Therefore, it has become increasingly important to measure SDM to ensure the proposed outcomes, such as, the extent to which patients feel ready and able to take part in decisions regarding their health care, as well as measuring the quality of the decisions made are met. Research in the area of SDM is growing and the quality of measurements are pertinent to capture the studies' intended findings.

Recent reviews have explored the existing SDM measurements and together have identified almost 40 evaluated instruments (Scholl et al., 2011; Simon et al., 2007). However, similar to the available SDM models, the identified measurements were either generic or non-child MH specific.

Measurements generally focus on 4 main areas: (1) if the patient was able to express a desire to be part of the decision-making, (2) if the patient felt SDM had occurred, (3) if the patient recalled that risks and benefits of options were presented, and (4) if a series of steps were followed from readiness to decision (Scholl et al., 2011). The following describes common SDM outcome measures:

The Control Preferences Scale

The Control Preferences Scale was originally developed to measure the degree of control an individual want to assume when decisions are being made about medical treatment (Degner & Sloan, 1992). The Control Preference Scale consists of five different scenarios describing different levels of control preferences in decision-making. The scenarios range from "I prefer to make the final decision about which treatment I will receive" to "I prefer to leave all the decisions about my treatment to the clinician". The original scale has been tested in a variety of populations, ranging from the general public to highly stressed groups. This measure has proven to be a clinically relevant, easily administered, valid, and reliable measure of preferred roles in healthcare decision-making (Degner & Sloan, 1992). Although this measure has been adapted and used in various health settings, it focuses on service users' involvement preference in hypothetical scenarios and not what happens in

practice. For example, CYP and parents may prefer to share treatment decisions with the HCP but encounter several factors hindering effective involvement. Therefore, this measure can be criticised for its capability to differentiate between service users' perception and ideal decision-making experiences.

9-item Shared Decision-Making Questionnaire (SDM-Q-9)

The SDM-Q-9 measure was developed for use in research and clinical practice. The tool is commonly used for the purposes of evaluation and quality improvement in health care. The measure has shown face validity, high acceptance and internal consistency with a Cronbach's alpha of 0.94. The nine statements on the measure are rated on a six-point scale from "completely disagree" (0) to "completely agree" (5) to evaluate the service user's perception of the SDM encounter using statements such as "My practitioner made it clear that a treatment decision needed to be made" (Kriston et al., 2010). Although this measure is one of the most frequently used and translated measure (Kriston et al., 2010; Scholl et al., 2011; 2012), the subjectivity of the self-report items questions its ability to accurately reflect service users' experiences, expectations, and behaviour, having limitations such as response bias (e.g. social desirability and inaccurate memory) and service users difficulty in fully comprehending the SDM process (Shay & Lafata, 2015).

Decisional Conflict Scale

The 16-item Decisional Conflict Scale was originally developed to elicit information concerning the decision maker's: (1) uncertainty in making a choice (2) modifiable factors contributing to the uncertainty, such as lack of

information, unclear values, and inadequate social support, and (3) perceived effective decision making (O'Connor, 1995). This 16-item scale quantifies factors which contribute to uncertainty both during the process and at the outcome. The measure includes items such as "I know which options are available to me" and "I know the benefits of each option". Each item is rated on a 5-point scale from strongly agree (0) to strongly disagree (4). Total scores ranged from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Previous studies have shown that the psychometric properties of the scale are acceptable, and this measure is feasible and easy to administer (O'Connor, 1995). This measure has been increasingly used as an outcome measure in intervention studies and favoured for capturing the SDM process and outcome (Garvelink et al., 2019). However, in the review by Garvelink et al., (2019) of 394 articles using this measure, it was reported that the measure was most commonly used in physical health care and with adult patients making decisions for themselves.

OPTION

Building on previous measures, the OPTION observer tool requires an observer to report when essential requirements of SDM are present in the clinical encounter. A score of '0' is allocated to the situation where the competency described was not observed, other scores (1 to 4) are allocated to increasing levels of achievement for the described competence. Competencies include statements such as "The clinician draws attention to an identified problem as one that requires a decision-making process" and "The clinician lists 'options', which can include the choice of 'no action'". Cronbach's α based on all 12 items have been 0.68 and the interrater correlation coefficient (ICC)

for the total OPTION score was 0.77 (Elwyn et al., 2003; 2005).These researchers emphasize the objective nature of the OPTION scale which is preferable to research. However, they also admitted that it is unclear how the 'patient mix' influences the scores and therefore it is difficult to compare scores across professionals. In specialist CAMHS where service users interact with multiple HCPs this may be an important factor to consider when measuring SDM.

Although several SDM instruments assess patient, HCP and observer perspective of SDM, researchers are yet to agree that existing measures accurately capture the SDM process. Researchers argue that "the lack of a core definition of SDM complicates efforts to identify the relationships between SDM and outcome measures" and that "variable instantiations of SDM definitions make comparisons across studies difficult, if not impossible" (Makoul & Clayman, 2006, p.301). Additionally, involvement in SDM may vary depending on the decision-makers and the decision being made, as the process can be influenced by factors such as prior experience, existing knowledge and individual states and traits (Elwyn et al., 2001). Nonetheless, it is important to continue to measure SDM if we are to gauge how its implementation differ among various groups and contribute to health outcomes.

What is already known about shared decision-making?

Shared decision making and demographics

Studies suggest that many parents generally report experiencing SDM in CYPMH care and treatment (Butler et al., 2014; 2015) and similar findings have been reported in the broader health literature (Fiks et al., 2012; Lipstein et al.,

2016; Valenzuela et al., 2014). A study across Europe including over 8000 participants found that over half (51%) of the sample reported experiencing aspects of SDM, for example, feeling listened to, given an opportunity to ask questions and being provided with clear explanations for their questions. Additionally, the highest percentage (71%) of UK respondents reported being satisfied with their level of involvement and being involved as much as they wanted to (Coulter & Jenkinson, 2005).

However, the SDM literature has highlighted that education, age, gender and ethnicity may be associated with involvement in SDM. Studies in general healthcare report that younger patients and those with higher educational levels preferred involvement in SDM (Clark et al., 2009). Further, a population-based survey in Canada reported that older persons experienced lower levels of SDM (Haesebaert et al., 2019) and a US-based national survey found that women desired to be more involved than men, while older adults desired involvement more than younger adults (James et al., 2019). Researchers have also observed lower involvement in SDM opportunities from ethnic minority groups (Ratanawongsa et al., 2010). However, studies have also shown no significant relationship between age, gender, ethnicity and level of health literacy with SDM (James et al., 2019). In that study, health literacy referred to personal characteristics and social resources needed for people to access, understand and use the information to make decisions about their health (Sørensen et al., 2012). In general pediatric care, parents' participation in decision-making also vary. For example, Hispanic parents report lower participation in child health decisions that non-Hispanic white parents (Xu, Borders & Ahmed, 2004).

Researchers in CYPMH mirror these mixed findings (Butler et al., 2014, 2015) suggesting there is no clear explanation for these observations. A common theme, however, has been that more SDM was observed during encounters involving families with Caucasian children vs. non-Caucasian children (Brinkman, Hartl Majcher, et al., 2013). Some qualitative studies, identified in Chapter 3, suggested that parents belonging to ethnic minority groups are more reluctant to participate in CYPMH activities (Bradby et al., 2007) and that culture can affect engagement with service providers (Dosreis et al., 2007; Mychailyszyn et al., 2008).

In more recent times children are encouraged to be active participants in the care and treatment decisions (Chapman et al., 2017; Edbrooke-Childs et al., 2019) and healthcare is moving away from traditional views where the child's contribution during medical visits had been limited, and the communication was dominated by the practitioner and parent (Sandman & Munthe, 2010). This is especially important for the nature of the triad relationship existing in CAMHS. However, determining capacity of service users to be involved in SDM remain controversial (Hamann et al, 2006). Therefore, the age and capacity of the child and the carer's relationship to the child may also be crucial to the SDM experience. Knowledge of this and other factors influencing SDM could inform and advance *successful* implementation of SDM in CAMHS. Similarly, an exploration of associations with additional problems, such as the presence of learning difficulties in the child, or parents' own health issues, maybe beneficial to provide further insight (discussed in Chapter 5). Findings within this thesis are discussed in light of the existing body of knowledge to help broaden our understanding of these important associations.

Shared decision making and outcomes

Researchers agree there are many benefits of implementing SDM in CAMHS (Brinkman et al., 2013; Edbrooke-Childs, Jacob, Argent, et al., 2015; Langer & Jensen-Doss, 2018). For example, Edbrooke-Childs and colleagues (2015) found that higher levels of improvement in the child's psychosocial difficulties were associated with higher levels of experiencing SDM as reported by the parents. Similar findings show that parents reported higher SDM when children were experiencing mild MH difficulties versus moderate to higher levels of difficulties (Butler et al., 2015). Another study conducted on a large US sample (n=2545), indicated that increased SDM was associated with decreased behavioural impairment scores in children (Fiks et al., 2012). However, an in-depth understanding of parents' involvement in SDM in CAMHS is still limited, with one study highlighting that parents of children experiencing serious MH problems experienced lower levels of SDM in CYPMH settings (Brinkman et al., 2013). Another study echoed these finding reporting that parents experienced lower SDM when their children experienced impairment at school or in extracurricular activities (Butler et al., 2015).

Nonetheless, in CAMHS, SDM is associated with higher levels of improvement in treatment outcomes over time (Edbrooke-Childs, Jacob, Argent, et al., 2015) and potentially improves treatment adherence (Brinkman, Hartl Majcher, et al., 2013; Langer & Jensen-Doss, 2018). Studies suggest that this improvement can be a result of better-informed service user regarding the disorder and treatment options (Hamann et al., 2006; Patel & Bakken, 2010); a more satisfied service user with increased adherence to treatment (Loh et al., 2007) and less uncertainty about the decision made (Metz et al., 2015).

Although the literature around the impact of SDM on health outcome in paediatric health is increasing, fewer studies have examined the outcome of parental SDM in CAMHS (Butler et al., 2015; Edbrooke et al., 2015). However, it should be noted that the evidence from physical and mental child health settings suggests that the use of SDM approaches is associated with higher levels of child-parent agreement, child-reported satisfaction with the decision-making process, decision-making quality and lower decisional conflict (Feenstra et al., 2014; Stacey et al., 2017; Westermann et al., 2013).

Legal and ethical implications of shared decision-making in children and young people's healthcare

There is an increasing demand from policymakers and practitioners to include more SDM in healthcare (Chief Medical Officer, 2014; Wolpert et al., 2012). However, with the uniqueness of the SDM process in CAMHS, there is a need for shared ethics among service providers (Smith et al., 1999). For example, in CAMHS, HCPs may need to decide to whom the duty of care is owed. On a practical level, it is recommended that parent support and cooperation are required for most healthcare interventions to be effective (Haine-Schlagel & Walsh, 2015). However, in actuality, duty of care is owed to the CYP. Therefore, if service providers, depending on the age of the child, engage in a doctor-patient (i.e. child or young person) relationship, an already stressed parent will feel excluded from the system (Paul, 2004).

Additionally, British law states that decisions should be made in the child's best interest (Allan, 2004). However, best interest can be difficult to decide as there are sometimes disagreements between parent, child and

clinician. For example, studies have found low agreement between parents and young persons on reasons for attending services (Koller, 2017; Simmons et al., 2011, 2013). As a result, the implementation of SDM in CAMHS is also suggested as one approach to reduce treatment disagreements and successfully manage the decision-making process that involves balancing multiple perspectives (Wolpert et al., 2012).

Policy guidelines to inform parental SDM in CAMHS (also see Chapter 11) is therefore pertinent as service providers are faced with balancing rights: the rights of the child to be able to give their opinion when adults are making decisions that will affect them (Allan, 2004; "Gillick v West Norfolk and Wisbech Area Health Authority.," 1984) and the rights of parents to act as proxy decision-makers or legal representatives on behalf of their child (Freeman, 2007; Ross, 1998). The Department of Health also outlined that there should be "no decision about me without me" which support the inclusion of younger services users in the health decision making process (Department of Health, 2012). In addition, best practice guidelines state "the aim of decision-making in health-care is always to reach consensus" (British Medical Association, 2001, p. 124). Therefore, service providers and service users (i.e. parents and children), based on competence and capacity, should be given the time, support and advice to assist them with the decision-making process. Some researchers agree that although children are not of legal age to make medical decisions, parents may involve children in broader healthcare and wellbeing decisions using appropriate decision-making roles (Lipstein et al., 2012). As a result, further research into how much, when and if to involve children and or

parents in decision making and whether this further complicates the SDM process, therefore requiring additional support interventions, is needed.

Decision support tools

There is growing interest in SDM (Légaré et al., 2018), and therefore tools to promote and support its implementation is also increasing (discussed in Chapter 7). Researchers generally conclude that providing information alone is unlikely to fully address the decision support needs of parents (Jackson et al., 2008). A recent systematic review by Cheng and colleagues (2017) identified six approaches used in decision support interventions in CAMHS. These included therapeutic techniques, decision aids, psychoeducational information, goal setting, discussion prompts and mobilizing patients to engage. However, advocates for SDM recommends that these approaches need to be tailored to accommodate varying levels of involvement depending on the CYP's age and capacity (Boland et al., 2019; Feenstra et al., 2014). As a result, identifying appropriate decision support would be another important step to an effective decision-making process (Ottawa Health Research Institute, 2005).

Findings from qualitative studies indicated that the implementation of SDM in CAMHS is effortful (Abrines-Jaume et al., 2016; Gondek et al., 2017). Therefore, while tools may help support SDM, researchers and developers recommend that clinicians be allowed to use the tools flexibly (Abrines-Jaume et al., 2016). Additionally, the Ottawa Decision Aid criteria and International Patient Decision Aid Standards (IPDAS) have been developed to ensure standards for the development of these interventions are followed (Ottawa Health Research Institute, 2005). Although there is growing interest, and an

increase in the development of SDM interventions in CYPMH, few studies exist

on efficacy and effectiveness (Hollis et al., 2017). Reviews have mainly

explored SDM from a wider perspective: interventions targeting children and

clinicians, targeting physical health or person-centred care, and limited to

literature published in peer reviewed journals (Cheng et al., 2017; Feenstra et

al., 2014; Gondek et al., 2017; Wyatt et al., 2015). Further rsearch is needed to

highlight specific components, such as modes of delivery and techniques that

are used with various CYPMH populations to promote SDM behaviour. An

updated review, which focus specifically on parent-targeted or parent-involved

interventions may also highlight important themes to understand parents'

involvement in the decision-making process. This is important as parents report

having a better understanding of their child's difficulties (Brinkman, Hartl

Majcher, et al., 2013), and feeling better equipped to manage their child's MH

(Ahmed et al., 2014) when allowed to participate in SDM. In addition, a clinical

report concluded that better decision-support tools and technologies is needed

(Adams & Levy, 2017). More investigations into existing interventions may

therefore be needed to inform future development and help strengthen

understanding of barriers and facilitators to usage (Chapter 7, Study 5).

Influencing factors to effective decision-making

The ecological framework recognises the interactions between the

individual, family, and the environment within which the family functions (World

Health Organisation, 2013). CYPMH problems extend beyond the individual,

and families with CYP with MH problems experience greater challenges than

the *typical* families (Estes et al., 2009; Griffith et al., 2010). Researchers in the

area of health decision-making generally agree that the context in which

decisions are made interacts with the individual to influence their decisions (Weissman & Besser, 2004). The ecological framework proposes that to understand an individual's decision-making behaviour, it is important to explore their "ecological niche" (e.g. family, religion, school, community). Therefore, by highlighting the influencing factors in CYPMH decision-making, there is an opportunity to advance the SDM scholarship within the broader literature on engagement in CYPMH care and treatment.

With the growing interest in SDM, researchers have broadened their scope of inquiry into SDM across ecological levels. Scholars propose that the individual-level context consists of factors such as personality traits, beliefs, and attitudes. Beyond the individual level is the microsystem, or the immediate social environment in which an individual lives, including peers and families. The exosystem consists of the broader social context, such as one's neighbourhood, and institutions and systems, such as schools and service providers. Last, the macrosystem refers to broader shared societal norms, guidelines and policies (Bronfenbrenner, 1986; Garbarino & Abramowitz, 2017). When applying this framework to CYPMH decision-making, at the core of the ecological framework is the child's MH and well-being, followed by the impact and interactions with parents and family, community (e.g. school and service provider) and finally guidelines and policies (Stormshak & Dishion, 2002). As a result, throughout this thesis, the implications of the studies' findings are considered across practice and policy levels.

Generally, the evidence on barriers and facilitators to SDM are divided into categories of knowledge, attitudes, agreement, lack of expectancy/hope,

and behaviours among service users and service providers (Adams & Levy, 2017). Reviews commonly highlight specific barriers such as patient/family characteristic (e.g. demographics and child health status), service constraints (e.g. time taken for consultation and trust in service providers), power imbalance, lack of available evidence-based treatment options, and service providers limited knowledge of SDM skills (Boland et al., 2019; Gondek et al., 2017). In addition, some researchers suggest that emotions can impact parents' preference to be involved in SDM (Légaré et al., 2013a) and threaten parents' assumed role in the decision-making process (Jackson et al., 2008). This area is understudied, and with the ongoing debate, experts have labelled the notion that SDM does not account for emotions as a myth (Légaré & Thomson-Leduc, 2014). A recent study in adult physical care also dismissed this notion and reported that emotions can impact SDM and highlighted that emotions are experienced in various combinations before, during and after SDM (Treffers & Putora, 2020). Similarly, recent interviews with clinicians, parents and CYP in CAMHS corroborated those findings, concluding that strong emotional states affected the SDM process (Hayes et al., 2019; 20). Therefore, further research in this area is crucial to *successfully* implementing SDM.

Common facilitators to SDM in general healthcare include: service users' capacity to be involved (e.g. age and health status), positive provider attitude and behaviours, positive impact on the clinical process, quality information, patients' health outcomes and use of additional SDM resources, and encouragement of support systems (Covvey et al., 2019; Gravel, Legare & Graham, 2006; Bee, Price, Bake & Lovell, 2015). Additionally, broader

paediatric studies suggest family factors (e.g. cultural norms), impact on the family, community standards and policies, previous experience (e.g. help-seeking) as influencing factors to SDM (Boland et al., 2019; Wyatt & Brinkman, 2015). The limited literature specific to CYPMH reported similar facilitators (Gondek et al., 2017) with recent findings adding that clinicians' skill of containment may be unique to SDM in CAMHS (Hayes et al., 2019). Hayes and colleagues' also highlighted that parents generally expressed their capability to be involved in decision making but reported that when experiencing strong emotional states such as feelings of being sad or low mood, it inhibited their involvement in SDM (Hayes et al., 2020). Studies focussing on influencing factors to SDM have mainly focused on barriers and facilitator to the SDM process or person-centred care. With the development and advancements of tools to enhance the SDM process, explorations of influencing factors specific to implementations and usage of SDM interventions is still lacking. Further investigations can supplement the above-mentioned literature by identifying specific groups of parents that may benefit from additional support.These findings also suggest that there are many potential influencing factors, outside of the severity of the CYPMH, that may affect involvement in SDM, that is yet to be fully understood.

The decision to seek help

The literature suggests that positive previous experiences may influence SDM, and based on the needs of CYP, help-seeking can be considered an initial first step to accessing CAMHS. However, on a practical level parents *struggle* with waiting times, thresholds for interventions being set too high, and a feeling of exclusion from the process by the CAMHS (Hagell, 2016).

Researchers explored help-seeking for CYP in Northern Ireland and reported that parents had difficulties in accessing MH services, due to lengthy waiting lists, a lack of information offered and a lack of effort to engage them (Fargas-Malet & McSherry, 2017). Furthermore, negative attitudes and beliefs related to seeking professional help and not accepting a need to seek help have been identified as significant barriers to help-seeking (Gulliver et al., 2010).

For CYP with MH problems, early diagnoses and interventions can lead to better prognosis and outcome in adult life (Elder et al., 2017; Fernell et al., 2013). There is evidence to show that early interventions such as peer support (Hoagwood et al., 2010), school interventions (Neil & Christensen, 2009), community MH services (Care Quality Commission, 2017) and informal support (Martínez-Hernáez et al., 2014; Skylstad et al., 2019a) can help children with MH difficulties. Despite these potential benefits, families are faced with long waiting times to access CAMHS (Mughal & England, 2016), causing a delayed identification of presenting problems. Similarly, studies have reported low levels of help-seeking among this population (Mitchell et al., 2017; Shanley et al., 2008), highlighting that the parent's sense of self-efficacy and competence in caring for their CYP may impact their ability or preference to engage with CYPMH providers (King et al., 2014).

The literature generally refers to help-seeking as actively seeking help from other people, which includes, seeking advice, information, treatment or general support from informal social relationships, such as friends and family, or from professional sources of help, such as mental and general health professionals, teachers, youth workers, and clergy (Rickwood et al., 2005).

Patterns in CYP help-seeking generally suggest a preference for informal support and different sources of support (i.e. parents, friends or teachers) depending on the type of problem experienced (D'Avanzo et al., 2012). However, studies suggest it is more likely that activated parents will ask questions, provide feedback, and participate in therapeutic activities (Karver et al., 2006). Parent activation, represents a parent recognising the presence and severity of a MH condition in their child and setting out to receive support by engaging with the necessary services (Macdonald et al., 2007). Research into parent activation in CYPMH is growing. Previous studies have found parents' stress levels (Bonis, 2016; Lovejoy et al., 2000) and the perception of severity of the child psychopathology (Butler et al., 2015; Edbrooke-Childs, Jacob, Argent, et al., 2015) to be associated with lower levels of parent activation. Other studies have also reported positive associations between parents' help-seeking and both parental worry and perceptions of child behaviour problems (Ellingson et al., 2004; Godoy et al., 2014).

Several theories and help-seeking models have been proposed but none have been widely accepted (Gulliver et al., 2012).The theory of planned behaviour has been used to demonstrate the mediating effect of attitudes on psychological help-seeking intentions (Ajzen, 2011), while the health belief model, explores the individual's appraisal of the perceived threat of illness and its severity, and the perceived barriers and benefits of the behaviour itself (Rosenstock, 1977). Similarly, the Andersen's behavioural model describes a 3-stage model for health services use, describing the factors of predisposing characteristics such as, the individual's demographic information and beliefs, enabling resources such as cost and access to care, and illness

level which is interpreted as the individual's perceived and evaluated need for help (Andersen, 1995). However, these models enable us to understand adults' dynamics in their decisions to seek help for their own health from various healthcare professionals.

Specific to CYPMH, the Gateway Provider Model has been developed and focuses on the central influences (i.e. the individual who first identifies a problem and seeks CYPMH treatment (the "gateway provider"); and the need those individuals have for information on youth problems and relevant potential resources). This model aims to reduce the gap between need and service access for CYP with MH problems (Stiffman et al., 2004). Although the Gateway Provider Model acknowledges that children are generally dependent on their primary caregivers to recognise their problems and to seek help on their behalf (Sayal et al., 2018; Thurston et al., 2015), parents' perception of their child's MH differs from teachers, clinicians and the child (Cleridou et al., 2017; Fält et al., 2017; Hawley & Weisz, 2003; Kramer et al., 2004; van Roy et al., 2010). Therefore, parents' help-seeking behaviours may vary across families and across time (Tanskanen et al., 2011). For example, research in general healthcare indicated that single parents were more likely to take their child to the emergency room (Costet Wong et al., 2015) or mothers were more likely than fathers to seek treatment (Zimmerman & Zimmerman, 2005).

Furthermore, in both adult and child MH care, persons of ethnic minority backgrounds were less likely to voluntarily access care (Edbrooke-Childs & Patalay, 2019; Jones et al., 2018; Memon et al., 2016). Similarly, persons of lower socioeconomic status (O'Brien et al., 2016) and non-native speakers

(Reardon et al., 2017) were less likely to seek out MH services for their child. The Longo model, identified in the extant literature, confirms these findings highlighting that personal factors (e.g. age, income, education, culture and language) influence information seeking (Longo, 2005). However, the existing literature suggests that there are disparities in help-seeking behaviours across health settings and a possible broad and diverse range of factors that may affect help-seeking. Further investigations are needed to examine parents' decision to seek CYPMH support and explore possible disparities in the CYPMH population (Chapter 4, Study 2).

Clinical decision-making models

Evidence-based practice has typically relied on the use of rationality in health care and treatment decisions. Models such as the Expected utility theory (Hellinger, 1989) and Evidence-based medicine approach to rational decision-making (Djulbegovic et al., 2009; Djulbegovic & Guyatt, 2017) are used in clinical care to explain decisions around healthcare and treatment. Rational models of health care decision-making generally include five core principles: (1) integration of benefits and harms; (2) reliance on evidence and cognitive processing to deal with uncertainties; (3) rational thinking; (4) context; and (5) ethical and moral implications (The National Academics of Sciences, Medicine, Services, Care & The National Academies of Sciences Engineering, 2015). Researchers have since criticised this rational approach to health decisions suggesting that the process is complicated, and individuals may not always make decisions in an entirely rational process (Lerner et al., 2015; Lerner & Keltner, 2000; Mellers et al., 1997). Therefore, these rational models fail to take into consideration the affective states of decision-makers.

Another perspective is the value-based model which promotes the integration of interventions that cares for the whole person (Djulbegovic et al., 2018). However, the value-based model is linked to evidence-based medicine in that it uses the best results of evidence-based medicine with a focus on health-related quality of life and patient well-being in health decision-making. This perspective recommended further investigations into the psychological aspects (i.e. psycho-cognitive variables) that come into play when each individual makes a personal choice concerning health, treatment, and care pathways. Therefore, researchers have recently begun further exploring more affective models of health decision making (Lerner et al., 2015). The next section discusses one such model.

Appraisal tendency framework

Feelings and consumer decision making are rooted in marketing research (Agrawal et al., 2007), and has expanded into various health settings (Lerner & Keltner, 2000). The appraisal tendency framework (ATF) is considered a general theory of emotion-specific influence on judgement and choices and has been applied to health decision-making (Lerner et al., 2015). This theory built on previous research that explored how global affective states such as positive and negative moods influenced health decisions. Lerner and colleagues (2015) focused on how specific emotions such as fear, guilt, pride and gratitude improved or degraded health-related decisions and interventions. Therefore, the appraisal tendency framework acknowledges individual differences in the tendency to respond to situations and the health context. In sum, the appraisal tendency framework predicts that each emotion has motivational properties that influence subsequent judgments and decisions.

The carryover effect is termed appraisal tendencies – "where the appraisal dimension and appraisal theme are together activated by the properties of a situation to shape behavioural action tendencies that predispose certain judgments, decisions, and actions" (Lerner et al., 2015, p. 805). These researchers divided the appraisal-tendency influences on judgment and decision making into two categories: content effects and depth-of-processing effects. Content effect considers the influence of emotions such as sadness and anger on judgments of blame and how these emotions influence the decision-makers' potential to process information. The deeper the decision maker's ability to process information, the easier it is to recall accurate information (Carik & Lockhart, 1972). The framework is yet to be applied to CYPMH, and therefore more research is needed to explore its applicability. See Figure 2.1 illustrating the appraisal tendency framework.

Figure 2.1 An illustration of the Appraisal Tendency Framework
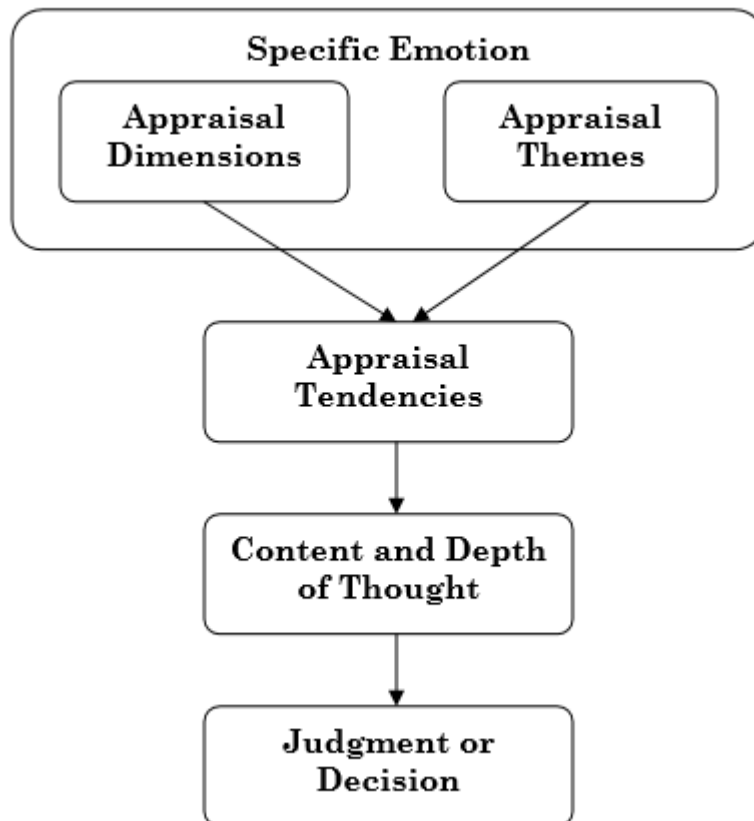
Note. Reprinted from (Lerner et al., 2015)

Critical review of the literature: Implications for this thesis

The research outlined in this chapter, identified a shift from paternalism to SDM and increasing efforts to include SDM across healthcare settings. However, these SDM efforts are implemented differently across physical health settings and with various populations. The majority of the literature proposed definitions, models and theories in relation to adults, dyad relationships (i.e. clinician and patient) or physical healthcare settings. Therefore, specific attention is warranted when investigating CYP, triad relationships (i.e. clinician, parents and child) or mental health settings. Nevertheless, the principles of

SDM have been well document in the extant literature highlighting common elements such as discussing pros and cons of treatment options and exploring value-based preferences (Makoul & Clayman, 2006). Despite the models proposed, clear guidance on how to accomplish SDM in CYPMH settings is still needed. Langer and Jensen-Doss (2018) proposed an SDM protocol to accomplish SDM in CAMHS. The protocol is accurate as it encompasses legal and ethical concerns to include voices of the young person and parents in the SDM process. However, the protocol has been criticised for describing an ideal straightforward process. Additionally, it is also still unclear whether all service users want to participate in SDM (Legare, 2014; Gabe et al., 2004). Recently, researchers in broader paediatric healthcare also proposed a practical 4-step framework positioning SDM on a continuum with potential for a provider or parent-guided SDM process (Opel, 2018). Although, this framework is yet to be tested in CYPMH, a major drawback is the failure to also include a child-guided SDM process. Additionally, this raises further questions of the *shared* nature of decision-making in CYP health care. More research utilising primary data from key decision makers in CYPMH is needed to further develop these models (discussed in Chapter 6).

Although there has been increased policy calls and guidelines for promoting SDM in healthcare, in addition to several positive outcomes, experts have identified several barriers to the SDM process. Apart from practical barriers, such as lack of available resources, fewer studies identified and addressed emotions as a major influencing factor to the SDM process. As discussed previously, and explored in more detail in Chapter 3, parents of CYP with MH problems reports enhanced affective states. Suggestions for

addressing this emotional influence on SDM are to allow more time for deliberation or utilise a provider-guided approach (Weiss, Clark, Rosenberg et al., 2019). Although further investigations may help support these recommendations, the researchers agree time may be inadequate as emotional states may not diminish. Additionally, a service provider-guided process may only result in low parental involvement. Therefore, a deeper understanding of the role affect plays in SDM is needed to help effectively support this population and provide clinical guidance on how to include emotionally enhanced parents in SDM.

It is also imperative that research and intervention evaluations are accurately capturing and measuring SDM (further explored in Chapter 7). Several measurement tools described above, has been proposed in attempt to measure SDM. However, measurements have been criticised for lack of evidence (e.g. inconsistent findings) (Gartner et al., 2018). This may not imply a lack of quality measurement but instead lack of validation studies. Nonetheless, there are currently several tools to assess patient, provider and observer views on SDM from which to choose. However, the current investigations may have implications for how researchers measure the effect of decision support tools and may require adjustments to existing measures or development of new measurement tool (discussed in Chapter 9).

Proposed SDM model underpinning this thesis

SDM experts agree that the SDM process may differ by healthcare setting, and therefore suggest it may be helpful to develop unique models or

extend existing models (Bomhof-Roordink et al., 2019). A synthesis of qualitative studies (discussed in Chapter 3) revealed that although *parents are expected to, they are not always able to* be involved in CYPMH care and treatment decisions due to their affective states. In light of this, and the above gaps in existing knowledge, a conceptual framework illustrating an affective appraisal approach model to SDM in CYPMH was proposed. The affective appraisal approach identified the inclusion of key decision-makers (i.e. child or young person, parents and service providers) and explored the influence of parental affective states on the SDM process. Similar to previous models, the CYP's age and capacity predicts involvement in the SDM process. Interviews and FGDs with parents and HCPs identified decision-makers' attitudes, beliefs and experiences, parents' emotional states and support systems, offering informational and emotional support, as key influencing factors to SDM. The affect refers to the positive emotions such as happiness and relief promoting involvement in SDM, and negative emotional experiences such as anxiety and fear hindering parental involvement in SDM. Appraisal refers to the ongoing appraisal process of value-based judgements, influenced by attitudes, beliefs and experiences, linking emotion and cognition. Taken together, the affective appraisal approach to SDM recognises that affect and appraisal interact in shaping the decision-making process, influencing each other in a circular way where the decision elicits the emotional reaction, that in turn influences the appraisal of the decision, that again may influence a change in the emotional reaction. It is assumed that adequately supporting decision-makers can activate parents to engage in high quality SDM (further discussed in Chapter 6).

Brief summary

This chapter reported the high prevalence of CYPMH problems and the many decision-making opportunities family's experience. In addition, decision-making roles were explored with an emphasis on SDM. The literature highlighted the growing interest in SDM as a person-centred approach to care and treatment decision-making in healthcare. However, when applied to CYPMH settings, several gaps in knowledge were identified. One such factor was the failure of existing SDM models to explicitly capture the emotional experiences of parents, resulting in the possibility for existing interventions to insufficiently address parental decisional burden for emotionally charged decisions. By linking these areas of research (i.e. parental affect) and SDM in the CYPMH context, this research contributes to addressing a critical gap in the literature opening new challenges and opportunities for academic enquiry. Therefore, this thesis aimed to add to the existing body of knowledge on SDM, utilising primary and secondary data, to inform the development and pilot feasibility testing of a novel SDM intervention suitable for the CYPMH context. In so doing, several questions surfaced that deserved further scrutiny.

Research questions

1. How do emotions (e.g. anxiety) affect parents' experience and involvement in CYPMH decisions? (Study 1)

2. What are the associations between CYP psychosocial difficulties, parental worry and parental help-seeking behaviours? (Study 2)

3. Do parents in the UK experience SDM at CAMHS, and are there associations with clinical characteristics? (Study 3)

4.   How do parents and healthcare professionals view SDM, and how do they describe the impact of parental emotions on the SDM process in clinical practice? (Study 4)

5.   What are the existing decision support tools for parents and carers of CYP with MH problems? (Study 5)

6.   Is a novel intervention (Power Up for Parents) accepted by parents and healthcare professionals, and is it feasible to upgrade to a full RCT to test its effectiveness? (Study 6)

The next chapter addresses the first research question, exploring parents' emotional experiences when involved in CYPMH decisions, as the first step in further understanding the target population of this research project.

Chapter 3 The Emotional Experiences of Parents making Child Mental Health Decisions: A Synthesis of Qualitative Evidence (Study 1)

The previous chapter introduced concepts of help-seeking and shared decision making in CYPMH, highlighting important influencing factors. This chapter presents a meta-synthesis of existing evidence to specifically investigate emotions as an intrapersonal level influencing factor to parental involvement in CYPMH decisions. The review adopts a social constructivist approach that discusses an emerging concept to possibly explain barriers and facilitators to parents' engagement with CAMHS. The review also synthesises the qualitative evidence of parents' experiences across different CYP age groups, disorders and countries, and presents a synthesis of parents' lived experience within the context of CYPMH decision-making.

Background & gaps in the extant literature

Emotion is generally referred to in the literature as an affective reaction to a specific person or situation (Mulligan & Scherer, 2012). Studies highlight some common emotional states, such as anxiety, distress, sadness and worry, among families involving a child or young person with MH problems (Charach et al., 2014; Ibrahim et al., 2016; Mychailyszyn et al., 2008). Research generally suggests that emotions can affect the health decision-making process. Parents in CYPMH settings also report lower involvement in care and treatment decisions compared to families of children with a physical health condition (Butler et al., 2014).

However, the evidence on the influence of parental emotion on SDM is still inconclusive (Chen et al., 2015; Weiss et al., 2019). Dicé, Dolce, and Freda (2016) examined conversational patterns of SDM amongst parents and paediatricians in primary care and found that the conversations focused on the procedures of care, with little opportunities of dialogue about the parent's emerging emotions. Despite this, little progress has has been made in the area of CAMHS.

Previous studies on parents' emotional experiences in a CYPMH context have reported mixed findings. On the one hand, one study found that more than 50% of parents of children with ADHD reported mild, moderate or severe anxiety which directly or indirectly influenced decision conflict, uncertainty and effective decision making (Bogliacino & Forero, 2015). Similarly, another study found that parents experiencing intense emotional states were more likely to recall the social stigma associated with having a child with ASD, which decreased their willingness to seek treatment (Bussing et al., 2011). On the other hand, parents experiencing intense emotional states were more activated to seek out and access MH services for their children (Gopalan et al., 2010) but were also more likely to drop out (Brown et al., 2012). The majority of parents also indicated the need for help to manage their fears, anxieties and uncertainties (Duppong Hurley et al., 2017), and therefore reported greater participation in support interventions (Bonis, 2016; Boshoff et al., 2016; Hayes & Watson, 2013).

Owing to the importance and relevance of this topic, previous systematic reviews have organised the existing literature to describe popular themes of

emotions. Parents are described as experiencing "an emotional roller coaster between hope and hopelessness" (Laugesen et al., 2016, p. 155), or "emotional stress and strain" (Corcoran et al., 2015, p. 358), among similar themes (Lipstein et al., 2012). However, previous reviews conducted in this area were disorder-specific (Corcoran et al., 2015; Laugesen & Groenkjaer, 2015; Laugesen et al., 2016), country-specific (Perkins et al., 2018), limited by age (e.g. <18) or employed quantitative methodologies (Hayes & Watson, 2013). Therefore, it was necessary to conduct a qualitative synthesis of studies exploring the experiences of parents of CYP (up to the age of 24) with any MH disorder or symptoms, across countries and cultures.

Based on the existing literature that focused on specific subpopulations, it is clear there is still much to discover about positive and negative emotional experiences of parenting CYP with MH problems. Additionally, the inconsistent findings on how these emotions influence parental decision-making leaves another under-researched factor. With the growing interest in how emotional states may influence judgement and decision making in the general healthcare literature, the CYPMH literature could benefit from an in-dept review of pooled evidence that can help further our understanding. This understanding can help address gaps in current service provision to support parents as agents of change (Kandel & Merrick, 2007) and facilitate the empowerment process (Gibson, 1995; Kandel & Merrick, 2007)

Aims and research questions

There were two overarching aims to this review. First, to describe parents' emotional experiences of having a child with MH problems. Second, to

understand how these emotions influence CYPMH decisions. An understanding of these concepts can provide useful evidence that can inform the emotions and health decision-making literature, in addition to providing evidence that has implications for CYPMH policy and practice. The following research questions were proposed:

1. What are the emotional experiences of having a child with MH problems?

2. How do parents' emotional experiences influence CYPMH care and treatment decisions?

Methods

Theoretical approach

Social constructivism focuses on the perception of what occurs in society and the knowledge built on the understanding that evolves from a process of mutual agreement linked to traditions, language, and culture of a community (Cottone, 2007, pp. 189–203). This approach is useful to help understand how emotional experiences become a social construct for parents during their working relationship with health care providers and other services.

Qualitative synthesis

Cochrane guidance on qualitative evidence synthesis suggests that qualitative evidence can increase the understanding of a phenomenon (Flemming et al., 2018). Therefore, a meta-synthesis was needed as it addressed the current research aims by synthesising qualitative research evidence through translation and interpretation of concepts from multiple studies to provide a more holistic interpretation of the evidence (Britten et al.,

2002; Erwin et al., 2011). This study adopts a social constructivist grounded theory approach which acknowledges the researchers as part of the research (Given, 2008), and therefore explored the parents' direct quotes (first-order) and the original authors' interpretations (second-order). The initial scoping of the literature highlighted a large number of studies in this area. Therefore, insights for synthesising large numbers (K>40) of qualitative studies was adopted to guide this review (Toye et al., 2014).

Literature search and search strategy

A literature search was carried out using the following online databases: CINAHL Plus, Cochrane Library, EMBASE, MEDLINE (Ovid version), PsycINFO and Web of Science. All searches were initially carried out in July of 2018, and updated in July 2019, and conducted within the same week to control for daily updates. Three key concepts informed the search strategy: "parents", "decision-making" and "child and adolescent mental health". Terms within similar categories were combined with "OR" and then the results from each category were combined with "AND" (see Appendix A). The search strategy was guided by recent reviews in CYPMH (Cheng, Hayes, Edbrooke-Childs, et al., 2017; Gondek et al., 2017), recommendations for qualitative literature searching (Shaw et al., 2004) and input from the University College London (UCL), Institute of Child Health librarian. Electronic searching of two key journals, Journal of Qualitative Health Research and Journal of Health Expectations, were also carried out. Reference lists of relevant articles identified through the database searches were scanned for additional studies.

Inclusion and exclusion criteria

Studies were included if they met the following criteria: 1) Used qualitative methods, for example, focus group discussions or interviews, 2) discussed parents' emotional experience of having a child with MH problems, and 3) examined any involvement in care and treatment, for example help-seeking or shared decision-making. Mixed method studies were included if there was sufficient detail to extract themes and participants' quotes. Studies were excluded if there was insufficient detail of the child's condition or diagnosis, or if parents' feelings were towards reproductive decisions, for example having a second child after the first child developed ADHD. Studies were also excluded if the data collected did not provide sufficient qualitative evidence of the parents' experience, for example verbatim quotes from the participants. Additionally, studies not published in peer-reviewed journals and not published in English were excluded from this review (see Table 3.1).

Table 3.1 SPIDER search strategy

	Inclusion	Exclusion
Sample	Parents or primary carers with responsibility for a child (up to age 24) or accessing CAMHS diagnosed with a MH problem or displaying symptoms relating to a specific MH disorder (e.g. parents of	Parents of children with a non-specified diagnosis (e.g. parents worrying about their child's MH without any detailed description of symptoms relating to a specific MH problem). Parents making perinatal/palliative care decisions. Studies where the children's age

	Inclusion	Exclusion
	children who experienced symptoms of ADHD).	were not easily identified, or mean age go beyond 25 years.
Phenomenon of Interest	Parents' experience, views, attitudes or feelings about having a child with MH problems **AND** on being involved in care and treatment including research (e.g. involvement in treatment decision for ADHD). Involvement/engagement should involve the reflection of the process (e.g. decisional conflict) and/or reflections on the outcome (e.g. decisional regret).	Reproductive decisions after having a child with a genetic disorder (e.g. Down's Syndrome). Studies referring solely to parental involvement in child's education or school activities. Studies discussing experiences of routine screening without any specific symptom, e.g., parents' experience of routine screening for socio-emotional development in children. Studies where parents did not mention their emotional experience or described only practical or day to day experience of the lived experience of having a child with MH problems.

	Inclusion	Exclusion
Design	Any qualitative research design (e.g. interviews, surveys, observations, case studies, diaries, commentaries etc.). Articles required to report verbatim text from parents to support the themes.	Survey studies reporting only statistical figures without sufficient (qualitative) detail of the parents' experience. Mixed samples or qualitative studies in which findings about the target population could not be separated from those about other populations (e.g., parents of children with asthma, parents of children with ADHD) Mixed methods studies in which qualitative findings could not be separated from quantitative findings.
Evaluation	Perspectives, perceptions, experiences, views, attitudes, concerns, feelings, and opinions of parents involved in child MH care and treatment. (e.g., parents	Studies describing experiences of parents of a child with physical health problems or parents' own MH problems not arising from the child's condition.

	Inclusion	Exclusion
	deciding on treatment medication; out of home care for child with ASD; disclosure of child's mental disorder)	
Research Type	Qualitative or mixed method studies including commentaries and case studies.	Quantitative studies, reviews, discussion articles. Studies published in non-English language.
	Only articles found in peer-reviewed journals and published in the English language.	Qualitative studies in which no human subjects participated (e.g., discourse or content analyses of media representations of parents' experience)
		Alternative-style qualitative research presentations containing no extractable findings (e.g. poems, plays, auto-ethnographies); journalistic or other non-research accounts.

Study selection process

A study protocol describing the planned methods for the review was developed at the start of the study to avoid any possible bias during the systematic review process. In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines, the PRISMA flowchart (Moher et al., 2009) provides step by step details of the study selection process (see Figure 3.1). The PhD candidate and a second reviewer (JP) independently screened all the articles. At each stage of the screening process, 10% of the records were screened together (SL and JP) to establish inter-rater reliability, and the remaining articles were screened independently. First titles were screened followed by abstracts and then full texts. Both reviewers indicated "include", "exclude" or "not sure" based on the eligibility criteria. If both reviewers agreed, the article was included or excluded, and any disagreements were resolved through discussions. Seventy-six percent (51) of the included articles were initially agreed and the remaining 24% (16) included after a consensus was reached.

Figure 3.1 PRISMA flow diagram of study selection (adapted from Moher et al., 2009)
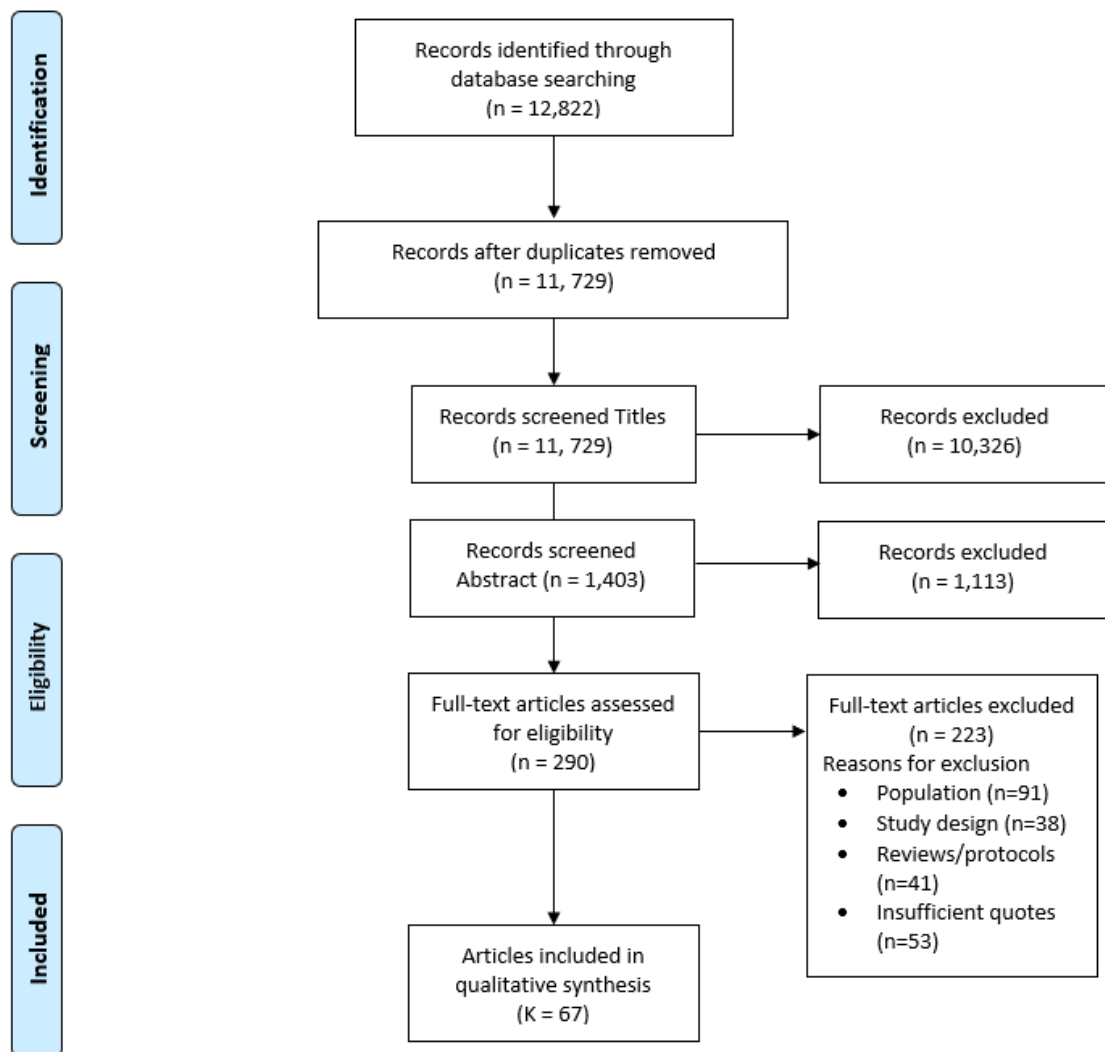
Quality Assessment

The eligible studies were quality assessed using the Critical Appraisal Skills Programme (CASP) tool for qualitative research (Critical Appraisal Skills Programme, 2018), and the scoring system proposed by previous reviews (Duggleby et al., 2010) was utilized for this study. The items were scored '1' where the response was 'NO'; '2' where the response was 'CAN'T TELL' and '3' where the response was 'YES'. This resulted in a minimum of 10 and a

maximum of 30 for each article. The PhD candidate (SL) assessed the quality of each study and another reviewer (BP) independently conducted appraisals on a randomly selected 20% of the articles. The two reviewers discussed any discrepancies in ratings, and, if necessary, consulted a supervisor (JEC) to reach a final decision.

Data Extraction

The standardized data extraction tool from Joanna Briggs Institute-Qualitative Assessment and Review Instrument (JBI-QARI) (Munn et al., 2014) was used to inform the development of a database to extract demographic and methodological information for each study. The table was piloted with the first ten studies and through an iterative process the finalized version was developed and approved by JEC and MW. The following information was extracted for each included study: 1) reference; 2) title; 3) country; 4) MH condition; 5) phenomenon of interest (e.g. seeking diagnosis or treatment); 6) methodology; 7) data collection and analysis method; 8) sample size and characteristics (age and culture) of participants and the children; 9) study's aim and findings and 10) emotional expressions. The PhD candidate extracted data from all the articles, and BP independently extracted data from a random 20% of the articles. The two reviewers discussed any discrepancies, and, if necessary, consulted JEC to reach a final decision.

NVivo v.12 software was used to code and extract first-order (participant quotes) and second-order (original researcher's interpretation) data (Noblit & Hare, 1988; Noyes & Lewin, 2011). Firstly, each article was read line-by-line (free-coding) to extract key words and phrases relevant to the research

question (i.e. emotional expressions), for example, "I get really anxious and angry sometimes". Another reviewer, experienced in qualitative research (ME), extracted and coded 20% of the articles at this stage to establish reliability. Any disagreements were resolved through discussions, and if unable to reach a consensus a third reviewer (JEC, BP, JP) was consulted.

Data aggregation & synthesis

At the second level of the data coding process, 2 reviewers (ME and SL) independently categorised and grouped individual codes and phrases to form concepts and differentiate subcategories (axial coding). For example, codes such as "I get really anxious and angry sometimes" and "I am actually afraid of her" were grouped together to form a subcategory/subtheme called *Anxious and Frustrated*. Both reviewers met to discuss any disagreements and to achieve consensus.

At the final stage, the PhD candidate identified relationships among the concepts (theoretical coding) by looking across the different papers for common and recurring concepts and translating the studies into one another before synthesising translations (Britten et al., 2002; Thomas & Harden, 2008). For example, affective states were explored in relation to the context of child mental health decision making to form a line of argument that explored parents' involvement in care and treatment decisions and engagement with services (see Table 3.2 in the Results section).

Results

Characteristics of included studies

A total of 67 articles from 66 unique studies published between 2003 and 2018, with a total of 2924 participants met the inclusion criteria (see Table 3.3). Studies were conducted in the following four regions (countries): North America (USA (k=23) and Canada (k=9)); Europe (UK (k=13), Denmark (k=1), Sweden (k=3), The Netherlands (k=1)); Australasia (New Zealand (k=1) and Australia (k=13)); and Asia (Taiwan (k=1), China (k=1), and Korea (k=1)). Participants included were primary carers of varying types: biological parents (fathers and mothers), adopted parents, foster carers and grandparents, with varying ages and socioeconomic statuses. The included studies varied widely on the demographic profile (with some focusing on ethnic minorities and immigrants), for example, African Americans, British Asians, South Asians and Latino. The studies focused on parents of children with an average sample age between 0 and 24, with 32 articles reporting on parents of children <12, 29 reporting on parents of CYP ages 12 to 19, and the remaining 6 articles focused on parents of young people 20 to 24. The children experienced various MH problems (diagnosed or symptoms only) such as ADHD (k=22), ASD (k=22), Emotional and Behavioural Disorders (EBD) (k=8), such as anxieties, depression, psychosis and conduct problems, and the remaining (k=14) were not specific or included a general sample with multiple childhood MH problems. Studies also varied on data collection (e.g. interviews and focus group discussions) and data analysis methods (e.g. thematic and grounded theory approaches). Articles explored various forms of involvement in CYPMH care and treatment, including treatment decisions, diagnostic help-seeking, non-pharmacotherapy involvement and intervention preferences (see Table 3.3).

Table 3.2 Characteristics of selected articles

	First Author, year	Country	Disorder	Stage of Disorder	Methods/ Data Analysis	Data Collection	Area of Interest	Sample size	Age of CYP (Range /Mean in years)	CASP Score
1	Ahmed, 2017	Australia	ADHD	Not reported	Framework content analysis	FGD	Medication adherence (avoiding disclosure)	16	3-12	28
2	Ahuja, 2010	UK	Any	Not reported	Thematic analysis	In-depth interviews	Participation in CAMHS	15	5-15	27
3	An, 2017	Korea	ASD	Not reported	Mixed method/Thematic analysis	Interviews	Involvement in parent training	4	3-9	27
4	Andershed, 2017	Sweden	Any[a]	Not reported	Deductive content analysis	Face-to-face interviews	Involvement in the care of the child	10	18-25	28
5	Andrighetti, 2016	Canada	OCD	Diagnosis	Grounded theory	Semi-structured interviews	The process through which parents adapt to a diagnosis of OCD	13	10-18	28
6	Arcia, 2004	USA	ADHD/ Disruptive Behaviours	Currently accessing CAMHS	Thematic analysis	Interviews	Medication use/professional help-seeking among Latinas	62	4-10	26
7	Attride-Stirling, 2004	UK	Any	Tier 2 CAMHS	Naturalistic qualitative experiment/Thematic analysis	Open-ended interviews	Parental engagement in a Tier 2 intervention with CAMHS	18	5-11	28
8	Auert, 2012	Australia	ASD	Prevention/Treatment	Thematic analysis	FGD	Early intervention usage	20	3-6	29
9	Baker-Ericzen, 2013	USA	Disruptive behaviour	Treatment	Inductive and Thematic content analysis	FGD	Involvement in treatment	14	2-18	29
10	Barnett, 2016	USA	Psychotic or non-psychotic	Treatment	Inductive thematic analysis	Semi-structured interviews	Decision to attend to treatment	13	0- 16+	30

	First Author, year	Country	Disorder	Stage of Disorder	Methods/ Data Analysis	Data Collection	Area of Interest	Sample size	Age of CYP (Range /Mean in years)	CASP Score
			conditions				decision making			
11	Benderix, 2006	Sweden	ASD	Treatment	Hermeneutic phenomenological/Thematic analysis	Interviews	Out of home care	5	10-11	30
12	Birkin, 2008	New Zealand	ASD	Treatment	Thematic analysis	Semi-structured interviews	Intervention program among Maori & Pasifka groups	8	M=5.5	25
13	Boden, 2016	UK	Psychosis	Treatment	Interpretive Phenomenological Approach	Semi-structured interviews	Hospitalisation for psychosis	6	18 - 25	29
14	Bone, 2015	UK	Any	All stages of CAMHS	Interpretive Framework/Thematic analysis	Semi-structured interviews	Participation in CAMHS	14	8-12	30
15	Bradby, 2007	UK	Any	All stages including pre CAMHS	Thematic analysis	FGD/interviews	Help-seeking among British Asians	35	CAMHS age range	27
16	Brinkman, 2009	USA	ADHD	Treatment	Not reported	FGD	Decisions about treatment	52	6 - 17	29
17	Bull, 2006	Australia	ADHD	Management of ADHD	Interpretive Phenomenological Approach	Semi-structured interviews	Decision to use CAMHS	10	5-15	29
18	Bussing, 2012	USA	ADHD	Treatment	Mixed Method- Grounded theory	FGD	Decisions about treatment	1356	14 - 19	27
19	Carlsson, 2016	Sweden	ASD	Diagnostic process	Phenomenological hermeneutic method/Thematic analysis	Interviews	Participation in the neuropsychiatric process	11	4-7	28
20	Charach, 2006	Canada	ADHD	Assessment/Diagnostic /Treatment process	Qualitative	FGD	Decision to use stimulant medication	17	7-14	27
21	Charach, 2014	Canada	ADHD	Treatment	Interpretive interactionist framework	In-depth interviews	Experiences of treatment and diagnosis	12	12-15	28

	First Author, year	Country	Disorder	Stage of Disorder	Methods/ Data Analysis	Data Collection	Area of Interest	Sample size	Age of CYP (Range /Mean in years)	CASP Score
22	Chavira, 2017	USA	Anxiety	Treatment/Diagnosis	Mixed method/Grounded theory	Semi-structured interviews	Help-seeking	29	8-12	29
23	Coates, 2009	Australia	Any	Discharged from services	Inductive thematic analysis	Interviews	Inclusion in the service	39	12-24	25
24	Coletti, 2012	USA	ADHD	Treatment	Inductive/deductive analysis	FGD	Treatment decision making/ adherence	27	5-12	28
25	Coogle, 2016	USA	ASD	Early intervention usage	Conceptual framework approach	Interviews	Early intervention	5	0 – 0.25	27
26	Cormier, 2012	USA	ADHD	Treatment	Grounded theory	Semi-structured interviews	Decision to medicate/ adhere to medication	16	6 - 11	27
27	Crawford, 2003	UK	Emotion/ behaviour disorder	Not clear	Content analysis	FGD	Experience with services	30	6- 17	27
28	Davis, 2012	USA	ADHD	Help-seeking	Grounded theory	Open-ended interviews	Involuntary hospitalization experience	28	6 - 15	27
29	dosReis, 2007	USA	ADHD	Help Seeking	Grounded theory	Qualitative interviews	Diagnostic process among African Americans	26	6-18	28
30	dosReis, 2010	USA	ADHD	Diagnosis	Grounded theory	Interviews	Diagnostic process among African Americans	48	6-18	29
31	Eaton, 2017	Australia	Any	Disclosure	Secondary thematic analysis	Interviews	Decision to disclose diagnosis	11	4-12	26
32	Edwards, 2018	Australia	ASD	Intervention usage (diagnosis to treatment)	Constructivist grounded theory	Semi-structured interviews	Intervention choices	15	2-11	30
33	Fiks, 2011	USA	ADHD	Treatment	Modified grounded theory/Thematic analysis	Semi-structured interviews	Decision to medicate	60	6-12	30

	First Author, year	Country	Disorder	Stage of Disorder	Methods/ Data Analysis	Data Collection	Area of Interest	Sample size	Age of CYP (Range /Mean in years)	CASP Score
34	Freuler, 2014	USA	ASD	Pre-diagnosis	Thematic analysis	Semi-structured interviews	Participation in intervention	14	19 -46 months	27
35	Gerdes, 2014	USA	ADHD	Pre-diagnosis	Grounded theory	Qualitative questionnaire	Decision to seek help among Latinos	73	5-12	25
36	Grant, 2016	Australia	ASD	Post-diagnosis	Thematic analysis	Interviews/FGD	Intervention usage	23	0-18	25
37	Gray, 2015	UK	ASD	Pre- and post-diagnostic stages	Case study design/ Thematic analysis	Informal discussions	Intervention strategies used among Irish Travellers	4	4-7	27
38	Gray-Brunton, 2014	UK	ADHD	Post-diagnosis	Qualitative exploration	Interviews	Parents' accountability	12	5-12	27
39	Hansen, 2006	Canada	ADHD	Treatment	Phenomenological study/ Thematic Analysis	Semi-structured interviews	Using stimulant medication	10	8-22	26
40	Harden, 2005a	UK	Any	Pre and post diagnosis	Thematic analysis	Qualitative study	Experiences pre and post diagnosis	25	13-16	26
41	Harden, 2005b	UK	Any	Post diagnosis	Thematic analysis	Semi-structured in-depth interviews	Engaging in care	25	13-16	29
42	Hart, 2005	UK	Any	Accessing specialist NHS CAMHS	Thematic analysis	FGD/ interviews	Specialist services	30	11-18	27
43	Herbert, 2014	USA	ASD	Treatment	Exploratory qualitative study/Analytic coding	In-depth interviews	Deciding interventions	23	3-6	26
44	Hodgetts, 2013	Canada	ASD	Post-diagnosis	In-depth, prospective, mixed-methods, multiple case-study design/Thematic analysis	In-depth, semi-structured interviews	Involvement in intervention	10	5-12	25
45	Honey, 2015	Australia	Any	Post-diagnosis	Grounded theory	In-depth qualitative interviews	Involvement in supporting the CYP	32	15-21	28
46	Hovish, 2012	UK	Any	Transition to AMHS	Thematic analysis	Interviews	Transition experiences and	6	CAMHS to transition age	23

	First Author, year	Country	Disorder	Stage of Disorder	Methods/ Data Analysis	Data Collection	Area of Interest	Sample size	Age of CYP (Range /Mean in years)	CASP Score
							involvement of parents			
47	Ibrahim, 2016	UK	ADHD	Treatment	Grounded theory	Semi structured interviews	Deciding on drug holidays	4	CAMHS age range	29
48	Ijalba, 2016	USA	ASD	Post-diagnosis	Thematic and Narrative Analyses	Phenomenological interviews	Hispanics decision to teach their children new languages	22	3 - 4	27
49	Jackson, 2008	Australia	ADHD	Post-diagnosis	Narrative-based methodology/ Thematic analysis	Interviews	Use of drug therapy	11	7-18	27
50	Kim, 2018	USA	ASD	Post-diagnosis	Constructivist grounded theory	Semi- structured interviews	Involvement in leisure time	12	M=13.92	27
51	Leslie, 2007	USA	ADHD	All stages including pre CAMHS	Grounded theory	Qualitative interviews	Medication use/professional help-seeking	28	6-15	25
52	Levy, 2016	USA	ASD	Treatment	Grounded theory	Open-ended questions	Shared treatment decision making	20	2-5	29
53	Lindly, 2017	USA	ASD	Treatment	Content analysis approach	In-depth interviews	Shared treatment decision-making	31	2-10	28
54	Lundkvist, 2016	Denmark	Anxiety	Treatment	Interpretative phenomenological analysis	Semi-structured interviews	Involvement in CBT (co-therapist)	24	M=12.90	29
55	Markoulakis, 2012	Canada	ASD	Post-diagnosis	Interpretive Phenomenological Approach	Semi-structured interviews	Caring for the child	8	4-10	29
56	Matthews, 2011	USA	ASD	Post-diagnosis	Grounded theory	Not reported	Caring for the child while working	112	M=9.2	26
57	Mychailyszyn, 2008	USA	ADHD	Pre-diagnosis	Grounded theory	In-depth interviews	Outpatient MH services	34	6-18	26

	First Author, year	Country	Disorder	Stage of Disorder	Methods/ Data Analysis	Data Collection	Area of Interest	Sample size	Age of CYP (Range /Mean in years)	CASP Score
							among African Americans			
58	Nicholas, 2016	Canada	ASD	All stages including pre CAMHS	Ethnographic study/observational	Semi structured interviews	Not reported	85	0-25	29
59	Peters, 2009	Australia	ADHD	Not reported	Thematic analysis	In-depth interviews.	Parenting	11	7-18	26
60	Pishva, 2017	Canada	Anxiety	Post-diagnosis	Grounded Theory	Interviews	Becoming therapeutic agents	19	M=10.68	28
61	Schraeder, 2018	Canada	Any	Currently accessing CAMHS	Constructivist grounded theory	In-depth-interviews	Continuing care into adulthood	10	12-15	28
62	Shyu, 2010	Taiwan	ASD	Treatment	Grounded theory/Deductive approach	Interviews	Help-seeking	13	3-7	29
63	Simmons, 2011	Australia	Major Depressive Disorder	Post-diagnosis	Social constructionist perspective/Thematic analysis	Interviews	Treatment shared decision making	5	12-18	27
64	Taylor, 2007	Australia	ADHD	Treatment	Symbolic interactionist qualitative study/Grounded theory	Interviews	Decisions about treatment	33	school age/teen	24
65	Valentine, 2010	Australia	ASD	Treatment	Thematic Analysis	In-depth, semi-structured interviews	Treatment choices	49	3-5	25
66	Van Tongerloo, 2015	The Netherlands	ASD	Post-diagnosis	Content analysis	Interviews	Not reported	29	M=13.75	28
67	Zhou, 2014	China	ASD	Post-diagnosis	Grounded theory	Interviews	Involvement in parent training	32	M= 6.75	29

Note. CYP=Children and young people; CAMHS=Children and adolescent mental health services; FGD=Focus group discussion;

OCD=Obsessive Compulsive Disorder; ADHD=Attention-deficit and Hyperactivity Disorder; ASD=Autism Spectrum Disorder; USA= United

States of America; UK=United Kingdom; IPA=Interpretative phenomenological analysis; RCT=Randomised controlled trial

[a]Any=The mental health disorder was not specified, or the study included a sample from the general CAMHS population

Quality appraisals

The included studies were critically appraised by two reviewers (BP and SL) and were found to be methodologically rigorous. The studies met an average score of 27 out of 30 points with moderate interrater reliability of 64%. The final CASP scores were included in Table 3.3, and all studies were of acceptable methodological quality to be included in this review.

Synthesis of the findings

Descriptive numerical summary.

This review found 44 codes which were aggregated into seven sub-categories (sub-themes used interchangeably), with two overarching themes (see Table 3.2). The first objective to understand the emotional experiences of parents was addressed through a meta-aggregation process of the first order and second-order concepts. The findings indicated that the seven sub-categories that best-described parents' experience of having a child with MH problems were: 1) *anxious and frustrated*; 2) *isolated and powerless*; 3) *blamed, guilty and ashamed*; 4) *empowered and respected*; 5) *relieved and hopeful*; 6) *exhausted and overwhelmed*; and 7) *distressed and sad*. Frequencies of these subthemes as represented across articles were considered and displayed in Figure 3.3. The majority of the studies (87%) described parents as anxious and frustrated. Subgroup explorations were also conducted to further understand parents' experiences across the different clinical characteristics, age groups, and countries. All articles on emotional behavioural disorders, or with young people over 19 years described parents as anxious and frustrated. All articles where the disorder was not specified or those studying Asian samples described parents as feeling isolated and powerless. Frequencies are shown in Table 3.4.

Table 3.3 Thematic Table

Category	Themes, subthemes and codes						
Themes	Parents' emotional experiences may be a barrier to involvement in child MH care and treatment decision					Parents' emotional experiences may promote involvement in child and adolescent MH care and treatment decisions	
Subthemes (conceptual categories)	Anxious and Frustrated	Blamed, guilty and ashamed	Distressed and sad	Isolated and powerless	Exhausted and overwhelmed	Empowered and respected	Relieved and hopeful

| Affective codes from emotional expressions | ambivalent, angry, anxious, confused, dissatisfied, distrust, fear, frustrated, hypervigilant, mixed feelings, things are difficult, uncertain, uncomfortable, wanting more help, worried | blamed or guilty, denial, judged, reprimanded, self-doubt, shame or embarrassed, shy, stigmatised, vulnerable | distress, sad, disappointed, depressed, stressed, emotional, full of grief | hopeless, alone, negative, lacking support, lacking confidence, lacking guidance, unqualified, excluded, difficulties with language barrier, uninformed, powerless, isolated, not feeling respected or listened to, feel like this is lifechanging, feeling inadequate | overwhelmed, drained, tired, wary, struggling, trapped, exhausted, desperate, burdened, defeated, going through the motions | included, empowered, becoming an expert, 'gut' feeling, supported, trust, respected, feeling helped, confident, less isolated | relieved, accepted, hopeful, grateful, positive, happy, awareness or realization |

Figure 3.3 Percentage of articles representing each subtheme
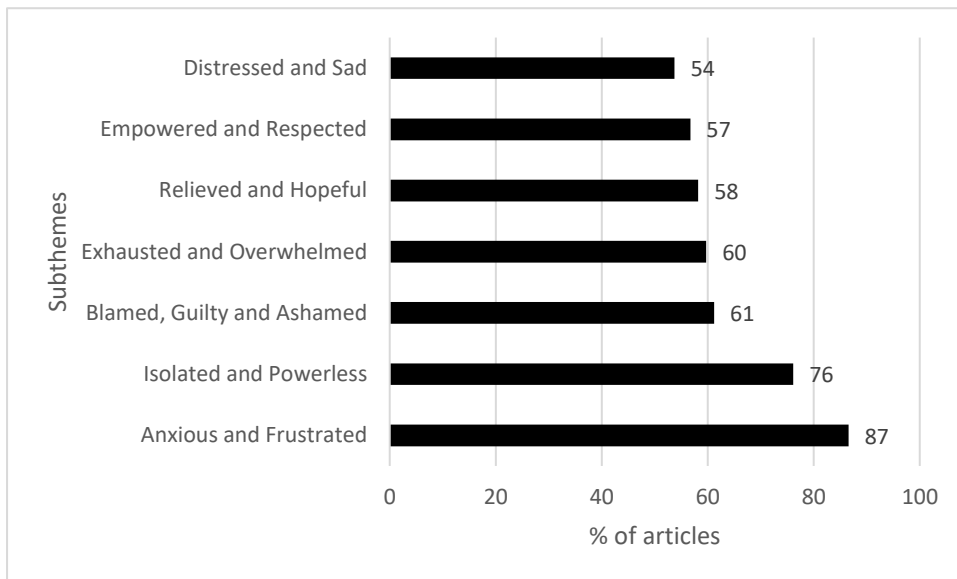
Table 3.4 Percentage of articles and subgroup analysis of the emerging subthemes

Characteristic (# of articles)	Subthemes and frequencies: count (%)						
	Anxious and frustrated	Blamed, guilty and ashamed	Distressed and sad	Isolated and powerless	Exhausted and overwhelmed	Empowered and respected	Relieved and hopeful
Overall (67)	58 (87%)	41 (61%)	36 (54%)	51 (76%)	40 (60%)	38 (57%)	39 (58%)
Disorders							
[a]ADHD (23)	20 (87%)	16 (70%)	11 (48%)	14 (61%)	13 (57%)	9 (39%)	15 (65%)
[b]ASD (22)	17 (77%)	13 (59%)	11 (50%)	16 (73%)	14 (64%)	17 (77%)	12 (55%)
[c]EBD (8)	8 (100%)	6 (75%)	5 (63%)	7 (88%)	3 (38%)	3 (38%)	4 (50%)
Not specified (14)	13 (93%)	6 (43%)	9 (64%)	14 (100%)	7 (50%)	9 (64%)	8 (57%)
Child's age							
Up to 12 (31)	25 (81%)	19 (61%)	17 (55%)	22 (71%)	18 (58%)	21 (68%)	15 (48%)
13 to 19 (30)	27 (90%)	19 (63%)	15 (50%)	24 (80%)	17 (57%)	13 (43%)	19 (63%)
Over 19 (6)	6 (100%)	3 (50%)	4 (67%)	5 (83%)	5 (83%)	4 (67%)	5 (83%)

Country

North America (32)	23 (72%)	13 (41%)	17 (53%)	11 (34%)	10 (31%)	9 (28%)	19 (59%)
Europe (18)	16 (89%)	10 (56%)	11 (61%)	14 (78%)	6 (33%)	2 (11%)	9 (50%)
Asia (3)	2 (67%)	2 (67%)	2 (67%)	3 (100%)	2 (67%)	1 (33%)	2 (67%)
Australasia (14)	9 (64%)	4 (29%)	6 (43%)	8 (57%)	3 (21%)	5 (36%)	7 (50%)

[a]ADHD – Attention Deficit and Hyperactivity Disorder; [b]ASD – Autism Spectrum Disorders; [c]EBD – Emotional and Behavioural Disorders

Theme 1: Parents' emotional experiences may be a barrier to involvement in CYPMH care and treatment decisions

The first theme highlighted that parents experiencing feelings of *anxiety and frustration; isolation and powerlessness; blame, guilt and shame; exhaustion and overwhelm; and distress and sadness* were less likely to seek help (Auert et al., 2012; Boden et al., 2016; Bradby et al., 2007; Bull & Whelan, 2006; Chavira et al., 2017; Harden, 2005a, 2005b; Hovish et al., 2012; Mychailyszyn et al., 2008), keep appointments (Matthews et al., 2011), disclose diagnoses (Eaton et al., 2017), disclose any alternative treatment being used (Lindly et al., 2017), adhere to medication (Ahmed et al., 2017; Bussing et al., 2012; Charach et al., 2006; Jackson & Peters, 2008), participate in treatment decisions (Ahmed et al., 2017; Ahuja & Williams, 2010; Baker-Ericzen et al., 2013; Brinkman et al., 2009;Coletti et al., 2012; Levy et al., 2016; Valentine, 2010), or engage with therapeutic interventions (An, 2017; Birkin et al., 2008; Bone et al., 2015; Gray & Donnelly, 2015; Lundkvist-Houndoumadi et al., 2016; Pishva, 2017; Zhou & Yi, 2014). Some parents felt that being involved in decisions around medication was overwhelming and they preferred to leave the decision up to the clinician (Valentine, 2010). Moreover, parents struggled with the multitude of decisions which needed to be made about their child's treatment (Hansen & Hansen, 2006). Even when parents decided to start medication, they sometimes decided to discontinue medications if their child continued to experience difficulties or because they were worried about side effects (Cormier, 2012). A parent seeking help for a child diagnosed with ASD expressed:

> *"The problem is that what actually happens is you're given so much paperwork at the beginning, too much. It is, it's just too much. It's just absolutely overwhelming [.] And you're just coming home and you're just*

piling papers up on top of each other and going, oh my gosh, which ones

do I read? Which ones apply to me?" (Valentine, 2010, p. 953)

Additionally, some parents decided to be less involved in group interventions. For example, one study reported that "Korean participants felt that the pressure of group participation might provoke some anxiety" (Birkin et al., 2008, p. 113) due to the language barrier and not being comfortable with speaking out in group settings. Similarly, Pacific Islanders spoke of the shyness that comes with being part of a minority group which may affect one's ability to fully participate in a program (Birkin et al., 2008). Parents also reported that participation in activities (e.g. therapeutic role) did not seem natural (Lundkvist-Houndoumadi et al., 2016) and several parents also opted not to attend services because they felt judged (Hart et al., 2005). One parent of a child attending CAMHS expressed:

"I don't know what you think, but a lot of people I have spoken to have felt

that they 're being judged as a family and then a lot of people I know don't

want to go to CAMHS anymore because they think they 've all been

sussed out." (Hart et al., 2005, p. 26)

Several parents avoided medication, disclosure and seeking a MH diagnosis because of stigma. For example, British-Asian parents indicated that the most important reason to delay seeking help "was the need to prevent gossip" and an "expectation that services could be discriminatory" (Bradby et al., 2007, p.2417). Parents who viewed mental illness as *madness* were reluctant to attend services and described it as shameful. A parent of a child with ADHD expressed:

"I was kind of embarrassed because . . . I don't really want to feel that he

needs help." (dosReis et al., 2007, p. 637)

However, several studies reported a *tipping point* or threshold that parents felt. One article described this feeling as a form of *resistance* where parents "acted to resist using medication and hold off as long as they could" (Jackson & Peters, 2008, p. 2729). This resistance was mostly influenced by uncertainties and worry about medications (Cormier, 2012; Schraeder et al., 2018). Parents also mentioned "ignoring and suppressing their own intuitions about their child's behaviours until they could not do it anymore" (Andrighetti et al., 2016, p.916). Although parents described voluntarily resisting involvement in CYPMH care and treatment, they sometimes felt "removed from clinical encounters, including treatment decision making" (Simmons et al., 2011, p.6). This feeling of exclusion added to parents' feelings of isolation and not feeling respected (Andershed et al., 2017; Bradby et al., 2007; Harden, 2005b). The following sub-themes support this overarching theme.

Anxious and Frustrated

Of the 67 articles included in this review, 58 (87%) described parents as experiencing anxiety and frustration. A common thread highlighted that parents felt as if they had to fight, struggle and stand their ground in order to protect their children (Andershed et al., 2017; Arcia et al., 2004; Baker-Ericzen et al., 2013; Brinkman et al., 2009; Cormier, 2012; Crawford & Simonoff, 2003; Hansen & Hansen, 2006). Studies often described parents as *struggling* to come to terms with the diagnosis (Shyu et al., 2010), to find help (Crawford & Simonoff, 2003) and the multitude of decisions (Hansen & Hansen, 2006). They reported being *frustrated and upset* over lack of quality services (Lindly et al., 2017; van Tongerloo et al., 2015) and unable to successfully manage their child (Mychailyszyn et al., 2008; Pishva, 2017).

Parents often recalled how *frustrating* it was to watch their child struggle (Coletti et al., 2012; Nicholas et al., 2016). Harden (2005), highlighted that "the most frustrating for parents was the inability of the psychiatrist to provide clear answers" on the reason for the [child's] illness (p.216). Authors also highlighted themes of parents' *fears and anxiety* over medication (Charach et al., 2014), stigma (Andrighetti et al., 2016; Cormier, 2012; T. Crawford & Simonoff, 2003; Harden, 2005; Ijalba, 2016) and their child's future (Harden, 2005a). One study also reported that even for a child with high functioning autism, the mother "worried that he [the child] will become a geek when he gets older and will not be able to fit in his group" (Shyu & Tsai, 2010, p.1327). Similarly. Peters & Jackson (2008) highlighted that parents also feared the social exclusion their children may face due to their illness.

Isolated and Powerless

The second sub-category was the feelings of isolation and powerlessness that parents experienced. Of the 67 articles highlighted in this review, 51 (76%) described this concept. Several studies described parents' feelings of isolation (Andershed et al., 2017; Benderix et al., 2006; Bradby et al., 2007; Carlsson et al., 2016; Coates, 2016; Hodgetts et al., 2013; Ijalba, 2016; Matthews et al., 2011; van Tongerloo et al., 2015). For example, parents often expressed their feelings of being '*unused*' and insufficiently consulted by the health professionals (Hart et al., 2005; Simmons et al., 2011; van Tongerloo et al., 2015). The parents reported that this led to feelings of inadequacy and neglect (An, 2017; Andershed et al., 2017; Edwards et al., 2018), in addition to the feelings of discomfort and being uninformed (Leslie et al., 2007). This was highlighted in one study which reported how a mother described being rejected by a medical practitioner (Eaton et al., 2017). Additionally, some parents expressed

their feeling of powerlessness and not knowing how to cope with their child's illness (Andrighetti et al., 2016).

Blamed, Guilty and Ashamed

Of the 67 included articles, 41 (61%) expressed parents' feelings of blame, guilt and shame. Parents described sources of blame being self (Andrighetti et al., 2016), professionals (Baker-Ericzen et al., 2013; Crawford & Simonoff, 2003) and society (dosReis et al., 2010). Even more so, among minority groups, parents described having to keep their child's difficulties private to avoid *gossip* (Bradby et al., 2007). This category also highlighted that parents felt reprimanded in the process of advocating on behalf of their child (Barnett et al., 2016; Lindly et al., 2017) and stigmatized by the perception of others (Bradby et al., 2007). They were embarrassed when their child displayed certain behaviours in public and felt as if they were being judged (Harden, 2005). Stigma and concerns of being labelled remained one of the main reasons parents opted not to disclose their child's condition (Eaton et al., 2017), to seek help (dosReis et al., 2007; dosReis et al., 2010) or to take medication (Cormier, 2012). Parents also mentioned feeling guilty if they pursued their own leisure activities (Kim et al., 2018) or for neglecting other members of the family (Shyu et al., 2010). Parents also expressed feeling like a failure or guilty if their children were hospitalized (Boden et al., 2016) or placed in group homes (Benderix et al., 2006).

Exhausted and Overwhelmed

Of the 67 articles, 40 (60%) highlighted parents' feelings of exhaustion and being overwhelmed, sometimes to the point of desperation. Parents' echoed feelings of being overwhelmed when having to make decisions with limited treatment options

or conversely, receiving large amounts of information at the same time (Edwards et al., 2018; Valentine, 2010). This also led to parents feeling exhausted as they described *always being on the clock* or having to constantly *keep watch* on their child (Peters & Jackson, 2009). Some parents expressed having to work part-time or quit jobs to stay at home as their children had full-time needs (Nicholas et al., 2016). Although the lifestyles were routine for some parents, they referred to caring for their children as tiring and demanding (Pishva, 2017). One article reported that the strain and burden often resulted in adverse effects to parents' own emotional and physical well-being (Hodgetts et al., 2013). Once parents were at the point of exhaustion, they described feeling desperate for direction from healthcare providers (Boden et al., 2016) and *help hungry* (Schraeder et al., 2018).

Distressed and Sad

Thirty-six articles (54%) described the emotional distress of having a child with MH problems. Parents described their experience of a diagnosis as distressing (Andrighetti et al., 2016; Brinkman et al., 2009; Pishva, 2017; Valentine, 2010) and often described the sadness and grief they experienced about their child's condition (Fiks et al., 2011; Grant et al., 2016; Nicholas et al., 2016; Peters & Jackson, 2009). Previous authors reported that the overall unhappiness was not only related to their child's illness but also from feeling unsupported (Bradby et al., 2007). Most parents described their experiences as being stressful resulting from emotional periods of *loss and grief, despair and confusion* (Grant et al., 2016). This stressful feeling also resulted from the disruption the child's illness had on the family (Ylva Benderix et al., 2006; Davis et al., 2012). One mother described her feelings as being forced to redefine her maternal and child expectations and accomplishments which was *very painful* and *heart wrenching* for her (Nicholas et al., 2016). Several parents

expressed sadness and disappointment at missing, what they perceived to be a *typical* parent experience (Peters & Jackson, 2009) resulting in parents experiencing stress-related illnesses (Carlsson et al., 2016). For example, one mother highlighted the sadness of witnessing her child struggling and feeling unable to help due to her own mental distress (Simmons et al., 2011). Several studies highlighted the theme of stress and noted that it resulted from many areas surrounding the child's illness. For example the stress of being told that there was nothing wrong with their child even though they knew something was wrong (Harden, 2005b), the stress of receiving negative reports from school personnel (Brinkman et al., 2009) and the stress being placed on marriages, jobs or the family structure (Cormier, 2012).

Theme 2: Parents' emotional experiences may promote involvement in CYPMH care and treatment decisions

Two sub-themes describing *empowerment and respect and relief and hope* emerged in support of this overarching theme. This theme highlighted that when parents were able to reappraise the situation they were able to be more involved in their CYP's MH care and treatment decisions. For example, once parents no longer saw the MH services as discriminatory or only *pushing* medication they began to trust the healthcare professionals, and were more involved in their CYP's MH care (Davis et al., 2012). Some mothers suggested the attitude of the provider sometimes created a feeling of family competence which motivated families to participate in early interventions (Coogle & Hanline, 2016). This involvement also made mothers feel more confident in implementing strategies on their own (Edwards et al., 2018). Additionally, having confidence in the health professionals allowed parents to *let go* of some of the responsibility of care as an advocate and be more involved as an

equal, and increased willingness to cooperate (Andershed et al., 2017). This was articulated by statements such as,

> *"I wasn't asked for my opinion but that didn't worry me because I thought, these people are supposed to know what they're doing" (Simmons et al., 2011, p. 7)*

> *"I feel comfortable enough talking to them. I feel like I can trust the staff here." (Coogle & Hanline, 2016, p. 255)*

Support from HCPs and other parents of children affected by MH problems also encouraged some parents to engage (Ahmed et al., 2017; Gerdes et al., 2014). Although some families expressed a desire for more information to aid them in the decision-making process (Davis et al., 2012), parents described a certain openness in which they were informed, respected and listened to once contact was established (Andershed et al., 2017). In some instances, interventions were able to assist parents in becoming more involved. For example, parents in all interviews about the Stepping Stones Triple P programme, discussed the impact it had on changing their perspectives of the cause of their child's disruptive behaviours (Hodgetts et al., 2013).

Similarly, once parents noticed improvements after the recommended treatment, they were more likely to continue to engage with services.

> *"You feel like [treatment] has become your friend, because you see your child happy and successful" (Coletti et al., 2012, p. 229).*

Hansen & Hansen (2006) reported that a father became hopeful about his 22-year-old son's future once he perceived some improvement, and then saw a role for

the medication in the young adult's future successes. Another mother found that the treatment enabled her to cope much better with the frequent struggles with her son. These results were associated with a sense of relief and feelings that the CYP were receiving the treatment they believed was needed (Hansen & Hansen, 2006). With the onset of acceptance of their child's condition, parents began to be more hopeful and more involved in care and treatment to bring about the perceived best outcomes for their child. Although some parents delayed accepting medication, others accepted it hoping for a positive impact on behaviours and schooling (Ibrahim et al., 2016). Researchers noted that present and future academic goals for the children were often reported as reasons for tolerating the medication's side effects. For example, one study reported how a mother justified her decision to keep her son on medication with her goal of having him continue on in school and get a *good* education (Hansen & Hansen, 2006).

Some parents also described their inner sense or *gut feeling* as being the main reason for seeking help (Hebert, 2014) or making decisions regarding interventions (Ijalba, 2016). For example, Edwards et al. (2018) reported that one parent reflected that she started to trust her instinct and made decisions more independently at the acceptance stage of the journey.

Religious beliefs also impacted some parents' evaluation of their child's illness and impacted whether they believed the disorder was health-related and therefore sought treatment or continued to seek spiritual healing (Ijalba, 2016). However, for most parents, after a period of seeking spiritual assistance, they arrived at a threshold that made them seek medical help (Leslie et al., 2007).

The following two sub-themes described parents' feelings at various stages of their child's illness and determined how parents engaged with the care and treatment services.

Empowered and Respected

Of the 67 articles, only 38 (57%) described parents' feelings of competence to manage their child's MH care and treatment. One study highlighted that parents eventually became experts in the research literature surrounding their child's condition (Edwards et al., 2018). This feeling came when parents were more knowledgeable and learnt strategies to help their child. One study highlighted that with this knowledge parents felt respected by the HCPs and it meant they could contribute to health care decisions (Andershed et al., 2017). The increase in knowledge meant that parents also gained independence in managing their child's problems which resulted in feelings of empowerment (An, 2017; Andrighetti et al., 2016; Auert et al., 2012). Informed parents were more likely to feel more confident and advocate more effectively for their child (Edwards et al., 2018). Parents' participation in care also helped them to feel *empowered* and more in control of their children as expressed in some studies (Grant et al., 2016; Hebert, 2014).

Some parents also described the empowering feeling gained through disclosure when they received an empathic response (Eaton et al., 2017) or when they finally had a diagnosis (An, 2017). However, researchers highlighted that these positive feelings sometimes coexisted with negative feelings, as one study described parents' experience of feeling *empowered but alone* (Carlsson et al., 2016).

Relieved and Hopeful

Of the 67 articles, 39 (58%) described parents' feelings of relief and hope. Parents described trusting in service providers, which encouraged a certain level of partnership and willingness to share information and take advice (Coogle & Hanline, 2016). This level of trust was important for parents and helped them to move forward more decisively (Cormier, 2012). A popular thread among parents was hope. Parents were hopeful for their children's future (Hansen & Hansen, 2006; Honey et al., 2015) and hopeful that interventions were effective (Andrighetti et al., 2016; Coletti et al., 2012; Cormier, 2012). Most studies described this feeling as *acceptance* or *letting go* or *help hopeful* (Brinkman et al., 2009; Cormier, 2012; dosReis et al., 2007; Harden, 2005a; Matthews et al., 2011). This feeling however, occurred at different stages for parents. For example, one study described an awareness that occurred among some parents that they could not fully protect their child from stigma and as a result a type of acceptance emerged (Andershed et al., 2017).

Parents also felt relief when their children received a diagnosis, which meant there was finally an explanation for the child's behaviour and they could receive the necessary treatment (Hansen & Hansen, 2006). This acceptance was a positive theme across studies and many parents with this feeling were able to accept management strategies and plan future goals (dosReis et al., 2007; Hodgetts et al., 2013). Once parents were able to realize the possibility of persistence into adulthood, some parents were able to release the resistance of seeking treatment and accepted their child's condition and hoped for the best future.

Similar to the subtheme of empowerment, parents did not seem to experience acceptance on its own. One study highlighted that although parents experienced the grief associated with receiving a diagnosis of ASD, they felt a strong sense of relief, and believed that services post-diagnosis would improve outcomes, thereby offering hope for the future (Edwards et al., 2018). This was also reflected in parents' description of having a child with MH problems as both a *delight and a challenge* (Bussing et al., 2012).

Discussion

The findings from this review suggest that parents are 'expected to, but not always able to' engage with CAMHS. The first aim of this qualitative synthesis was to pool evidence of parents' emotional experience of parenting CYP with MH challenges. Through a meta-aggregation process, direct quotes from parents, and primary authors' interpretations, were utilised in the analysis, yielding seven categories (i.e. subthemes) of emotions. Consistent with previous studies in child physical and MH, the results confirmed that parents do experience an '*emotional roller-coaster'* (Corcoran et al., 2017; Gómez-Ramírez et al., 2016; Laugesen & Gronkjaer, 2015; Laugesen et al., 2016; Corcoran et al., 2015). Additionally, consistent with previous research in broader paediatric care, the meta-synthesis revealed that the identified categories of emotions may influence engagement with CYPMH care and treatment decisions (Boland et al., 2019; Lipstein et al., 2012). Findings were also in line with the Appraisal-Tendency Framework (Lerner et al., 2015) identifying groups of emotions that influence decision-making, and the Ottawa Decision Support Framework (O'Connor et al., 2011) which posits that factors such as emotions can impact the quality of a decision.

The seven aggregated subthemes describing parents' emotional experiences were similar to previous reviews and quantitative studies. First, parents experienced feelings of blame, guilt and shame, which have been a dominant theme in the CYPMH literature (Ahmed et al., 2013; Corcoran et al., 2015; Gondek & Lereya, 2018). Isolation and powerlessness have also been identified in previous studies (Boshoff et al., 2016; Reardon et al., 2017). Researchers also agree that anxiety and frustration, sometimes under the umbrella term "parenting stress", are higher among parents of CYP with MH problems (Bonis, 2016; Corcoran et al., 2017; Hayes & Watson, 2013). Relief and hope were also identified and discussed in previous studies (Geffken et al., 2006). Quantitative findings also suggest high levels of distress and sadness (e.g. depression) among parents of CYP with MH problems (Hastings, 2003; Rezendes & Scarpa, 2011). Additionally, researchers agree parents experience exhaustion and overwhelming feelings (Boshoff et al., 2016; Giallo et al., 2011). Lastly, feelings of being empowered and respected, although present in fewer studies, have also been identified in previous research (Boland et al., 2019; Boshoff et al., 2016; Edwards et al., 2009). These categories of emotions are also represented in various models of emotions (Plutchik, 2001; Scherer et al., 2013).

The identified emotional experiences appeared not to be unique to any type of disorder, age of child or culture. Although the frequency of certain themes differed across different groups, primary and secondary themes were not unique to any particular group. Participants from many different countries (n=11) were represented in this review. This is in line with prevalence data in CYPMH indicating that this area is of global concern (Kieling et al., 2011; Polanczyk et al., 2015; WHO, 2013). The majority of the articles focused on ADHD (k=23) and ASD (k=22) which was not surprising as research also indicates a large number of diagnoses in this area (Davis

& Kollins, 2012; Laitner, 2012). Researchers also indicate heightened emotional states in parents of children with these neurodevelopment disorders. This review advances previous research by quantifying studies to help understand parents' experiences across cultures, disorders and age groups. The findings highlight that all studies focusing on emotional behaviours disorders, or with children over 19 years described parents as *anxious and frustrated*. In addition, all studies where the disorder was not specified or those studying Asian samples described parents as feeling *isolated and powerless*. These findings identify specific areas for further investigations.

The second aim of this review was to synthesise the initial findings in the context of CYPMH decision-making. The study identified two main themes suggesting that based on parents' emotional states they may either be more inclined to participate in CYPMH decisions or find their involvement in care and treatment decisions to be challenging. These two themes were supported by the seven categories of emotions with potential to influence decision-making.

Parental emotional experiences may be a barrier to effective involvement in CYPMH care and treatment decisions

Five sub-themes representing integral emotions emerged in support of this overarching theme. The findings are in line with the previous quantitative literature in CYPMH suggesting the interrelationships between emotions (i.e. anxiety), decisional conflict and effect on the parents (Chen et al., 2015). Further studies highlight that some emotions can trigger some responses or reactions in persons and influence decisions (Elwyn et al., 2016; Forster et al., 2016; Hamilton et al., 2016; Hayes et al., 2019; Lerner et al., 2015; Starcke & Brand, 2012). This finding coincides with other

research by suggesting that stages of grief over the "loss" of having a *typically* developing child affects parent engagement in care and treatment (Taylor et al., 2006). Similar to the Kubler-Ross's (1969) model of loss, parents may choose to deny the diagnosis, leading them to seek alternative treatment options; failing this, they may experience emotional turmoil over an inability to rationalise decisions to medicate causing them to withdraw or feel socially isolated. Therefore, the current findings mirror that of the cognitive-affective literature (Lerner & Keltner, 2000) suggesting that in the presence of various emotions, engaging with decisions can be challenging (Lerner et al., 2015; Starcke & Brand, 2012) and influence judgement and choices (Lerner & Keltner, 2000).

The findings can also be discussed in relation to the *involvement in the light, involvement in the dark* theory of caregiving. The theory suggests that the way in which the care culture is designed should influence parents' possibilities for involvement (Andershed & Ternestedt, 2000). The findings in this review support this theory by highlighting the experience of exclusion from care and treatment decisions that parents face (Andershed, Birgitta & Ternestedt, 2001) resulting in an involvement in the dark experience.

Parental emotional experiences may promote effective involvement in child and adolescent MH care and treatment decisions.

Although the impact of parent empowerment interventions is not well studied in CYPMH (Farmer et al., 2004), the evidence suggests that increased parent engagement in care and treatment positively influences treatment adherence, effectiveness and promotes person centred care (Clarke et al., 2015; Edbrooke-Childs, Jacob, Argent, et al., 2015; Gondek et al., 2017). Therefore, the subthemes

describing parents' feelings of *empowerment and respect and relief and hope* is an important finding if we are to improve CYPMH outcomes. Supporting parents not only as secondary service users but also as agents of change (Hoagwood, 2005) is of great importance to CYPMH. Gibson (1995) described the 4 key components of empowerment. Firstly, similar to the current findings, Gibson identified the understanding and acceptance of the child's diagnosis. This acceptance allows families to function in the face of a crisis and demonstrate resourcefulness and the ability to adapt (Kandel & Merrick, 2007). Secondly, the critical reflection of the situation allows parents to develop hope for the future and a belief that they are able to continue to support their child as identified in the included studies. This re-evaluation of the situation, and increase in knowledge, can lead to parents' decisions to be more involved in care and treatment (Ahmed et al., 2017; Brinkman et al., 2013; Jackson et al., 2008).

Practice implications

The exploration of the wide range of emotions expressed by parents may further inform more effective communication strategies between HCPs and families since previous research highlighted that parents' emotional states are not always considered by healthcare providers (Dicé et al., 2016). Knowledge of these emotional experiences may inform practitioners working with families since difficulties managing emotions can have a negative impact on the psychological and physical well-being of parents (Karimzadeh et al., 2017). Therefore, the findings of the present review may support clinicians to further develop therapeutic relationships by creating more trusting relationships between families and services beyond emotional experiences discussed in clinical encounters. This coincides with the

person-centred model of care (Nolte, 2017) which is currently advocated across health care settings (Chief Medical Officer, 2014; Institute of Medicine, 2001).

Additionally, the broad range of emotions identified could further inform family therapy practices and parent training modules. The importance of parent engagement could be further highlighted in training and the initial stages of parent interventions. This may require a broader approach to decision making and family support. Therefore, it may be necessary to extend beyond the family support groups (Friesen & Koroloff, 1990) and similar meetings currently expected to meet the decision support needs of the families involved in CYPMH care and treatment. Findings may also further inform the development and implementation of parent peer support services.

Policy implications

This review may begin to inform conversations around inequalities in CYPMH care as family satisfaction with services vary (Barber et al., 2006). This review can aid an attempt at addressing inconsistencies across services and help identify the most efficient use of resources. The lack of parent support resources (Chapters 6 and 7) may suggest increased funding or rather the better use of funding to evaluate and explore new ways to optimize the availability and relevance of currently available resources for families.

Research implications

It is important to carry out program and intervention evaluation of currently existing decision support interventions to identify which resources are most beneficial (discussed in Chapter 7). More qualitative studies are also needed

targeting specific geographic locations and socio-demographic characteristics (e.g.

studies in South America and Caribbean, and parents of sexual minority youths) not

covered by the included studies. More studies are also needed to investigate

parents' emotional experiences specifically in relation to SDM to further develop this

theory. Quantitative studies can also be conducted to obtain support for the themes

highlighted in this review. For example, investigations on the role of parental worry

on all stages of the CYPMH help-seeking process. Research in this area is very

limited, however, it is crucial if researchers are going to investigate the impact and

implementation of SDM interventions. Additionally, further research specifically

focusing on parents' preferences and experiences (differentiating between views and

attitudes) would also be welcomed on this topic to inform an affect approach to

CYPMH decisions.

Strengths and Limitations

The first strength of this review is that the PhD candidate extracted both first

and second-order data, where possible, from the identified articles. This is congruent

with the aims of this review to understand the emotional experiences of parents

using their own "voices", and those of an "observer". Nevertheless, this review can

be considered as a unique secondary analysis, including only a biased collection of

published articles. Utilizing alternative methods would require access to a reanalysis

of the primary data of a sample of the studies reviewed. However, by doing this I

would potentially lose the primary authors interpretations and fail to follow the social

constructivist approach. Secondly, a very broad search and including two reviewers

at various stages was used to correctly identify as many articles as possible.

However, the searching was limited to only articles published in peer-reviewed

journals and only 20% of data extracting, and coding was conducted by a second

reviewer. As a result, I could have missed valuable information and fail to identify studies available through the grey literature. However, the decision to only include peer-reviewed literature was based on evidence that suggests the scarce contribution of unpublished studies to the results of systematic reviews in child-relevant studies (Hartling et al., 2017). Additionally, the consideration that the aim of this systematic review was not related to efficacy and safety, which could be more impacted by publication bias.

Another strength of this review is the qualitative nature of the study, carried out and audited using guidelines and recommendations for qualitative research (Braun & Clarke, 2006; Erwin et al., 2011). The review also incorporated descriptive subgroup analyses exploring the findings across age groups, cultures and disorders. Despite these efforts, the interpretive nature of this review limits the findings to reaching generalizability within the field of CYPMH decision-making and may be criticised for the chosen methodology. Therefore, further investigation of emerging themes and concepts are recommended.

Conclusion

Parents of CYP with MH challenges experience a broad range of emotions that may influence their involvement in care and treatment decisions. This qualitative meta-synthesis affords insight into these challenges and may help to inform service provision and to promote discussions around parents' feelings about engagement with services. Nonetheless, implications for practice, research and policy were considered to inform methods for further support of families responsible for CYP with MH problems.

Brief summary

This chapter reported the findings from a qualitative evidence synthesis of parents' emotional experiences across different CYP age groups, disorders and countries, within the context of CYPMH decision-making. The study identified two main themes suggesting that based on seven categories of emotions parents' may either be more inclined to participate in CYPMH decisions or find their involvement to be challenging. The next chapter will build on this review by conducting a quantitative evaluation of the emerging theme to further triangulate these findings.

Chapter 4 Associations between Help-seeking, Child Psychosocial Impairment and Parent State of Worry (Study 2)

Chapter 3 provided a review of existing evidence on parents' emotions and CYPMH decision making. The review highlighted important themes in line with the extant literature in various health settings suggesting that parents' emotional states influence CYPMH judgement and decision-making. More specifically negative categories of emotions, such as: 1) anxiety and frustration; 2) isolation and powerlessness; 3) blame, guilt and shame; 4) exhaustion and overwhelm, and 5) distress and sadness, were generally identified as barriers to effective involvement in CYPMH decisions. Positive emotions, such as: 1) empowerment and respect, and 2) relief and hope were identified as promoting parental involvement in CYPMH decisions. The themes emerging from the review informed the current study. This study aimed to quantitatively investigate the role of parents' emotion (e.g. worry) in CYPMH help-seeking, the first decision in the process of treatment, in a sample of parents of school-aged children in the UK. Possible associations and implications were also considered.

Gaps in the extant literature

As discussed in Chapter 2, a wealth of knowledge exists on practical barriers, such as lack of transport and difficulty to make appointments, to help-seeking in CYPMH (Fortune et al., 2008). However, researchers are beginning to acknowledge that a carer's emotional state may affect their help-seeking behaviour (Chapter 3). In addition, parental perception of CYPMH problems play a key role in determining service use. Yet few parents express their concerns in primary care consultations (Sayal & Taylor, 2004). Therefore, CYPMH problems sometime go unrecognised. As

discussed in previous chapters, studies mainly focus on either formal or informal sources of help only or investigate preferences. This limits our knowledge of a broad approach to help-seeking in CYPMH as fewer studies bring together both formal and informal help-seeking.

Previous studies have also reported demographic associations with help-seeking, reporting that British-Asian parents were less likely to seek help (Bradby et al., 2007). There are mixed results in the existing literature examining parents' help-seeking. Although the studies are both quantitative and qualitative, they mainly focus on families already accessing care and with non-UK samples (Chapters 2 and 3). In light of the current waiting periods to access CAMHS in the UK (NHS Digital, 2019), and only a subset of parents of children with MH problems accessing CAMHS (Gopalan et al., 2010; Ozbek et al., 2019), it is important to investigate help-seeking in a non-clinical population. In addition, to improve the quality of care and early interventions for parents and children, it would be important to study the factors affecting help-seeking behaviours and identify the predictors of parent help-seeking. Therefore, it is critical that efforts to understand help-seeking bring together parental affective states (e.g. worry), CYPMH problems and demographics. Additionally, by exploring help-seeking experiences of parents in a non-clinical population (i.e. pre-CAMHS) we can identify; 1) areas suitable for early interventions; 2) families who are less likely to access early intervention or parental support; and 3) areas to target that will require further investigation.

Aims and research questions

The overall aim of the present study was to explore factors associated with parents' help-seeking for a child's MH in a representative sample of school-aged

children in the UK. To better understand the associations between parent-reported

help-seeking and parents' perceptions of a) their child's psychosocial difficulties and

level of impairment, b) self-reported state of worry and c) demographics, the

following research questions and hypotheses were examined:

1. Are parents' perceptions of their child's MH associated with their state
of worry?

It was hypothesised that there will be a significant positive relationship between

parents' state of worry and their child's MH.

2. What factors are associated with parents' decision to seek child MH
support?

It was hypothesised that there will be a significant positive relationship between

parents' decision to seek help and their child's psychosocial difficulties and level of

impairment. Additionally, based on findings from the previous chapter, it was

hypothesised that parents who worried about their child's MH may not seek help.

Methods

Participants

A secondary analysis was conducted on data collected from parents of

children 8-12 years of age from year 4 and year 7 in primary and secondary schools

who participated in the 2008-2011 Targeted Mental Health in Schools programme

(TaMHS). TaMHS was funded by the Department for Education (DfE) as part of a

wider government programme developed to improve the psychological health of

children, young people and their families. This was a phased project starting with 25

pathfinder local authorities, selected by the Department for Education, in 2008 and

ending with 151 by 2011. This totalled 2500-3000 schools participating in TaMHS,

with the main aim to develop innovative, locally determined models to provide early

intervention and targeted support for children (aged 5 to 13) at risk of developing MH problems and their families.

Local authorities used deprivation as a key factor when selecting schools (high proportion of free school meals) resulting in 50-60% of schools being selected on this basis. Data were collected from children, parents, teachers, school coordinators (e.g. head-teachers or deputy head) and the local authorities. The current study analysed baseline parent data collected in 2008. Further details of the TaMHS programme have been reported elsewhere (Department for Education, 2011). As this was a secondary data analysis, no identifiable data was available to the PhD candidate and therefore, no ethical approvals were needed (Tripathy, 2013; University College London, 2018). The original TaMHS study received the necessary ethical approvals for collection and analysis of the primary data.

The study sample composed of parents of 1857 children between the ages of 8 and 12 years with a mean total psychosocial difficulty score of 8.37 (SD = 6.1), on the Strengths and Difficulties Questionnaire (SDQ), out of a total possible score of 40. The sample was predominantly White, English-speaking families. The majority of participants in the study (n = 1560) were mothers. In general, all the children had "close to average" scores on all subscales of the SDQ (Goodman et al., 2003) as reported by the parents. The highest psychosocial difficulty score reported for children was an average score of 3.34 (SD = 2.54) on the hyperactivity scale. The majority of the parents (73%) reported being worried because their child seemed unhappy or disruptive. See Table 4.1 for a descriptive summary of the sample.

Table 4.1 Socio-demographic and clinical characteristics of the total sample (N=1857)

Characteristics	M (SD) n (%)
Child's age	9.85 (1.56)
Child's gender	
Boys	907 (48.8%)
Girls	950 (51.2%)
Language	
English	1683 (90.6%)
Other	174 (9.4%)
Ethnicity	
Black	44 (2.4%)
Asian	134 (7.2%)
White	1623 (87.4%)
Mixed race	45 (2.4%)
Other	11 (0.6%)
Relationship to child	
Father	275 (14.8%)
Mother	1560 (84%)
Guardian	18 (1%)
Other	4 (0.2%)
Psychosocial difficulties	
Hyperactivity	3.34 (2.54)
Emotional problem	2.08 (2.14)
Conduct problems	1.38 (1.62)
Peer problems	1.57 (1.78)
Prosocial behaviours	8.41 (1.7)
Impact Score	0.53 (1.48)
Total difficulties score	8.37 (6.1)
Parental worry	
Yes	1352 (72.8%)
No	505 (27.2%)

Note: N=1857 (n refers to the count for each condition); M=mean; SD=standard

deviation

Measures

Socio-demographic characteristics

Relationship to the child was reported by the parent and categorised as

father/mother/guardian/other. The child's age was calculated based on the child's

date of birth obtained at baseline. Based on the available data, gender was also

obtained categorizing pupils into either male or female. English as a first language

was obtained and using binary coding categorised pupils into "English" or "Other"

speakers. Race/ ethnicity was coded into 5 major categories using the 2001 Census

classification (Office for National Statistics, 2012), as White, Black, Asian, Mixed

race and Other.

Child Mental Health

The SDQ consisted of 34 items completed by parents, which included the

impact supplement. The SDQ is a short emotional and behavioural screening

questionnaire for 3-17-year olds and is commonly used in clinical practice and

research. Included items asked for parents to respond on a Likert scale (not true,

somewhat true, or certainly true) based on the child's behaviour (e.g. "Constantly

fidgeting or squirming?") or the child's mood (e.g. "Many worries or Often seems

worried?") over a specified timeframe of the last six months. The SDQ examines 25

attributes, divided into 5 scales (emotional problems, conduct problems, hyperactivity

and inattention, peer relationship problems, and prosocial behaviour). The impact

supplement examines the nature of the child's difficulties and reports on social

impairment, burden to others, chronicity and distress related to the child's difficulties

(Goodman et al., 2003). A total difficulties score (excluding prosocial behaviour) was

calculated ranging from 0-40, with an increased score corresponding to an "increase

in the risk" of developing a MH disorder (Edbrooke-Childs, Jacob, Law, et al., 2015).

The prosocial scale suggests that higher scores correspond to fewer difficulties in

prosocial behaviour (Goodman et al., 2003; Patalay et al., 2018). The 25-item SDQ

had adequate internal consistency (Cronbach's alpha = 0.74) for the current sample.

Parent self-reported state of worry

Worry has been defined as a state of feeling anxious or troubled about a person or situation (Hirsch & Mathews, 2012). A parent's state of worry was assessed using a binary question, based on a modified version of the General Help-Seeking Questionnaire (Olivari & Guzmán-González, 2017). Parents were asked "Have you ever been worried because your child seemed to be unhappy or disruptive?" to which parents responded "Yes/No". This question was intended to be a gateway question to answer the help-seeking measure. Similar to the Health Anxiety Questionnaire (Lucock & Morley, 1996) and the Health Anxiety Inventory (Salkovskis et al., 2002), used to report on a person's worry about their own physical or MH, the single-item measure used in this study was aimed at capturing a parent's anxiety/worry about their child's MH.

Help-seeking

Based on the modified version of the General Help-Seeking Questionnaire (Olivari & Guzmán-González, 2017), the following single item measure was used to assess the help-seeking of parents: Did you try to get help from any of the following: A family member/ A friend/ A form/class teacher/ A family doctor. Parents' responded "No" or "Yes, but not helpful" or "Yes, a little helpful" or "Yes, and helped a lot". To address the research questions of the present study, the responses were aggregated to reflect "Yes" or "No" responses. Therefore, "Yes, but not helpful" or "Yes, a little helpful" or "Yes, and helped a lot" were coded as 1 and 0 for "No".

It was important to note that only a subset of the sample (n=529) responded to this question. However, possible differences among the completers and non-completers were explored in the analyses. Cases, where the help-seeking

experience questionnaire was completed, were coded as 1 and cases with no response were labelled as 0. A binary logistic regression to explore differences between variables responsible for predicting completion were conducted. The model was statistically significant, χ^2 (17) = 1998.19, $p < .05$. Prosocial behaviour was the only significant predictor indicating a difference between the groups (p<.05). Parents reporting higher prosocial scores for their children were less likely to complete the help-seeking questionnaire. There were no other significant predictors between the completers and non-completers of the help-seeking measure.

Design and statistical analysis

The sample used in the secondary data analyses was limited to responses from parents who completed the survey items necessary for the SDQ total difficulties score and the parent's state of worry. Once all assumptions were met, binary logistic regression was conducted to explore how psychosocial variables (emotional problems, conduct problems, hyperactivity and inattention, peer relationship problems and impact) were associated with a parent's state of worry about their child's MH while controlling for demographic variables (child's gender, relationship to child, child's age, race/ethnicity and first language). Similarly, binary logistic regression analyses were performed to evaluate associations between these same variables, demographic and psychosocial (including parents' state of worry), and the parent's help-seeking. Odds ratios (ORs) and corresponding 95% confidence intervals (CI) were used as estimate measures of the associations.

An exploration of variation of parent's help-seeking between schools was conducted to investigate if parents at the same schools displayed similar help-seeking behaviours than other schools. An intraclass correlation coefficient (ICC)

score of .047 suggested that the school-level factors in the current sample were low

and only accounted for less than 5% of the variation in parent's help-seeking.

Therefore, conventional logistic regressions instead of multilevel analysis were

appropriate (LeBreton & Senter, 2008). Statistical analyses were conducted using

Statistical Package for Social Sciences (SPSS), version 24 (IBM Corp., 2016).

Results were considered significant if the two-sided p-value was <0.05 (du Prel et al.,

2009).

Results

Association between parent state of worry, socio-demographics and perceived

MH of the child.

Table 4.2 shows the variables included in the binary logistic regression where

the outcome was the parent self-reported state of worry about their child' MH

(yes/no). 1857 cases were used in the analysis after exclusion for missing data. The

logistic regression model was statistically significant, χ^2 (16) = 576.54, p < .05.

The model explained almost 39% (Nagelkerke R^2) of the variance in the

parents' state of worry and correctly classified 81% of cases. Ethnicity, relationship

to the child, emotional, conduct and peer problems, and impact score were

significant in the model. The model suggested that guardians were less likely to

worry about their child's mental health than mothers (OR=.092, 95% CI=.011, .741])

and the odds of Asian parents worrying were less than White parents (OR=.258,

95% CI = .107, .624). Parents who rated their children as having higher levels of

emotional problems (OR=1.418, 95% CI= 1.326, 1.516), conduct problems

(OR=1.237, 95% CI=1.123, 1.363), and peer problems (OR=1.172, 95% CI=1.084,

1.268) also had higher levels of worry. Higher impact scores were also associated

with increased parent worry (OR=1.371, 95% CI= 1.202, 1.563). The child's age, gender, language, hyperactivity problems, and prosocial behaviours were not significant predictors of the parent's state of worry (see Table 4.2).

Table 4.2 Regressions of associations between parent state of worry, socio-demographics and perceived mental health of the child (N=1857)

Variable	Odd ratio	95% CI	P value
Child's age	.994	.918, 1.076	.878
Child's gender (Boy vs girl)	1.279	.987, 1.657	.063
Language (English vs Other)	.564	.264, 1.207	.140
Ethnicity			.021
White vs Black	.817	.332, 2.012	.660
White vs Asian	.258	.107, .624	.003**
White vs Mixed	1.584	.719, 3.490	.254
White vs Other	.340	.058, 1.999	.232
Relationship to child			.035
Mother vs father	.690	.472, 1.007	.054
Mother vs guardian	.092	.011, .741	.025**
Mother vs other	.594	.053, 6.694	.673
Psychosocial difficulties			
Hyperactivity	1.020	.960, 1.085	.524
Emotional problems	1.418	1.326, 1.516	.000**
Conduct problems	1.237	1.123, 1.363	.000**
Peer problems	1.172	1.084, 1.268	.000**
Prosocial behaviours	.932	.858, 1.013	.097
Impact score	1.371	1.202, 1.563	.000**

Note. N=1852; CI=Confidence Intervals

** indicates significance value, p<.05

Association between help-seeking, socio-demographics, parent's state of worry and perceptions of their child's MH.

Analyses were conducted on the sample of parents completing the help-seeking measure (n=529). A binary logistic regression was performed to ascertain the effects of the independent variables on the likelihood of parents seeking support (yes/no). The logistic regression model was also statistically significant, χ^2 (17) = 45.94, $p < .05$. The model explained 18% (Nagelkerke R^2) of the variance in help-

seeking and correctly classified 92% of cases. Table 4.3 shows the variables

included in the regression model. Relationship to the child, impact score and parent's

state of worry were significant in the model. Fathers were less likely than mothers to

seek help (OR=.386, 95% CI=.163,.915) and parents' worry was negatively

associated with help-seeking (OR=.134, 95% CI=.051, .349). In addition, higher

impact scores (OR=1.514, 95% CI=1.085, 2.114) was associated with increased

help-seeking. None of the other variables were independently significant in predicting

help-seeking (see Table 4.3).

Table 4.3 Regressions of associations between help-seeking, socio-demographics, parent's state of worry and perceived mental health of the child (n=529)

Variable	Odd ratio	95% CI	P value
Child's age	.973	.792, 1.197	.797
Child's gender (Boy vs girl)	.787	.404, 1.535	.483
Language (English vs other)	.601	.088, 4.092	.603
Ethnicity			.413
Relationship to child (Mother vs father)	.386	.163, .915	.031**
Psychosocial difficulties			
Hyperactivity	1.045	.899, 1.227	.596
Emotional problems	.891	.768, 1.033	.127
Conduct problems	.885	.716, 1.095	.262
Peer problems	1.124	.921, 1.372	.250
Prosocial behaviours	1.016	.832, 1.240	.879
Impact score	1.514	1.085, 2.114	.015**
Parental worry (Yes vs No)	.134	.051, .349	.000**

Note. CI=Confidence Intervals

** indicates significance value, p<.05

Discussion

The current study aimed to explore factors associated with parents' help-

seeking for CYPMH by exploring parents' formal and informal help-seeking in a

representative sample of school-aged children in the UK. Logistic regression models were significant suggesting that parents' perceptions about a child's MH and their state of worry play an important role in seeking CYPMH support.

Firstly, to investigate if parents' perceptions of their child's MH are associated with parental worry, it was hypothesised that there will be a significant positive relationship. The hypothesis was accepted, and the regression model was significant (p<.05) suggesting ethnicity, relationship to the child, emotional problems, conduct problems, peer problems and impact scores were significant predictors of parents' state of worry. The current study added that Asian parents were less likely than White parents to be worried about their child's MH. This finding does not support previous evidence in an American sample suggesting that Asian mothers may report more parent stress than other mothers (Nomaguchi & House, 2013). This may be partly explained by the differences in sampling as the American sample referred to Asians belonging to dominant subgroups such as Chinese, Filipinos and Indians. Whereas, the current British sample represented South Asian subgroups (i.e. Pakistani, Bangladeshi, Indian) and Chinese. However, parent's worry about their child's MH is only one factor that can lead to parenting stress (Biswas et al., 2015). The current study was limited to the number of situational and environmental factors associated with having a child with a MH problem that could be included in the model. For example, a qualitative study found that British-Asian parents are worried about being 'gossiped' about or stigmatized which prevented them from seeking help (Bradby et al., 2007). Further evidence suggests that Black, Asian and minority ethnic (BAME) groups may be more likely to access CAMHS through compulsory rather than voluntary care pathways (Edbrooke-Childs & Patalay, 2019). Therefore,

the findings of this study should be further investigated to identify specific factors that may influence parents' worry about their child's MH.

Guardians were also less likely to be worried about the child's MH than mothers. This was an unexpected finding since the existing evidence indicates that foster parents are more likely to experience increased strain (Farmer et al., 2005). However, the current sample did not discriminate between foster parents, sibling or relative parenting or other non-biological parents. Additionally, the parent's state of worry was specific to child MH. An increase in emotional problems, conduct problems, peer problems and impact scores increased the chances of parents worrying. These findings coincide with existing studies highlighting that parents of children with MH challenges are at increased risk of parenting stress and worry (Crawford et al., 2017; Crawford & Simonoff, 2003; Ibrahim et al., 2014, 2016; Peters & Jackson, 2009). Additionally, this finding is in line with previous models highlighting a positive association between parents' negative affect (e.g. stress and depression) with parents' appraisal of the child's MH problems (Godoy et al., 2014). More specifically, a similar study in a US sample reported parents were more worried when experiencing higher impact and disruption in family routines due to the CYPMH (Ellingson et al., 2004).

Secondly, to investigate factors associated with the decision to seek help, it was hypothesised that there would be a positive significant relationship between psychosocial difficulties and help-seeking. The hypothesis was only partially accepted on the basis that the impact of the psychosocial difficulty was significant ($p<.05$) instead of any specific problem. In addition, relationship to child, and parent's state of worry were significant predictors of help-seeking. Generally, these findings

are in line with the Gateway provider model (Skylstad et al., 2019a) and the Longo model (Longo, 2005) which posit that demographic and individual factors, such as perceptions of health may influence help-seeking. In the current sample, fathers were less likely to seek help than mothers. Although studies show fathers do worry about their child's MH (Skylstad et al., 2019a), this finding is consistent with existing knowledge indicating that the presence of the father in the household inhibits the likelihood that the child will receive treatment (Zimmerman & Zimmerman, 2005).

The current findings are also in line with previous research suggesting that higher impact scores were related to increased chances of seeking help (Ellingson et al., 2004; Godoy et al., 2014). MH problems can result in impairment of education, social functions and quality of life (dosReis et al., 2010; Jokela et al., 2009; Patel et al., 2007) which parents can interpret as serious (Timlin-Scalera et al., 2003) and therefore may be inclined to seek help. Previous studies identified a link, suggesting that parental recognition of (1) the existence of a child's MH problem, (2) the severity of the problem, and (3) the associated impact could influence the decision to seek help (Reardon et al., 2017). These findings partly align with the current results and suggests that parents of a child with higher levels of impairment (e.g. low grades or constant problems at school), would be more likely to recognize the child's behaviour as problematic and seek help. However, research on problem type and presence of CYPMH problems suggests that parents of children with externalizing problems and symptoms (e.g. hyperactivity and conduct problems) are more likely to seek help than parents of children with internalizing problems (e.g. emotional problems such as depression and anxiety) (Godoy et al., 2014). This was not replicated in the current sample implicating a need for further investigations to differentiate between presence and impact of the child's MH on the parent's decision to seek help.

In line with the theme of the thesis and supported by the literature, parents who indicated they worried about the child's MH, were less likely to seek help. Some researchers are in agreement that parents hesitate to seek support due to negative attitudes towards seeking help (Andershed et al., 2017), concerns about trust (Coogle & Hanline, 2016; Simmons et al., 2011), belief about being able to manage the problem themselves (Bull & Whelan, 2006), and denial and fear of being stigmatized or judged (Bradby et al., 2007; Gray & Donnelly, 2015). This finding can also be partly due to parental perceived level of burden as previous studies highlight that the symptom severity and ratings of impairment predict service use (Algeria et al., 2004). However, this finding is contrary to similar US based studies that reported a positive association between parental worry about the child's behaviour and help-seeking (Ellingson et al., 2004; Godoy et al.,2014). Those studies focused on parents of younger children (<5 years) and those seeking formal support. Additionally, Ellingson and colleagues indicated that based on raw scores, only a small number of parents (<20%) who were worried spoke to a healthcare provider about the problem. Those studies may also be criticised for its smaller sample size (<300) when compared to this study. Similarly, Sayal and Taylor (2004) indicated only a 33% of the parents in their sample who had concerns expressed their concerns during primary care consultations. This further underscore the importance of the parent's emotion as an influencing factor to help-seeking and the need for further investigations. In addition, these findings further question which CYPMH problems parents consider as atypical in preteens and therefore warrants seeking help.

Policy, Practice and Research Implications

This was a study of parents' decision to seek help and not a formal preference trial or evaluation of the depth of support received, so no conclusions about the effectiveness of the informal versus formal support or which support parents prefer can or should be drawn from these findings. Further studies on effectiveness and preference on various sources of support in CYPMH is warranted as satisfaction has an important influence on help-seeking and whether parents go onto seek further help (Gulliver et al., 2010) or accept the support offered (Henderson et al., 2013).

In CYPMH, recognising the need for help can be challenging as parents perceptions of their child's MH difficulties differ from that of their child's, teachers and health professionals (Cleridou et al., 2017; Fält et al., 2017; Hawley & Weisz, 2003). These disagreements are reflected in parents reporting not feeling listened to or respected, further adding to frustrations and disappointment (Andershed et al., 2017; Hart et al., 2005). As a result, this can develop into a cycle of deciding to seek help then deciding to not seek further help. More rigorous studies in this area controlling for any previous experience parents have had with accessing support would be beneficial to the help-seeking literature.

Results from this study are useful in identifying possible areas of shortcomings that may require further investigation. For example, failing to include necessary subgroups in the development and delivery of early-stage interventions. From the results of this study, parents do access informal support and therefore, these support systems should be provided with the knowledge base to offer the necessary support. Information about identifying CYPMH disorders, ways to access help and treatment, and early-stage interventions should be widely disseminated and

accessible to the public. Additionally, embedded in policy should be the necessary emotional support guidelines for working with parents of children accessing CYPMH support. Furthermore, lowering parents' state of worry through routine screening and education about CYPMH could be considered.

Strengths and Limitations

This study accessed data from a large representative sample of parents of school-aged children in the UK. The sample also included various ethnic minority groups to aid with generalization. However, this study acknowledges some limitations. First, the authors only used data from 2008 of the TaMHS data to represent a cross-section of the population and as a result, causality cannot be addressed. Second, the data collected was based on self-report data from parents/carers. Due to self-report bias, some parents may report underestimated or inflated scores on psychosocial difficulties (Cheng et al., 2018). In addition, less than half of the total sample (n=529) responded to the help-seeking measure. This can be interpreted as a shortcoming in the measure used, as responses were limited to general practitioners (GPs), teachers, family members and friends. Parents who seek help from online resources or other sources were not reflected in the chosen measure. Future research may benefit from comparisons between face-to-face and online resources. In addition, parents were asked if they had ever been worried because their child seemed to be unhappy or disruptive. Due to parents' interpretation of worry and the subjective nature of the question, participants may have selected to express their first or most recent recall of their child being unhappy or disruptive, therefore neglecting other instances or lack thereof. Similarly, parents may not have reported being worried when their children were experiences other MH challenges. Finally, analyses were not conducted on parents' cultural, religious or

spiritual beliefs, or other contextual factors such as the promotion of MH and wellbeing programs at the schools. Such factors can influence whether parents seek help for CYP with MH problems (Choudhry et al., 2016; Health, 2004). Further, investigations into the difference in completers and non-completers of the help-seeking measure showed that increased prosocial scores resulted in parents not completing the help-seeking measure. Higher prosocial scores generally correspond to fewer difficulties in prosocial behaviours (Boe et al., 2016). Therefore, the current findings should be interpreted with caution and may not be generalisable to families reporting higher prosocial scores.

Conclusion

In conclusion, the findings from this study suggest that demographics, psychosocial difficulties and parents' state of worry can influence the decision to seek help. Involving informal support systems in the development and dissemination of information resources and interventions can help reach families where parents are less likely to seek formal help. It is agreed that SDM can lead to better outcomes, including help-seeking behaviour (Wakefield et al., 1998) and reduced worry about stigma (Hamann et al., 2006). SDM encourages families and service providers to work together to decide on care and treatment decisions including assessments (Charles et al., 1997). This suggestion is twofold in that help-seeking may also be viewed as an important first step to experiencing SDM. Therefore, collaborations between formal support systems, informal support systems, researchers and policymakers can promote patient-centred care throughout the CYPMH care and treatment journey.

Brief summary

This chapter investigated the role of parental emotions on help-seeking, and the findings suggest a negative association between parental worry and help-seeking. Ethnicity, relationship to the child, emotional, conduct and peer problems, and impact scores were significant predictors of parents' state of worry. Impact of the psychosocial difficulty, relationship to child, and parent's state of worry were significant predictors of help-seeking. Thus far the thesis has argued that parental emotions may influence CYPMH decision-making. The next chapter explores SDM in CAMHS, building on the methods used in this chapter to consider contextual factors within which CYPMH decisions are made, and utilising clinician reported psychosocial difficulties.

Chapter 5 Associations between Clinical Characteristics and Parental Experience of Shared Decision Making using Administrative Data from Child and Adolescent Mental Health Services (Study 3).

The importance and benefits of parental involvement in care and treatment decisions, more specifically, SDM, have been established in the previous chapters. This chapter adopts a realist perspective to quantitatively explore parents' experience of SDM in CAMHS and discusses associations with demographics, MH difficulties, additional problems and the impact of the MH problems on the CYP. These associations are discussed in the context of previous studies and recommendations are discussed for future research, interventions and target groups. Limitations of the study are also considered.

Aims and research questions

This study has two overarching aims. First to explore the frequency of *quality* parent-reported experience of SDM in CAMHS and second to examine associations between parental reported experience of SDM and clinician's perceptions of a) the CYP's MH status, b) additional complex problems, and c) impact the MH problems have on the CYP. Findings from this study may broaden our understanding of the frequency of which parents experience SDM at CAMHS and help identify and target priority groups who are at risk for lower quality SDM. Based on the review of the literature and the study's aims, the following research questions and predictions guide the selected analyses in this study.

1. How often do parents report experiencing SDM in CAMHS?

2. What is the relationship between the child's clinical characteristics (i.e. presence of MH difficulties, presence of additional complex problems and impact on the CYP) and parents' experience of SDM when controlling for demographic characteristics (i.e. child's age, gender, ethnicity, relationship to child)?

H_1: There is a positive relationship between clinical characteristics and parents' experience of SDM.

H_2: There is a relationship between demographic characteristics and parents' experience of SDM.

3. Which model is best to predict parents' experience of SDM when adjusting for the influence of service-level characteristics?

H_3: It is expected that the best-fitting model for predicting parents' level of SDM would include a combination of individual (i.e. clinical and demographic characteristics) and service level factors.

Methods

Participants

A secondary analysis was conducted on administrative data routinely collected from parents and clinicians at CAMHS, more specifically those accessing the Children and Young People's Improving Access to Psychological Therapies (CYP IAPT). The CYP IAPT programme was an initiative led by the Department of Health and NHS England. During 2011 and 2015, data were collected from 81 services within the NHS, local authorities, and voluntary sector providers. Data collection included: (1) demographic information, (2) outcome and experience measures, including in-depth measures to help plan an intervention and agree key goals, and (3) the clinician recorded problem descriptions and contextual information (e.g. family situation). Data were uploaded via secure data handling to a data storage provider and collated centrally (Fonagy et al., 2017).

The sample included in the current study was composed of 3175 cases of CYP accessing care from 58 NHS CAMHS in the UK. The CYP were between the ages of 0 and 23 years with a mean age of 11.08 (SD=3.93) years at the point of data collection. The sample was predominantly White (68%) with a little over half the sample being parents of girls (52%), and the majority of the sample being mothers (66%) (see Table 5.1).

Table 5.1 Characteristics of the sample

Characteristic	n (%)
Demographics	
Relationship to child	
Mother	2084 (66)
Father	192 (6)
Both parents	790 (25)
Other	109 (3)
Age of child	
0 to 10	1304 (41)
11 to <25	1871 (59)
Ethnicity	
White	2167 (68)
Mixed race	182 (6)
Asian	232 (7)
Black	150 (5)

Characteristic	n (%)
Other	444 (14)
Gender of child	
Male	1539 (48)
Female	1636 (52)
Psychosocial difficulties	
Separation Anxiety	706 (22.24)
Social Anxiety	782 (24.63)
General Anxiety	845 (26.61)
[a]OCD	403 (12.69)
Panic disorder	511 (16.09)
Agoraphobia	358 (11.28)
Depression	796 (25.07)
Self-harm	448 (14.11)
[b]ADHD	440 (13.86)
Conduct disorders	507 (15.97)
Difficult to manage	588 (18.52)
Family problems	777 (24.47)
Attachment problems	496 (15.62)
Peer problems	757 (23.84)
Other	1824 (57.45)

Characteristic	n (%)
Additional problems	
Learning disabilities	283 (8.91)
Autism	375 (11.81)
Child in need	218 (6.87)
Experience of abuse	395 (12.44)
Parental health issues	704 (22.17)
Financial difficulties	238 (7.50)
Other	614 (19.34)
Impact on CYP	
Home	833 (26.24)
School/work	796 (25.07)
Community	488 (15.37)
Service engagement	261 (8.22)

[a]Attention-deficit and hyperactivity disorders; [b]Obsessive compulsivity disorders; M=Mean; SD= Standard deviation; CYP= Children and young people

Note: N=3175 (n refers to the count for each condition). Percentages representing psychosocial difficulties, additional problems and impact may not total 100 due multiple responses for each case.

Measures

Demographic characteristics

The dataset reflected family demographics including the service attended. The child's gender was categorised as male, female or other. Age of the child was

measured on a continuous scale ranging from 0 to 23. Ethnicity was recorded using the 2001 Census classification (Office for National Statistics, 2012), and based on self-report by the young person or their parent/guardian. However, for the purpose of analysis, ethnicity was collapsed into 5 broad categories: White, Mixed-race, Asian, Black and Other ethnic groups. The relationship to child was categorised as father, mother, both parents, and other to reflect the person completing the SDM measure. The anonymised site identifier was also reported to denote the CAMHS the families attended.

Clinician reported psychosocial difficulties

The Current View Tool (CVT) allows clinicians to rate a number of presenting MH problems, and additional complex and contextual factors according to their understanding of the presence or impact upon the CYP at the time of completion (see Appendix B). The CVT is a clinician-reported measure that routinely captures information about the child and family. The clinician utilises information from meetings with the CYP and family, pre-meeting liaison (e.g. referrals, teachers and other health professional notes), patient-reported outcomes measures and clinician-rated measures. The CVT records 30 presenting problems, 14 additional complex problems, as well as six contextual problems (i.e. impact on the school or home) and issues in education, employment or training. Generally, the ratings of the CVT do not imply a diagnosis (Jones et al., 2013; Martin et al., 2017). However, routinely collected data have several strengths including comprehensiveness, cost-effectiveness and ability to capture the same data throughout the NHS allowing for comparison (McKee & Chenet, 1997). The items on the CVT were used to inform the following variables:

Clinician reported CYPMH difficulties

Responses to the severity of the CYPMH problems were rated on a five-point scale with the response categories "None", "Mild", "Moderate", "Severe", and "Not known". To capture the presence of the MH problem, responses "None" and "Not known" were coded as 0 and labelled as condition absent. All other responses were coded as 1 and labelled as condition present. Therefore, responses to statements such as "Anxious away from home" or "Eating issues" or "Depression/low mood" represented the presence or absence of the CYPMH problem as reported by the clinician. Items with low frequencies (i.e. those representing less than 10% of the sample) were grouped together in a single category and labelled "Other" to avoid including under-powered groups in the main analysis. This group included items such as Gender Identity Disorder, Selective mutism and Substance abuse which clinicians reported on fewer occasions. As a result, 14 distinct problem types were represented in addition to "Other" totalling to 15 constructs. For the current sample, clinicians reported that the CYP experienced a mean 3.22 (SD=2.26) of the 15 categories of MH difficulties.

Clinician reported impact of the MH difficulties on the child or young person

To measure the impact of MH difficulties on the CYP, the contextual problem items of the CVT were used. Responses to the impact of MH difficulties were also rated on a five-point scale with the response categories "None", "Mild", "Moderate", "Severe", and "Not known". To capture the impact, responses "None" and "Not known" were coded as 0 and labelled as absent. All other responses were coded as 1 and labelled as present. The questions provided insight into 4 contextual problems (i.e. difficulties at Home, School, work or training, Community and Service

Engagement). The sample included in this study had a mean 0.75 (SD=0.90) out of 4 on the impact on the CYP functioning.

Clinician reported presence of additional complex problems

To measure the presence of additional complex problems, 14 items including statements such as "Looked after child", "Parental issues" and "Deemed child in need of social services input" were included. Responses to additional complex problems were categorised as "Yes", "No" and "Not known". To capture the presence of additional problems, the responses "No" and "Not known" were coded as 0 and labelled as absent. "Yes" to any of the items were coded as 1 and labelled as present. Similar to MH difficulties, the additional complex problems with low frequency (e.g. having current protection plan and contact with the justice system) were grouped into a category called "Other" resulting in 7 constructs in total. The current sample had a mean of 0.89 (SD=1.15) additional complex problems out of the possible 7.

Outcome Variable

Parent-reported experience of SDM

To measure parent-reported experience of SDM using the available measures collected in the dataset, the following four items of the Experience of Service Questionnaire (ESQ) were used: 1) I feel that the people who have seen my child listened to me; 2) It was easy to talk to the people who have seen my child; 4) My views and worries were taken seriously and 6) I have been given enough explanation about the help available here. Previous studies have also utilised these items as a composite score for SDM (Edbrooke-Childs et al., 2015). Responses to these questions were dichotomized and coded as Yes = 1 and No = 0. For the

purpose of this research, an overall composite score of the 4 items were tallied and a

parent with a total of 4 was classed as experiencing higher levels of SDM and any

value less than 4 was classed as experiencing lower levels of SDM. Previous

researchers have utilised similar approaches to discriminate between levels of SDM

(Solberg et al., 2014). The 4-item SDM measure displayed high internal consistency

(Cronbach's alpha 0.9) with the current sample (Tavakol & Dennick, 2011).

Design and statistical analysis

Preliminary tests

To ascertain whether Logistic Regression models could be used for the study

and to ensure the validity of the data, all assumptions were tested. Firstly, the

dependent variable was measured on a dichotomous scale and all predictor

variables to be included in the analyses were measured on categorical scales which

met the basic requirements for conducting logistic regressions. Secondly, the cases

were independent observations (i.e. episodes of care) and did not include repeated

or matched data. Additionally, the sample size of 3175 was deemed adequate given

the number of predictor variables (n=30), resulting in a ratio of 635:6 (Tabachnick &

Fidell, 2007). The assumption of no multicollinearity was also met. All Variance

Inflation Factor (VIF) scores were <5 with a mean VIF of 1.57 implying that none of

the independent variables correlated highly with each other (Coakes, 2007). All

potential outliers were removed prior to analysis (Stoltzfus, 2011).

Main analysis

Before constructing the multilevel models, exploratory analyses were

conducted to investigate the associations between clinical characteristic variables

and parent-reported experience of SDM controlling for demographics and using a

conventional (i.e. standard/simple single-level) logistic regression (model 1). This unadjusted model included only individual/family level variables and did not consider the service level influence. This was based on the assumption that age and gender may influence the parents' SDM involvement in addition to the CAMHS attended. For instance, some services may distinguish clinics between age groups, and CYP may change services once achieving a specific age. This approach limits compositional confounding in later regression analyses (Merlo et al., 2016).

The multilevel mixed-effect logistic regression analysis was then conducted with MH difficulties, additional complex problems, and the impact of the MH difficulties as potential predictors of parents' experience of SDM (higher vs lower) while controlling for demographics. The results of associations are shown as ORs with a 95% CIs. A two-sided p-value of <0.05 was considered significant (du Prel et al., 2009).

In this study, multilevel modelling was used to account for the clustered data structure (adjusted model) where service users are nested within service providers. The data have a two-level structure with individuals (level 1) nested within NHS CAMHS (level 2). Families attending the same CAMHS site may share similar experiences compared to families who are attending other CAMHS. This sample dependency biases estimates of standard errors when examining the effects of services providers. Therefore, given the nature of the current clustered data, multilevel modelling was favored for adjusting for the biased standard errors (Merlo et al., 2016).

To estimate service level variation in the parent's experience of SDM, first, a null model was fitted using the Service ID. In model 2, demographic variables (i.e. age, ethnicity, relationship to child, gender) and clinical characteristics (i.e. presence of MH difficulties) were included and model 3 included additional complex problems and impact on the CYP. The third model was also important as the additional needs of the family may influence the parents' SDM experience.

To address the aims of the study, the model derived from the simple logistic regression analysis was compared to those in the multilevel analysis. Researchers argue that estimates of specific effects (e.g. OR) provide insufficient information if they are not accompanied by measures of general contextual effects (i.e. area under the receiver operating characteristic curve, AUC) (Merlo et al., 2016). Comparisons of effects variations were conducted to estimate the amount of variation explained by each model while controlling for various factors. Percentage (%) variation of the model was calculated using ICC (LeBreton & Senter, 2008) for adjusted models (service level) and pseudo R-square (Smith & McKenna, 2013) for the unadjusted model (individual level). In line with Merlo et al., (2016) recommendations for multilevel logistic regression of discriminatory accuracy, the AUC was estimated and compared. AUC represented the degree or measure of separability. It explained how much the model is capable of distinguishing between groups. (Wagner & Merlo, 2015). Therefore, higher the AUC, better the model was at distinguishing between lower and higher quality experiences of SDM. An increase in AUC represented the added value of the potential service level variables.

Additionally, the Akaike information criteria (AIC) was used as a measure of goodness of fit of the models. Models with the smaller AIC suggested a better fitting

model for the sample and differences of 5 or more were considered substantial (Akaike, 1987). STATA (v 11) was used to conduct the analyses (STATA, 2013).

Ethical approval

Secondary analysis of routinely collected administrative data from CAMHS was conducted for this study. The Child Outcomes Research Consortium (CORC) constructed the initial dataset that houses data from various CAMHS across the UK. The PhD candidate applied for permission to analyze the data, and the request was granted (Appendix C). Data was received in an anonymous format and only accessible via the CORC's password-protected server. As a result, this study did not require any institutional ethical approvals (NHS, 2020; Tripathy, 2013) and the PhD candidate was given permission to proceed by the UCL REC.

Results

Frequency of parental SDM in CAMHS

First, an exploration of SDM was conducted using descriptive data from the SDM measure. Overall, almost 69% (2198/3175) of the parents reported experiencing higher levels of SDM. For each of the four items on the SDM measure, over 90% of parents reported that it was "true" the healthcare provider related to them in ways consistent with SDM.

Association between predictor variables and parents experience of SDM (unadjusted model)

An exploration of associations between 1) demographics (i.e. child's age, child's gender, relationship to child and ethnicity) and 2) clinical characteristics including MH difficulties, additional problems, the impact on CYP functioning, and the

parents' experience of SDM revealed statistically significant (p<.05) associations

between ethnicity, relationship to the child, presence of conduct problems or learning

difficulties and the parent's SDM experience. More specifically, Asian parents

(OR=1.95, 95% CI =1.4, 2.73) and parents having children with learning difficulties

(OR=1.45, 95% CI =1.06, 1.97) were more likely to report higher levels of SDM.

However, having both parents involved in the child's care and treatment decisions

(OR=0.3, 95% CI =0.21, 0.44) and being a parent or carer of a child or young person

experiencing conduct problems (OR=0.78, 95% CI =0.63, 0.98) were associated with

lower levels of SDM. The regression model explained 6% of the individual level

variance in SDM. No other significant associations were identified. Results of the

model are presented in Table 5.2.

Factors predicting parents' experience of SDM (adjusted model)

Due to the nested nature of the dataset, the ICC was computed using the

CAMHS service ID and revealed almost 48% (ICC=.479) of the variance was

explained at the service-level (null model). In model 2, which included demographic

information and the presence of MH difficulty items, only the presence of conduct

problems was found to be significant and predicted lower levels of SDM (OR=0.75,

95% CI =0.59, 0.94). In model 3, which further included additional complex problems

and impact factors, again only the presence of conduct problems remained

significant and associated with lower levels of SDM (OR=0.29, 95% CI =0.52, 0.58).

No other significant associations were identified. The results of the models are

presented in Table 5.2.

Model diagnostics

Overall, 3 models were fitted in addition to the null model: one unadjusted model and 2 adjusted models. It was observed that the adjusted models (2,3) accounted for a higher variation in parents' experience of SDM than the unadjusted model (AUC change of 8%). This indicated that the added value of service level data introduced a higher chance of that model being able to distinguish between parents experiencing higher or lower levels of SDM. Model 2 had the lowest AIC and as such was selected as the model that best fitted the current dataset and also estimated a better variation in parents' experience of SDM. In model 3, the inclusion of additional problems explained 1 % more service level variation but higher AIC than model 2. AUC and AIC scores are reported in Table 5.2.

Table 5.2 Regression coefficients, variation and fit indices across fitted models

Parameters	Simple logistic regression analysis (unadjusted)		Multilevel logistic regression analysis (adjusted)			
	Model 1[a]		Model 2[b]		Model 3[c]	
	OR (SE)	95% CI	OR	95% CI	OR	95% CI
Age of child:						
11 to <25 vs 0 to 10	1.02(.09)	.86-1.21	.97(.09)	.8-1.12	.96(.09)	.79-1.16
Gender of child:						
male vs female	1.03(.88)	.87-1.22	1.06(.1)	.89-1.27	1.06(.1)	.85-1.27
Ethnicity of child:						
Mix vs white	.94(.16)	.67-1.32	1.04(.2)	.71-1.51	1.02(2)	.7-1.49
Asian vs white	1.95(.33)**	1.4-2.73	1.45(.3)	.99-2.14	1.43(.28)	.97-2.11
Black vs white	1(.19)	.69-1.46	.81(.16)	.55-1.19	.81(.16)	.55-1.2
Other vs white	1.19(.14)	.94-1.51	1.06(.15)	.8-1.4	1.07(.15)	.81-1.41

Parameters	Simple logistic regression analysis (unadjusted)		Multilevel logistic regression analysis (adjusted)			
	Model 1[a]		Model 2[b]		Model 3[c]	
	OR (SE)	95% CI	OR	95% CI	OR	95% CI
Relationship to child:						
Father vs mother	1.1(.19)	.78-1.55	1.05(.91)	.74-1.5	1.05(.19)	.73-1.5
Both parents vs mother	.3(.56)**	.21-.44	.76(.18)	.47-1.2	.75(.18)	.47-1.2
Other vs mother	1(.292)	.57-1.77	1.22(.35)	.69-2.15	1.16(.35)	.64-2.1
MH difficulties:						
Separation anxiety	1.12(.11)	.91-1.36	1.21(.14)	.97-1.51	1.21(.14)	.97-1.51
Social anxiety	.99(.1)	.81-1.21	.96(.1)	.77-1.18	.97(.11)	.78-1.21
General anxiety	.85(.08)	.7-1.02	.85(.09)	.7-1.04	.84(.09)	.69-1.03
OCD	.94(.12)	.74-1.2	.99(.13)	.76-1.29	.1(.14)	.77-1.3
Panic disorder	1.06(.12)	.85-1.33	1(.13)	.79-1.28	.1(.12)	.78-1.3

Parameters	Simple logistic regression analysis (unadjusted)		Multilevel logistic regression analysis (adjusted)			
	Model 1[a]		Model 2[b]		Model 3[c]	
	OR (SE)	95% CI	OR	95% CI	OR	95% CI
Agoraphobia	.98(.13)	.76-1.28	1.03(.14)	.78-1.35	1.02(.15)	.77-1.35
Depression	.96(.09)	.79-1.16	.94(.1)	.77-1.15	.96(.1)	.78-1.17
Self-harm	.94(.11)	.75-1.19	.88(.11)	.7-1.12	.87(.11)	.68-1.12
ADHD	.88(.1)	.7-1.11	.9(.11)	.71-1.16	.91(.12)	.71-1.16
Conduct disorders	.78(.09)**	.63-.98	.75(.09)**	.6-.94	.75(.09)**	.59-.94
Difficult to manage	1.09(.12)	.88-1.34	1.12(.13)	.89-1.42	1.14(.14)	.9-1.44
Family problems	.99(.11)	.8-1.23	.98(.12)	.78-1.14	.98(.12)	.78-1.24
Attachment problems	1.07(.12)	.85-1.34	1.17(.15)	.91-1.49	1.16(.15)	.91-1.5
Peer problems	.89(.09)	.73-1.07	.87(.09)	.71-1.07	.88(.09)	.72-1.9
Other	.87(.09)	.72-1.06	.83(.09)	.7-1.02	.82(.09)	.66-1.02

Parameters	Simple logistic regression analysis (unadjusted) Model 1[a]		Multilevel logistic regression analysis (adjusted) Model 2[b]		Model 3[c]	
	OR (SE)	95% CI	OR	95% CI	OR	95% CI
Additional problems						
Learning difficulties	1.45(.23)**	1.06-1.98			1.16(.19)	.84-1.6
Autism	.91(.12)	.7-1.18			.9(.13)	.68-1.19
Child in need	.74(.12)	.84-1.03			.71(.13)	.5-1
Experience of abuse	.87(.12)	.67-1.14			.88(.13)	.66-1.18
Parental health issues	1.04(.11)	.85-1.27			1.12(.13)	.89-1.4
Financial difficulties	1.12(.18)	.81-1.52			1.01(.17)	.72-1.42
Other	1.18(.13)	.95-1.47			1.2(.14)	.95-1.52
Impact:						
Home	1.09(.1)	.9-1.31			1.04(.11)	.85-1.28

Parameters	Simple logistic regression analysis (unadjusted) Model 1[a]		Multilevel logistic regression analysis (adjusted) Model 2[b]		Model 3[c]	
	OR (SE)	95% CI	OR	95% CI	OR	95% CI
School/work	.9(.09)	.75-1.09			.84(.09)	.68-1.03
Community	1.01(.12)	.8-1.26			1.09(.14)	.85-1.4
Service engagement	1.14(.17)	.85-1.54			1.05(.17)	.76-1.44
Amount of variance						
Pseudo R_sq (%)	.06 (6)					
ICC (%)			.44 (44)		.45 (45)	
AUC	.6511		.7354		.7391	
AUC change*			.0843		.0037	
Goodness of fit						
AIC	3756.85		3422.85		3433.82	

Parameters	Simple logistic regression analysis (unadjusted)		Multilevel logistic regression analysis (adjusted)			
	Model 1[a]		Model 2[b]		Model 3[c]	
	OR (SE)	95% CI	OR	95% CI	OR	95% CI
AIC change*			-334		10.97	

Note. AIC= Akaike information criteria; AUC= Area under the receiving curve; ICC=Intraclass correlation coefficient; OR= Odds ratio; CI= Confidence intervals; MH= Mental health; OCD= Obsessive compulsive disorder; ADHD= Attention deficit hyperactivity disorder

N=3,175

**p>.05

*: change in relation to the previous model

Null model: SDM + Service ID

[a]Model 1: SDM + demographics, MH difficulties, additional problems and impact (unadjusted)

[b]Model 2: SDM + demographics, and MH difficulties (adjusted)

[c]Model 3: Model 2 + additional complex problems and impact (adjusted)

Discussion

The current study aimed to describe parents' experience of SDM in addition to examining associations between parental reported experience of SDM and clinician's perceptions of the CYPMH, additional complex problems and the impact of the MH problems on the CYP. The results of this study indicated that almost 70% of parents reported experiencing higher levels of SDM at CAMHS. This high proportion of self-report SDM is also represented in previous CYPMH literature (Butler et al., 2014, 2015). However, the percentage of parents experiencing SDM is lower than parents reporting SDM in families accessing care for physical health conditions, (80%; (Valenzuela et al., 2014) and above families experiencing other chronic health conditions, (51%; (Fiks et al., 2012). This is consistent with the broader health literature discussed in Chapter 2 and in the European study by Coulter & Jenkinson (2005), reporting over half (51%) of their sample experiencing aspects of SDM.

In general, studies report adequate levels of SDM, but researchers agree that not all service users want to be involved in healthcare decision-making (Levinson et al., 2005). Furthermore, although parents in the current study reported high levels of SDM, it is not sufficient to represent the complex nature of SDM in a triad (Charles et al., 1999; Gabe et al., 2004) since observational and qualitative research found parent participation engagement in CAMHS to be low (Brinkman et al., 2009; Butler et al., 2014). However, it must be noted that these studies usually represent specific decisions, for example, parents facing challenges during medicinal decision-making (Brinkman et al., 2009). Also, with the increasing promotion for CYP to be actively involved in their care and treatment decisions (Koller, 2017), future studies can further explore how decision type and number of decision-makers affect levels of SDM in CAMHS.

To address the second research question, only individual -level data was used to explore relationships between the child's clinical characteristics, additional complex problems, impact and parents' experience of SDM while controlling for demographic characteristics. This study found significant associations between ethnicity, relationship to the child, presence of conduct problems and learning difficulties and SDM. It was hypothesized that there would be a positive relationship between clinical characteristics and parents' experience of SDM. This hypothesis was partially supported in that parents of children with learning difficulties experienced higher levels of SDM and those with behavioural problems reported lower SDM. There were no other significant relationships with the remaining clinical characteristics or level of impairment and SDM.

This finding aligns with previous research suggesting that patient and clinical characteristics is associated with SDM in CYPMH. Previous studies have demonstrated that higher levels of psychosocial difficulties were associated with lower experiences of SDM among parents (Edbrooke-Childs, Jacob, Argent, et al., 2015). More specifically, the more severe the behavioural difficulties the lower levels of parent SDM was reported (Lipstein et al., 2016). Similar to this, the current study suggests that the presence of conduct problems was associated with lower experiences of SDM and remains when controlling for service level factors. However, due to the cross-sectional nature of the study it is not feasible to determine the direction of the relationship. These results also corroborate qualitative findings suggesting that parents of children with behavioural problems *struggle* to be involved in SDM (Baker-Ericzen et al., 2013). Although previous studies found associations between other psychosocial difficulties (e.g. anxiety) and level of impact and parent's SDM (Edbrooke-Childs, Jacob, Argent, et al., 2015; Butler et al., 2015), these

findings were not replicated in the current sample. One possible explanation for this might be that previous samples used continuous variables for the clinical characteristics and therefore captured severity whereas the current study explored the mere presence of the MH difficulty as measured on a dichotomous scale which limits the capacity to explain variability (Altman & Royston, 2006).

The results of this study also revealed that the involvement of both parents in the CYP's MH care and treatment resulted in lower levels of SDM. The area of triad relationships in SDM in CAMHS is yet to shed light on this phenomenon and therefore, further investigations of who should be involved in the decision-making process may provide further explanations. However, this finding is not surprising as researchers in adult healthcare suggest that the involvement of additional family member increases the complexity of the interactional dynamics (Charles et al., 1997).

Parents identifying as Asian in the current sample was associated with higher levels of experiencing SDM. This is surprising because research focusing on minority ethnic groups (e.g. Blacks and Hispanics) report lower experiences of SDM than White Caucasians families (Brinkman, Hartl, Majcher, et al., 2013), and the previous chapter reported that help-seeking were less likely among Asian parents. Similarly, parents of children with learning difficulties reported experiencing higher levels of SDM. However, this was expected as policy guidelines for SDM among people with learning difficulties recommend the involvement of family members to support the patient (Royal College of Nursing, 2013). Additionally, this is not uncommon as parents usually assume the role of advocate and key decision-makers depending on age and capacity of the child (Brinkman et al., 2009).

For the third research question to select a best fitting model, it was hypothesized that the best-fitting model for predicting parents' SDM would include a combination of clinical and demographic characteristics. Model 2 was selected as the model that best fit the current dataset and did include a combination of clinical and demographic characteristics. This is consistent with the general SDM literature indicating the influence of both clinical and demographic characteristics on SDM among service users. For example, systematic reviews exploring factors influencing SDM have reported both service level and individual level characteristics influencing involvement in care and treatment decisions, highlighting demographic and health status as influencing factors (Boland et al., 2019; Gondek et al., 2017). Fitting the single-level model (model 1) accounted for a small percentage of individual-level variance (6%) in the parent's experience of SDM. When accounting for service-level influence and fitting the two-level models (models 2,3) a high percentage of service-level variation in SDM was explained by the model. Further investigations confirmed that models accounting for service-level data had an 8% better chance of distinguishing between parents' experience of SDM. This aligns with the existing literature confirming the importance of higher-level factors such as time constraints at the clinics, motivation and skills of the clinician, and available resources (Boland et al., 2019; Hayes et al., 2019; 2020). For the most part, these findings suggest that targeting factors at individual and larger ecological levels will remain important. Failing to acknowledge the service user characteristics and efficacy downplays the important role that individuals may play in contributing to their own care and treatment. At the same time, relying too heavily on only individual-level change neglects the role that environments and context have in influencing individuals' decisions and behaviors.

Future directions

The findings of this study suggest that policies and interventions to improve SDM in CAMHS should target both services and individuals. However, to give further insight into identifying target groups (e.g. parents of CYP with conduct problems), more information is needed. Therefore, future research including specific service level variables, such as population size of the service or number of clinicians will further enhance our understanding of factors influencing SDM. Additionally, it may be just as important to identify clinician-level variables such as years of experience or area of expertise that may further explain variation in experiences of SDM. Hence, a three-level analysis will help to inform our knowledge of this phenomenon. As confirmed by this exploratory study, more qualitative research is needed to help inform the SDM predictor variables (for example, presence of the MH problem vs severity of the problem vs impact) in order to capture critical thresholds that may influence parents' experience of SDM. Another recommendation for future research would be to repeat this study using a longitudinal sample to capture the directional nature of the variables and infer causality. Lastly, similar to Edbrooke-Childs et al. (2015), it is recommended that future studies include child-reported experiences of SDM, in addition to clinician reported SDM to fully capture the triad relationship. This is an important factor that can possibly influence parent's level of involvement (Gabe et al., 2004).

Strengths and limitations

First, this study incorporates a variety of observer-reported predictor variables beyond MH difficulties to help explore SDM. The majority of previous studies focused mainly on the self-report severity of the CYPMH difficulties. Additionally, using various constructs of MH difficulties added to the potential to target specific disorders

such as types of anxieties and mood problems that could influence SDM, as opposed to categorizing difficulties into broader groups of anxiety and depression. Second, considering the nested nature of the data and utilizing an innovative multilevel analytic approach highlighted the important potential influence of service level factors on an individual level experience of SDM. This is crucial to the study of SDM as without this knowledge, interventions and policies may be developed and implemented without taking this contextual level variation into account. This can result in the inefficient allocation of NHS funds and unproductive use of both the clinician's and service user's time.

In spite of these strengths, the findings of this study should be considered as exploratory and interpreted with caution due to several design and measurement limitations. The current data represents a cross-section of the population and therefore it was not possible to suggest directional correlations. Second, the items used to calculate the composite SDM score were taken from the self-report ESQ measure and therefore may be prone to bias. Although this measure has been used in previous studies as a measure of SDM (Edbrooke-Childs, Jacob, Argent, et al., 2015), a high percentage of the sample scored 4 out of 4 suggesting ceiling effects which are common in these types of measures (Sitzia & Wood, 1997). A qualitative exploration of parent's definition of SDM may help to identify if this measure is sufficiently capturing parent's perception of SDM in CYPMH. In the absence of the "ideal" measure, it may be important to use other methods of measurement such as observational measures (e.g. OPTION). On a similar point, the CVT, used in this study is not a diagnostic tool and simply a tool that captures information about the families. Therefore, the CVT can also be prone to bias as different clinicians may complete this measure differently. Another limitation is the low representativeness of

fathers and ethnic minorities in the sample due to the constraints of conducting secondary analysis of routinely collected data. This in itself is a limitation as the data was not collected under controlled conditions and there may be variations among sites on how data was collected. Another limitation of the dataset, with implications for the analysis and interpretation, was the pooled categorization of clinical characteristics (e.g. selective mutism and Gender Identify Disorder) which represented less than 10% of the sample. Together these low frequency problems accounted for over 50% of the total sample. This may influence the study's findings raising assumptions that these characteristics influence parents' experience of SDM in the same way. Despite the study's limitations it remains one of the few quantitative studies to examine parents' SDM in CAMHS in the UK and the knowledge gained can be used as a basis for future research.

Conclusion

In summary, this study has highlighted the need for using a multilevel approach to promoting and implementing SDM interventions in CAMHS, as suggested by the high service level variation (ICC=0.48) in parent-reported SDM. This identifies CAMHS sites to be a potential target for effective intervention. However, the findings of this study suggest that more research is needed if CYPMH data is to be modelled in this way. Ethnicity, learning difficulties, relationship to the child and conduct disorders were the only potential service user level factors that predicted parental SDM in a simple logistic regression and the presence of conduct disorders remained the only significant predictor variable when accounting for service level factors. Future analyses of SDM could aim to utilise more detailed measures of SDM and include HCP's level factors, such as, the clinician's years of experience, and service level factors, such as, population size, to help explain a

greater proportion of the variability in SDM. Future research could also obtain healthcare professionals' and parents' views to further understand the observed variance. Nonetheless, this exploratory study highlights the evident influence of service-level factors on parent's experience of SDM and suggests that families with children experiencing behavioural difficulties should be targeted for additional support if they are to be involved in the SDM process.

Brief summary

This chapter quantitatively explored parents' experience of SDM in CAMHS and highlighted the importance of individual and contextual factors on CYPMH decision making. Individual level factors, ethnicity, learning difficulties, relationship to the child and conduct disorders predicted parental SDM. However, the presence of conduct disorders remained the only significant predictor variable when accounting for service level data. Owing to the high frequency of parental SDM reported in CAMHS, contradictory findings in the extant literature, and significant influencing factors identified, the next chapter will aim to further understand parental SDM and the influence of emotions on decisions in clinical practice.

Chapter 6 Views and Experiences of Parents and Healthcare Professionals on Shared Decision-Making in Child and Adolescent Mental Health Services (Study 4)

Chapter 3 highlighted the emotional experiences of parents of CYP with MH problems and discussed the potential for these emotions to influence parents' engagement with care and treatment decisions. Themes underpinning positive emotional states such as relief and hope and negative emotions such as anxiety and frustration emerged. The themes were tested in Chapter 4, and the results confirmed that parents' state of worry had a negative association with parents' decision to seek help for CYPMH problems. The current chapter builds on these findings with a qualitative investigation to further triangulate findings and test the transferability of the theory. This study explored and discussed the influence of parental emotions, specific to SDM, and revealed key knowledge about SDM experiences including healthcare professionals' and parents' understanding of SDM in routine clinical practice.

Aims and research questions

This chapter has four primary aims. First, to provide insight into how HCPs and parents perceive SDM at CAMHS. This understanding can inform and provide a common language for researchers to use when studying this phenomenon. Second, to describe experiences of SDM from the perspective of HCPs and parents. Third, to qualitatively explore emotions as an influencing factor for involvement in CYPMH decisions. Lastly, to identify support systems used. This knowledge can inform the development of evidence-based decision support interventions and highlight the additional needs of decision-makers.

Several research questions were developed to address the above aims:

1.   How do parents and healthcare professionals describe SDM in current practice?

2.   What are parents' and healthcare professionals' views on the emotional experience of being involved in CYPMH decisions?

3.   How do parents' emotional experiences impact their involvement in the SDM process?

4.   Where do parents access decision-making support?

Methods

The research team and reflexivity analysis

The interviews and FGDs were mainly conducted by the PhD candidate. However, 2 FGDs were conducted by the NHS Trust's own clinical researchers to maintain the privacy of the parents. The PhD candidate has a background in health psychology, psychiatric research and policy development. The PhD candidate was empowered, as a non-UK national, to ask neutral questions as there were no professional affiliations. The PhD supervisors (JEC, PF, MW) with a background in CYPMH research and practice, provided guidance throughout this study. The social constructivist approach accepts the researcher as part of the research process and therefore, reflective journaling of thoughts was kept, and responses to data were discussed during supervision meetings.

Study design

A social constructivist grounded theory guided this study to develop a better understanding of parents' emotional experience as a concept that has implications for SDM. The relativist perspective of social constructivism grounded theory

assumes that reality is constructive and can differ across individuals and change over time (Charmaz, 2016). A priori knowledge obtained through literature reviewing (Chapter 3) was used to inform this study's research questions and was used extensively in the interpretation and final integration of the theory. A qualitative study design, analysing data from semi-structured FGDs and interviews, was deemed suitable to explore beliefs, views, attitudes and experiences, and was viewed an appropriate approach for exploring new areas of research (Guest et al., 2017).

Study settings

Participants were given the opportunity to choose between face-to-face interviews, phone interviews or in-person FGDs. Participants also had the opportunity to request that interviews be conducted at the NHS site or the university campus. These strategies were adopted to offer convenience, comfort and ensure privacy when conducting interview sessions.

Participant identification and selection

Parent participants in this study were recruited from the UK in two strands: 1) as part of the feasibility study for the Power Up for Parents (PUfP) trial within the NHS (Liverpool et al., 2019), and 2) through social media platforms or in-person advertising. Parents were eligible if they (1) had at least one child with a MH problem (0 to 24 years), (2) were over the age of 18, (3) had no known diagnosed MH problems and (4) had the ability to speak and understand English.

Parents were not invited to participate if they indicated current involvement in any other research that had the potential to influence this study or if the child or young person was being treated under the Mental Health Act (1983). Parents were

recruited through the NHS via referrals from clinicians. HCPs at the identified sites who participated in the Power Up for Parents trial relayed brief information about the study to the families, and parents who expressed interest were contacted by the site collaborator to be given further details about the study. Once the parents were happy to proceed, informed consent was taken, and the contact details of the parents were securely transferred to the PhD candidate to make contact and arrange an interview. Contact was made via email and/or phone call. If no answer, a reminder or follow up was sent a further 2 times, one week apart. If unable to make contact, participants were categorised as "unavailable".

HCPs were also recruited as part of the feasibility study for the Power Up for Parents trial. Information about the study was provided through presentations by the PhD candidate at staff meetings. The site collaborators also identified and recruited HCPs and contact details were passed to the PhD candidate to arrange interviews. Contact was made via email and/or phone call. If no answer, a reminder or follow up was sent a further 2 times, one week apart. If unable to make contact, participants were also categorised as "unavailable". All NHS staff working with families consisting of a child or young person experiencing MH problems were eligible to be part of the study. No further inclusion criteria were specified. Thus, the sample consisted of HCPs with different expertise, from varying levels of the organisation and a broad range of years of work experience.

Sample characteristics

Overall, data from N = 55 participants were included in the study. Four focus groups were conducted, n=2 FGDs with parents and n=2 with HCPs. The mean duration of the FGDs was 41.5 minutes and the mean number of participants was

5.5. Additionally, *33* interviews with a total of n = *19* HCPs and n=14 parents were conducted. The mean duration of the interviews was 26.2 minutes. Of the total number of interviews and FGDs, 2 parent interviews and the 2 parent FGDs were conducted by the research assistant at an NHS CAMHS due to concerns around confidentiality and privacy. All remaining interviews and FGDs were conducted by the PhD candidate. In order to ensure anonymity when reporting, the descriptive characteristics of participants were not matched to the participant ID, instead only informative labels were attached to the contributions. Additional quotes are presented in Appendix J.

Parents

Thirty-six parents consented to be part of this study. However, only 14 parents were interviewed and 10 participated in FGDs. For the remaining "unavailable" participants who consented it was either not possible to contact them on the email address or phone contact provided by the site collaborator or not possible to arrange a convenient time for an interview. Of the total number of parents, there were n=22 mothers and 2 fathers with a mean age of 44.88 (SD=6.76). The majority of the sample (96%) identified as White or White British ethnicity and the remaining (4%) identified as Asian. The mean age of their children was 13.88 (SD= 2.8) and experiencing a range of MH problems as reported by the parents. Seven (29%) were boys, sixteen (67%) were girls and one (4%) other. Table 6.1 presents the characteristics of the parents who participated in this study.

Table 6.1 Characteristics of parents participating in interviews and focus group discussions

Variable	Interviews (n=14)	FGDs (n=2)	Total sample (n=24)
Parent's age			
Mean (SD)	45.93 (6.12)	43.4 (7.65)	44.88 (6.76)
Range	36-53	31-54	31-54
Relationship to child n(%)			
Mother	14 (100)	8 (80)	22 (91.67)
Father	0 (0)	2 (20)	2 (8.33)
Ethnicity n(%)			
White	14 (100)	9 (90)	23 (95.83)
Other	0 (0)	1 (10)	1 (4.17)
CYP's age			
Mean (SD)	14.36 (3.61)	13.2 (0.63)	13.88 (2.8)
Range	8-22	13-14	8-22
CYP's gender n(%)			
Male	5 (35.71)	2 (20)	7 (29.17)
Female	9 (64.29)	7 (70)	16 (66.67)
Other	0 (0)	1 (10)	1 (4.17)
[a]CYP's clinical characteristics n(%)			
[b]ADHD	1 (7.14)	0 (0)	1 (4.17)

Variable	Interviews (n=14)	FGDs (n=2)	Total sample (n=24)
Anxiety	0 (0)	4 (40)	4 (16.67)
[c]ASD	1 (7.14)	0 (0)	1 (4.17)
Depression	2 (14.29)	0 (0)	2 (8.33)
[d]PTSD	1 (7.14)	0 (0)	1 (4.17)
Comorbidities*	8 (57.14)	0 (0)	8 (33.33)
Undiagnosed	1 (7.14)	6 (60)	7 (29.17)

*Comorbidities included a subset of ADHD, Anxiety, ASD, Depression, self-harm, suicide attempt, psychosis and Asperger's Syndrome

[a]Children and young people; [b]Attention Deficit and Hyperactivity Disorders; [c]Autism Spectrum Disorders; [d]Post-Traumatic Stress Disorders; SD= Standard deviation

Healthcare Professionals

Thirty-three HCPs consented to be part of the study. Nineteen were interviewed and twelve participated in FGDs. For the remaining "unavailable" 2 HCPs, it was not possible to arrange a time that was convenient during the recruitment period. HCPs represented a broad range of clinical expertise, worked with CYP from ages 0-25 years in an outpatient capacity and had an average of 7.54 (SD=6.24) years working experience in CAMHS. Table 6.2 presents the characteristics of the clinicians who participated in this study.

Table 6.2 Characteristics of HCPs participating in interviews and focus group discussions

Variable	Interviews (n=19)	aFGDs* (n=2)	Total sample (n=31)
Occupation n(%)			
Psychiatrist	4 (21.05)	1 (8.33)	6 (19.35)
Psychologist/Psychotherapist	2 (10.53)	5 (41.67)	9 (29.03)
Nurse	2 (10.53)	4 (33.33)	6 (19.35)
Other*	11 (57.89)	2 (16.67)	10 (32.26)
Clinical expertise n(%)			
Eating disorders	2 (10.53)	0 (0)	2 (6.45)
General*	17 (89.47)	12 (100)	29 (93.55)
Experience in CAMHS (years)			
Mean (SD)	6.36 (5.87)	9.40 (6.62)	7.54 (6.24)
Range	0.58-20	2.25-20	0.25-22

*Other represents Registrar, Occupational Therapist, Social Worker, Support Worker and Team Manager.

*Working in general children and youth MH settings which includes, but not limited to, behavioural, attention deficit and autism spectrum disorders.

[a]Focus group discussions

Data collection

Interview sessions (i.e. FGDs or individual interviews) were conducted between October 2018 and October 2019. Once participation eligibility requirements were met, the interview date and time was established. Before the interviews and FGDs, participants were briefed, and informed consent was taken (see Appendices D-F). For face-to-face sessions, consent forms were signed in the presence of the interviewer and for phone interviews, consent forms were signed in advance and permission to proceed with the interview was taken over the phone (see Appendix G). Demographic data specific to the nature of this study was also obtained (see Appendices H, I). Semi-structured interviews with open-ended questions were conducted. Probes were designed and utilised to generate further explanation from the participants without 'leading' the interviewee (Singer & Couper, 2017). Interview guides were informed by a previously published interview schedule and modified and refined to meet the aims of the current study (Eliacin et al., 2014). As this study was part of a larger study, Tables 6.3 and 6.4 present questions that were specific to the current study. Interview schedules were used as a guide and there was freedom within the interview protocol to explore some of the answers given (Ellis, 2016). Participants were debriefed at the end of the session and asked to contact the interviewer on the details attached to the information sheet if any further queries or ideas came up. Two initial phone interviews were conducted and used as a pilot. Interviewer's style and skills were discussed and refined during supervision before proceeding. Data collection was terminated once theoretical saturation was achieved. The data was deemed as saturated when the analysis did not produce any

new concepts nor further inform the theory development (Guest et al., 2006).

Interviews and FGDs were audio-recorded and transcribed verbatim.

Table 6.3 Interview schedule and related probes (parent interview)

Questions	Probes
What does SDM mean to you?	Who should be involved?
	Can you give any examples of you being part of the SDM process for your child's MH?
	What sort of decisions are you involved in?
How do you feel about the experience of SDM?	Do your experiences (feelings) affect your interest in the decision-making process?
Why is being part of the process important to you?	
Where do you access decision making support?	Is any additional support needed?

Table 6.4 Interview schedule and related probes (HCP interview)

Questions	Probes
What does SDM mean to you?	Who should be involved?
	Can you give any examples of you being part of the SDM process with families about a child's MH?
	What sort of decisions are families involved in?
How do parents appear when engaging SDM?	What is their emotional state?
	Do the experiences (feelings) affect their interest/input in the decision-making process?
Why do you think it is important for parents to be part of the SDM process?	
Where can parents access decision-making support?	Is any additional support needed?

Focus Groups

A minimum of 4 FGDs (parents, n=2 and HCPs, n=2) were planned and each expected to last 90 minutes. Participants were assigned to groups based on availability and preference. All participants were encouraged to express their thoughts sincerely and openly. HCPs with varying professional backgrounds (e.g. nurses, occupational therapists, psychologists, psychiatrists) or hierarchical positions (e.g. trainee positions and senior members of staff) were encouraged to respect each other's views. FGDs have been shown to be a useful qualitative tool to encourage active exchange of ideas and opinions among participants (Guest et al.,

2017). Focus groups for the HCPs were led by the PhD candidate and 2 parent FGDs were led by the NHS site's research assistant. The PhD candidate and the research assistant had three meetings to establish internal consistency on how the interview sessions should be conducted.

Individual Interviews

Individual face-to-face interviews or phone interviews were provided as options to account for participants' time and preference. Interviews were expected to last up to 60 minutes. Parent participants were offered full travel reimbursements if they decided to travel to the NHS site or the university to participate in face-to-face interviews. HCPs were not offered financial compensation but encouraged to participate in interviews during scheduled working hours. All clinician interviews were conducted by the PhD candidate and the majority of the parent interviews were also conducted by the PhD candidate with an exception of 2 interviews which were conducted by the NHS site's research assistant.

Data analysis

For this chapter, only responses to questions listed in Tables 6.3 and 6.4, addressing the current study's aims were analysed. The first four interview recordings (2 parents and 2 HCPs) were transcribed by the PhD candidate and a certified transcription company, with whom the AFNCCF and the UCL had an existing agreement, transcribed the remaining FGDs and interviews. All transcribed data were read in their entirety for accuracy and to obtain familiarity and an overall understanding of the content. Interviews were examined for more detailed descriptions of participants' views, and FGDs were examined for consensus or

disagreement between participants. Data were analysed using an overall thematic analysis approach (Braun & Clarke, 2006). More specifically, an iterative process consisting of open, axial and theoretical coding using inductive and deductive concepts were adopted. The iterative process involved moving backwards and forwards between the data and the emerging concepts. The first step generated initial codes from open coding in which units of meanings were derived from line-by-line analysis followed by axial coding to integrate and differentiate among subcategories. An independent investigator (JP, an experienced applied psychology data analyst) reviewed 3 random transcripts and generated codes. Codes were compared and discussed before inclusion. Theoretical coding was then used to identify relationships among categories. Themes were informed by Charles and colleagues' (1997) definition of SDM and the theoretically-driven themes identified in Chapter 3. The analysis was also deductive identifying new emerging themes from the data. Demographic data and anonymous transcripts were linked and coded in NVivo 11 (QSR International Pty Ltd, 2015). Memos were written during the coding process to capture impressions and to facilitate interpretations.

Ethical approval and trustworthiness

Ethical approvals were obtained from the NHS (see Appendix I.1) and university (see Appendix I.2) ethics committees. The participants received both written and oral information about the study's purpose, confidentiality, voluntary participation and their right to terminate the interview at any point. Participants had access to this information at least 24 hours before the interview sessions and were given the opportunity to ask any further questions before the start of the interview sessions. A relationship was established briefly with each interviewee before the interview. At the point of analysis, weekly discussions occurred during supervision

meetings to discuss emergent themes and achieve consensus. Additionally, response checking was done in the form of clarification probes throughout each interview to ensure the interviewer understood the information as the participant intended. The credibility was enhanced by triangulation, collecting data from parents and HCPs who may have different perspectives (Brooks et al., 1996).

Results

An overall concept, corroborating findings from Chapter 3, suggesting that parents are 'expected to, but not always able to' engage in SDM at CAMHS encapsulates the findings. Themes and subthemes described: 1) views and experiences of SDM, 2) parents' emotional state, 3) the (dis) advantages and (4) support systems parents accessed. The overarching themes were organized into a conceptual framework illustrating an evidence-informed affective appraisal model of CYPMH SDM (see Figure 6.1) The figure depicts the key decision-making actors and influencing factors. The affective appraisal approach to SDM recognises that affect and appraisal interact in shaping the decision-making process, influencing each other in a circular way where the decision elicits the emotional reaction, that in turn influences the appraisal of the decision, that again may influence a change in the emotional reaction. It is assumed that adequately supporting decision-makers can activate parents to engage in high quality SDM. In this way, emotional support would allow the identification of value and need associated with the decision-making process which are relevant to the parents, thus facilitating their involvement in SDM. An extended version of the model, including participants' quotes as evidence, can be

found in Appendix K. Table 6.5 also presents a summary of the findings, and how

the emerging themes addressed the research questions.

Figure 6.1 Conceptual framework of an emerging affective-appraisal model of parental involvement in SDM
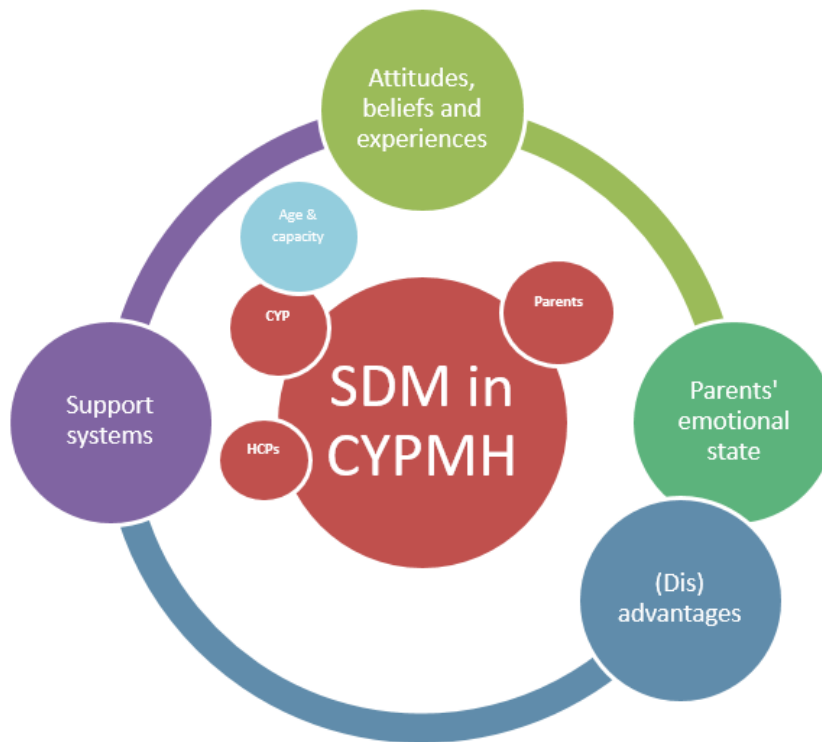
Table 6.5 Summary of how the qualitative findings address the research questions

Research Question	*Themes* and Subthemes
How do parents and healthcare professionals describe SDM in current practice?	*Views and experiences*
	Definition of SDM
	Positive experiences
	Negative experiences
What are parents' and healthcare professionals' views on the emotional experience of being involved in CYPMH decisions?	*Parents' emotional state*
	Positive emotions
	Negative emotions
	Mixed emotions
How do parents' emotional experiences impact on their involvement in the decision-making?	*(Dis) Advantages*
Where do parents access decision-making support?	*Support systems*
	Family's support network
	External agencies
	Online resources
	CYPMH site's internal resources

How do parents and healthcare professionals describe SDM in current

practice?

Views and experiences

Defining SDM

Generally, HCPs and parents both expressed an overall understanding that
SDM was the "involvement" of key decision-makers in a process described as
"collaborating", "exchanging information" or "working together" to identify a care or
treatment plan that is in the "best interest of the child". Most participants were
familiar with the concept and those who were unfamiliar were able to draw from their
personal, lived experiences to describe SDM.

> *For me, I suppose shared decision-making means some joined up thinking*
>
> *between clinicians, parents and young people if they're of an age where*
>
> *they can contribute and make their wishes known and their voices heard.*
>
> *(HCP, 13 years' experience)*

> *Oh, it means sitting down together, discussing things, listening and then*
>
> *coming up with a plan. (Parent of a 17-year-old)*

Some participants expressed that the extent to which each decision-maker
participates should also be considered. The age of the child, capacity and the nature
of the decision were key factors to determine inclusion.

> *I mean, because of her age at the moment, it is, I would say, mostly parent*
>
> *led. However, from when she was diagnosed, she was six when she was*
>
> *diagnosed, I made sure that I spoke to her about the diagnosis in an age*
>
> *appropriate way and what she understood from ADHD was. (Parent of an*
>
> *8-year-old)*

> *Erm.. Well depends on the sensitivity and age of the child because there*
> *are some things that I discuss and I am not ok for my son to be around.*
> *(Parent of a 10-year-old)*

Some participants also expressed that the consideration for levels of involvement may influence who makes the "final" decision. This suggested that at least one of the key-decision-makers remains with the "final" decision making power. However, participants reported that the "final" decision occurs after the exchange of information and ideas. In some instances, it meant that a subset of the decision-makers is involved in the "final decision".

> *Umm. I think it has been a mutual sort of everyone throwing ideas into the*
> *pot and then we kinda come up with a plan. The final decision is my*
> *daughter's. (Parent of a 17-year-old)*
>
> *…she's [the child] making a choice and she's compos mentis to make that*
> *choice, she's competent. (HCP, 4 years' experience)*
>
> *But it's not my decision, but I provide information so that they can make a*
> *decision. But they do rely on me providing a good quality set of*
> *information, without any bias. (HCP, 6.5 years' experience)*

Despite the CYP's age, participants generally expressed that it is important to include parents in the SDM process. Parents and HCPs stressed the importance of parents "being in the loop" and the impact on treatment outcome. However, it appeared that levels of involvement from parents varied.

> *Not necessarily involved but informed is probably a better way to put it.*
> *Just to be informed as to what they were covering. Maybe what they'd*

advised her to try and do over the week. That kind of thing just to be more

informed, I think. (Parent of a 16-year old)

One, it gives the child a sense of they're not doing it alone, they've got

somebody to go to who is informed and understands where they're going

and what they've been through and if they're not involved, they often feel

very alone and in my experience, there's a lot of worse outcomes when the

child is feeling alone. (HCP, 4 years' experience)

Positive experiences of SDM

When SDM, as understood by the participants, occurred, it was mainly described as a positive experience. HCPs expressed the usefulness of SDM and how it helped facilitate the care and treatment process. They also valued the CYP input and described it as very positive.

There are many occasions when a parent will not want a particular

intervention. And the child is saying, "Actually, I think I do." And the parent

will support that child, even though they don't necessarily agree with it,

which is heart-warming in a sense that they're giving the child the

opportunity to express their own wishes. (HCP, 6.5 years' experience)

Personally, I find it very useful because if you get the young person, the

parents and clinicians all get together to target the same goal then I find it

more successful, it's more likely the intervention works. Yeah (HCP, 1.5

years' experience)

Parents also found the experience of SDM very helpful. Some parents reported that this "shared" decision-making also occurred outside of the medical encounter and was practised within the family network. Therefore, experiencing SDM

within CAMHS was viewed as empowering and supported what some parents described as "interfamilial" decision-making.

> *I think it's quite helpful. I think it's something that we generally did as a family anyway before my child became unwell in autumn last year. But I think we had, I don't know, lost the skill of that maybe by what had happened. And, so, it's been quite helpful and quite empowering and helpful that CAMHS have helped us to re-establish that, really. (Parent of a 16-year-old)*

> *Yeah, I mean, I would have been able to make the decision on my own but it's nice, obviously, having the input from other people. (Parent of a 16-year-old)*

Negative experiences of SDM

There were more references made to negative experiences of not successfully achieving SDM. It was expressed that the lack of available resources limited options and therefore, impacted SDM. SDM was viewed as appropriate when more than one choice was available. This was challenging for services as parents and CYP were aware of additional resources that were not currently being offered by the CAMHS they attended, resulting in further disagreements. Similarly, disagreements existed between the parent and the CYP on various topics (e.g. reasons for accessing service) and this was difficult for HCPs to manage, especially if the parents were not actively engaged.

> *…there may not be much of a lay understanding about MH within a family. So, when it's come to asking them what they think or what they might want etc., they really have no idea because they've not come across anything*

like MH with their child or with any of their family members either. So, they really do then say, "Whatever you think is best, doctor." So, I think that then, obviously, makes shared decision making very hard. (HCP, 2.5 years' experience)

I would have liked a bit more communication from the people around us – as in just speaking to us, telling us what's going on, what they think, what the process is, what would be happening next – because we were literally waiting on people all the time. We didn't have a great deal of information, maybe because they didn't know, themselves. (Parent of a 14-year-old)

What are parents' and healthcare professionals' views on the parents' emotional experience of being involved in CYPMH decisions?

Parents' emotional state

Parents identified a broad range of emotional experiences that was categorised into positive and negative based on the finding of Chapter 3. Similarly, HCPs described a broad range of emotions observed in the parents they encountered in routine care. These emotions (e.g. anger, stress, frustration, relief) were described on a spectrum going "from one extreme to the other".

Well, it can be a massive range; some are relieved, some are frustrated, some maybe angry, some are just really grateful that they're being seen. It just goes from one extreme to the other. It depends on the person and from the family of the young person's personal experience of being in the service. (HCP, 20 years' experience)

So, quite often, the families are in a sort of high arousal state in that initial assessment and it can go both ways, really. (HCP, 16 years' experience s)

> *Obviously, there have been very, very emotional times. (NHS Parent of a*
>
> *16-year-old)*

Positive emotions

Participants described positive emotions arising after a challenging period. Some described feeling a sense of relief of finally receiving a diagnosis or finally getting seen at CAMHS. Additionally, after struggling with MH difficulties, parents also expressed joy in seeing a positive outcome from treatment decisions or being able to share the burdens.

> *Enthusiasm, sometimes. It's rare, but you do see it occasionally. Oh,*
>
> *another that pops into my head, not defensive, but almost like survival*
>
> *humour to get through, almost to normalise what the child is going through*
>
> *and what the family's going through. So, humour often pops out with some*
>
> *parents. (HCP, 4 years' experience)*

> *…it is more a sense of relief and being a bit more hopeful by the time they*
>
> *finish the session. (HCP, 10 years' experience)*

> *Because after I understood what he is going through, or what I can do to*
>
> *help him, it became much, much less stressful. And in general, I am very*
>
> *happy with him and I don't have much stress anymore. (Parent of a 14-*
>
> *year-old)*

Negative emotions

On the other end of the spectrum, parents experienced negative emotions such as anxiety, worry, anger, frustrations and fear. These feelings seemed to be easily identifiable by HCPs in most cases and participants reported that these emotions varied among persons and situations.

They can be anxious themselves, obviously, about their situation. (HCP, 7 months experience)

I see a lot of frustration. Sometimes a lot of anger from the young people's families about the time that they've had to wait for specific treatments. (HCP, 1 year's experience)

…we were all quite lost and not really knowing the right way forward and what to do with J. And, at times, that was horribly overwhelming and incredibly stressful. (Parent of a 16-year-old)

I'm just anxious that I am making the right decision. That I have got all the information I need to be able to make that decision. And then I think afterwards, I'll still have a bit of a niggle, "Have I chosen the right path?" (Parent of a 16-year-old)

Mixed Emotions

Parents also described emotions as co-occurring or described having "mixed" feelings. Parents reported having to focus on the outcome of involvement and therefore, despite experiencing negative emotions, they felt a need to be involved. This conflict within themselves resulted in positive and negative feelings co-occurring. To illustrate, one parent stated,

Erm. Very mixed emotions. I mean you would rather not be in those decisions at all. But when you are in that situation, I am glad that she wants me there, I am glad that she wants me to support her and I am very glad that I have some idea of what is going on so I can support her more effectively. Umm I mean all of us are highly anxious. The anxiety of worrying about the wellbeing of my child. You got the anxiety at the initial sessions of what are these people thinking of you. There are lots of lots of

feelings to be anxious, but you manage it because you have to. (Parent of

a 17-year-old)

How parents' emotional experiences impact their involvement in the decision-making process?

(Dis) Advantages

Parents' emotions influenced their involvement in care and treatment decisions. In some instances, the reverse also occurred where the involvement also affected the parents' emotional state. Both negative and positive emotions influenced involvement. More expectedly negative emotional states resulted in parents not being actively involved and positive emotions encouraged involvement. In some instances, the negative emotions appeared to complicate the SDM process as it made it difficult to participate even if they wanted to. However, participants also expressed that negative emotions made some parents more "forceful" suggesting a form of over-involvement. Similarly, with some positive emotions, when parents were comfortable or fully trusting of the HCPs, they decided to be less involved. Other emotions such as relief, content, satisfaction and hope had a more positive impact on the SDM process and appeared to encourage parents to be actively involved.

If you're [parents] anxious and distressed, the anxiety may want you to

kind of take full control and therefore, you're [parents] going to want to be

more involved. But it might make them back off, so they might not want to

be involved. In way of hopeful, if they've got that feeling of hope, because

they think that they're in a position where I'm talking like I know what I'm

on about, then they may think, "All right, the doctor knows; I don't need to,

maybe, be so involved." (HCP, 2.5 years' experience)

Well, I think if you're at that end of the scale where you are relieved and you're grateful and you know, willing to accept any help there is out there, the more willing they are to participate but if they've been left to the point where they are feeling frustrated and a little bit out of control and not knowing what's going on, I think that sort of clouds anything positive that then comes up. (HCP, 20 years' experience)

It was a very difficult and very stressful time. I think I was pretty passive at that time, yes. I wanted other people to tell us what was the right way to go to make life better for my daughter. Yeah. (Parent of a 16-year-old)

…it was so intense, I didn't actually have time to even look, or think, or even actually want to access information at that point. I wouldn't have known where to start, if I'm honest with you. I could look at – try to look at – what I felt was wrong with her. It was a bit overwhelming, so I decided at that point just to leave it. (Parent of a 14-year-old)

Where parents of CYP with MH problems access support?

Support systems

HCPs and parents reported accessing various sources of support during decision-making periods. Parents generally appreciated contact with and support from the family's own support network, external agencies, CAMHS and online services. Emotional support and knowledge support appeared to be almost used interchangeably. For example, although, family members and friends offered emotional support, in some instances, parents relied on their decision-making input. Strategies that were described as "helpful" or "useful" varied in the participants' responses. The majority of the HCPs referred parents to more than one resource, and many parents reported accessing multiple sources of support.

Families' own support network

The support the parents needed and received from others varied between parents, over time and decision type. Many received support from family members, friends, and other parents, who had been through similar issues. In some instances, parents received support from extended family members, e.g. grandmothers. In other instances, they described leaning on support only between parent(s) and child.

> *Unfortunately, some of them don't and sometimes we try and poke them to get their own support. (HCP, 2.5 years' experience)*

> *Obviously, my husband. He's always my first port of call really with things like that. And then outside of that, friends and family. (Parent of a 16-year-old)*

External Agencies

Parents reported accessing charities and other services for support. This was both practical (e.g., financial, information) and instrumental (e.g., seeking advice from persons with similar experiences). Similarly, HCPs also reported referring parents to known charities and other support services.

> *We often refer them to the Early Help Hub, I don't know if you know who they are, but they're kind of like a signposting service and they can access through them family therapy and family support workers. That's something I've done a couple of times recently. (HCP, 4 years' experience s)*

> *I accessed from a local charity that we have in our area that supports children and their families with ADHD. So, a lot of my emotional support and information gathering has come from them. I've done my own research online as well, but most of my support has come from the local*

charity. I have found that although all the medical staff and the doctors

have been very nice in the appointments - no problem with them at all - as

a service, CAMHS, I don't think it does really offer the emotional support.

(Parent of an 8-year-old)

Online resources

The majority of the HCPs reported signposting parents to online resources from "trustworthy" sources. There were some concerns about parents using "Dr Google" and encountering inaccurate or worrying information. However, parents admitted to using a wide variety of online websites and resources to gather information.

I direct them to the Royal College of Psychiatrists for patient information

leaflets about conditions and a little bit about treatment, as well. I try and

tell people not to just Google it and do give them the direct sites instead.

(HCP, 2.5 years' experience)

I think a couple of people have given us websites that we can look at,

which has always been useful. But then I'm the sort of person that will, if I

think I can find some information out that might help me to help my

daughter, then I'm happy to do that. (Parent of a 16-year-old)

First, on the internet. (Parent of a 12-year-old)

CAMHS as a resource

Generally, the CAMHS were seen as a vital resource. Although some parents described the help as being solely for the CYP, parents appreciated this as they felt happy knowing their child was being seen. However, HCPs reported having to spend time responding to parents' concerns outside of appointments. Interventions offered

by the CAMHS were limited but included interventions such as information outlets, signposting, parent groups and family therapy. When reporting family therapy and parent groups as sources of support, parents described shortcomings such as long waiting times and lack of time to attend group sessions.

> *That's probably the one downside is that my husband and my daughter are both on the list for family therapy, but the waiting list is so long I don't know when that's going to happen. (Parent of a 16-year-old)*

> *We provide a leaflet now. We didn't used to, but we provide one now. It's got information that they can read at their own leisure about the group. Because it's quite specific to our service, well, it's not widely available information; it's not on a website or anything. (HCP, 2.5 years' experience)*

> *But on paper, we have family therapy, but it's pretty hard to get because of the waiting list. I think we have maybe one or two teams in our service that I'm aware of. But again, not enough service in my locality. (HCP, 4 years' experience)*

> *I would just literally talk to the practitioner really, in terms of what that has to offer. (Parent of a 14-year-old)*

Summary of findings

The study's findings highlighted a framework describing an affective appraisal approach to SDM in support of the overarching concept that parents are 'expected to, but not always able to' engage in SDM. Themes and subthemes described: 1) views and experiences, 2) parents' emotional state, 3) the (dis) advantages and (4) support systems, in relation to the affective-appraisal SDM process. The study revealed an SDM model specific to CYPMH. The model identified key decision

makers (i.e. CYP, parents and healthcare providers) associated with SDM and how emotions influence the process. The appraisal process refers to ongoing value-based judgements linking emotion and cognition occurring before, during and after SDM. Key support systems and decision maker's views of SDM were also seen as essential to SDM.

Discussion

This study provided a novel insight into the experiences of parents involved in CYPMH care and treatment decisions from the perspective of both HCPs and parents. Although previous researchers have investigated the experiences of families including barriers and facilitators to SDM, little qualitative research has focused on the emotional experience of parents in the UK and how this can be a barrier or facilitator to involvement in CYPMH SDM (Hayes et al., 2019;2020). The overarching concept illuminated the framework (Figure 6.1) that revolved around an interactive parent, child and HCP SDM process where parents were "expected to, but not always able to" be involved in SDM. This framework captures the influence of emotions on the parent's active involvement in SDM, as parents "struggle" with caring for the CYP with MH problems. The current findings highlight themes describing: (1) views and experiences of SDM, (2) parents' emotional state, (3) (dis) advantages of the emotional experiences, and (4) the support systems accessed.

Definition of SDM

This study documented how HCPs and parents generally understood SDM. As highlighted in Chapter 2, previous studies have mainly focused on the dyad relationships between physicians and patients, and therefore, the areas where triad relationships exist have been less understood (Boland et al., 2019; Gabe et al.,

2004). For example, some researchers believe that when children are unable to participate due to age or capacity the decision making was not regarded as SDM (Park & Cho, 2018). Therefore, the findings of this study confirm the uniqueness of the triad in CYPMH decision-making and disagrees with Park and Cho. Instead levels of participation in the SDM may vary in different aspects of the process depending on the legal context, capacity, experience and expertise of the participants and type of decision.

Further investigations are needed to identify if existing SDM measurements are accurately capturing the levels of involvement taking into account the "informed" versus "involved" approach to SDM in CYPMH settings. This is crucial to the body of knowledge on SDM as parents and professionals using self-report measures may report SDM as occurring even though the "shared" nature existed between family members (interfamilial) only or among healthcare professionals (interprofessional) only. Such misconceptions can affect the successful implementation of SDM in CAMHS (Park & Cho, 2018). This confirms there may be a lack of knowledge on SDM involving caregivers, especially when the primary service user is a child or young person (Gabe et al., 2004; Haine-Schlagel & Walsh, 2015). Therefore, these findings further highlighted that service users' involvement in decision-making is a complex and dynamic process (Wolpert et al., 2012). These challenges were reflected in the individual expressions of negative experiences of SDM.

The Youth SDM framework (Crickard et al., 2010) and the youth SDM protocol (Langer & Jensen-Doss, 2018) may account for these levels of involvement as it encourages a dialogue between youth, parent and professionals. However, these models discuss "shared decisions" which were not clear in the current findings

as some participants stated that there remains a "final" decision-maker at the end of the process. This understanding suggested that the "final" decision should not be viewed as the end product of the decision-making process, but further steps such as agreeing on the final decision (outcome) could be explored and may be unique to the field of child health. Having professionals and parents explicitly agreeing with a child or young person's choice of treatment may be empowering.

The emotional experience of parents

This study extends on what is already known about the 'emotional roller coaster' that parents of CYP with MH experience (Chapter 3). Findings confirmed that parents experience a broad spectrum of emotions ranging from more positive emotions such as relief, hope and satisfaction to negative emotions such as anxiety, fear and frustration. This is in agreement with the literature aimed to explore the experiences of parents caring for CYP with MH problems. There is currently a wealth of literature on the emotional experiences of parents of children with MH problems as identified in Chapter 3. However, to the best of my knowledge previous studies in the UK have qualitatively explored the emotions of parents of children with specific MH disorders (Boden et al., 2016; Crawford & Simonoff, 2003; Gray & Donnelly, 2015; Ibrahim et al., 2016), belonging to specific minority populations (Bradby et al., 2007), of specific age groups below age 18 (Ahuja & Williams, 2010; Bone et al., 2015; Harden, 2005b; Hart et al., 2005; Hayes et al., 2020) or making specific treatment decisions. This study is the only one in recent years to report on the emotional experiences of the general parent population accessing CAMHS for any MH problem or symptom. More specifically, this study explored the emotional experiences in relation to the SDM process. Nonetheless, the current finding corroborates previous UK studies describing parents as experiencing frustration, fear, anxiety and isolation,

in addition to, hope and relief (Chapter 3). This study also enriches the large body of quantitative studies that more widely focus on parents of CYP with MH problems (Ahmed et al., 2014; Laugesen & Groenkjaer, 2015). This study also adds to the diversity of voices captured within the international studies in Chapter 3, reinforcing the overwhelming feelings and difficulty coping with CYP with MH problems. While it is not yet clear why emotional states vary among different populations and at different times, CYPMH appears to be a key source of parenting stress, and therefore ongoing research should continue to explore this phenomenon.

Impact of parental emotions on SDM

The little research in this area has identified types of emotions as either a barrier or facilitator to involvement in care and treatment decision-making (Boland et al., 2019; Hayes et al., 2020). The current findings are in line with this; however, building on this knowledge by identifying specific emotions as influencing factors. Further to this, the current findings suggest a two-way interaction that emotions may be influencing parents' involvement and vice versa. This supports theories in the cognitive literature around decision-making and emotions (Lerner et al., 2015) highlighting that decision making is challenging during emotional periods. The current study also confirms the findings of Chapter 3 suggesting positive and negative emotions influence parental CYPMH decision-making. Similarly, other studies show that decision-making under stressful conditions was shown to be difficult in participants in quantitative and qualitative studies (Bernthal et al., 2015; Kim et al., 2017). Therefore, the results of this study are not surprising as parents of children with MH challenges experience higher levels of stress and anxiety than parents of children with physical health conditions or *typically* developing children (Butler et al., 2014; Lipstein et al., 2016). However, some parents in this study

expressed having to "get on with it" despite their own personal feelings. This raises

further questions around active and effective involvement. In line with previous

research, the current findings also support the expectation that parents should be

involved in the decision-making process despite their emotional states (Dice, Dolce

& Freda, 2016). As a result, policymakers, researchers, practitioners and families

should work together to develop and promote support mechanisms that are suitable

and effective in this population.

Support systems

As CAMHS adapt to better address challenges faced by families accessing

services, various strategies may be adopted to inform practice. Firstly, this study

highlighted that parents rely on additional support from service providers, and

therefore, HCPs may have to invest time to offer the necessary support to parents.

CAMHS mainly provide services for CYP and limited resources are available within

service to support parents (Association of Young People's Health (AYPH), 2016).

Therefore, having interventions that can be used outside of regular appointments

can impact both clinicians and parents.

Secondly, in this study, many clinicians reported signposting parents to

external agencies and websites, and parents themselves reported accessing

charities and online services. The latter is in line with the help-seeking literature that

suggests parents are increasingly seeking information from online resources

(Hardey, 1999; Knapp et al., 2011). The relative importance of the internet and

external agencies was expressed by both HCPs and parents. Therefore policy-

makers and practitioners should take note as poor quality information may exist

online and some external agencies may not follow appropriate ethical and practice

guidelines (Pretorius et al., 2019). An exploration and standardisation of the role the internet and external agencies play in providing information or added emotional support to parents are warranted so services can harness these resources as tools.

Finally, the current findings suggesting parents sought support from familiy members and friends are in agreement with the broader help-seeking literature. More specifically, in CYPMH, research suggests that parents mainly relied on family members, their friends, support groups and other informal sources for support (Association of Young People's Health (AYPH), 2016; Bussing et al., 2005; Hassett & Isbister, 2017; Hoagwood et al., 2010; Shanley et al., 2008). However, studies investigating barriers to formal help-seeking suggest parents may lack knowledge of the formal help-seeking process (O'Brien et al., 2016; Reardon et al., 2017) suggesting this barrier could be a valid reason for informal support seeking.

Relevance to clinical practice and policy

Families sometimes experience long waiting times to access services and between appointments. As a result, a decision-making process that is efficient can help minimise frustrations and anxiety around care and treatment options. Clinicians and parents expressed positive experiences when involved in SDM, and also highlighted the potential for positive health outcomes. This study also highlighted that the triad should consider each other's preference for the level of involvement, and "informed" versus "actively involved" should be explored. This approach can help further minimise the burden and anxieties parents face when being the sole decision-maker (Bernthal et al., 2015). If parents are able to share this responsibility in a "trusting" relationship while feeling listened to, this may positively influence the SDM process. Additionally, encouraging a wider partnership with schools and

organizations can help support the SDM process by providing families with information and emotional support.

The findings of this study also highlight the lack of or limited support for parents accessing CAMHS. Although the child is viewed as the primary service user, the importance of parent involvement in the decision-making was crucial for successful care and treatment. Therefore, increasing the time spent per client may allow time for HCPs to inform and involve parents in the care and treatment plans, especially depending on the age and capacity of the CYP. Alternatively, implementing additional programmes to support parents throughout crucial decision-making time points may help improve experiences of SDM. Additionally, due to the "24-hour on the watch" of caring for the child with MH problems, services could ensure programmes are flexible enough to account for this. Lastly, it was noted that parents often access charities and other services outside of CAMHS to receive the necessary support. Therefore, it would be recommended that policy guidelines are in place to provide a bridge between the community and CAMHS to ensure consistency, competence and ethics are maintained.

Future directions

As recommended in Chapters 2 and 3, it is important to carry out program or intervention evaluations to identify and evaluate currently existing SDM support programs to identify which resources are most beneficial. The theory of "parents being expected to, but not always able to" be involved in CYPMH care and treatment decisions suggests that it would be of great value to develop and implement SDM interventions to promote collaborative decision-making. To achieve this, the current chapter suggests an affective appraisal approach to SDM is critical. This approach

may help to support parents throughout the CYPMH journey. As the theory's transferability is strengthened by this study, the theory can be the basis for intervention development and future research. Similarly, taken together, the quantitative findings exploring the current state of SDM in routine care in CAMHS (Chapter 5) can also help to inform interventions and identify families that need additional support (e.g. parents of children experiencing behavioural disorders). Finally, a quantitative exploration informed by the grounded theory of parents being "expected to but not always able to" be involved in CYPMH decision-making can help develop inferences around group differences. This is especially important to ensure traditionally underserved families are targeted (Barnett et al., 2019).

Strengths and limitations

This study adhered to established guidelines for qualitative research and the research credibility was enhanced through triangulation by collecting data from parents and HCPs who may have different perspectives (Braun & Clarke, 2006). Additionally, this study included a large enough sample size allowing for the attainment of data saturation (Guest et al., 2006). Most importantly, this study highlighted the views and experiences of parents of children of varying ages and experiencing a range of MH problems. In addition, HCPs with a variation in clinical backgrounds were involved in this study, allowing for a much broader understanding of the field.

However, this study is not devoid of limitations. First, the sample was mainly recruited through referrals from various NHS sites as part of a larger feasibility trial and therefore local investigators at sites were responsible for identifying participants in accordance with the study protocol. It is possible that parents and HCPs who are

more inclined to be involved in SDM may have expressed interest and therefore biased the study sample. For example, a larger representation of parents of children with neurodevelopment disorders and comorbidities. However, a range of views and experiences of SDM were discussed by participants. Second, when reporting the findings of this study, the participants' characteristics were not matched to their contributions for the purpose of examining any potential variability among the different professionals or among parents of children within different age groups. Therefore, the purpose and design of this study may minimize the generalisability of the findings, although generalisability is not a key consideration of qualitative research. Although experiences may be specific to this sample, the variety of the sample reflects multiple perspectives and a multidisciplinary view on SDM. As per the aims of the study, data were not collected from CYP. However, previous qualitative research suggested that CYP appreciated the inclusion of parents in their care and treatment as it facilitated SDM (Hayes et al., 2019). Another limitation to acknowledge is, only three transcripts were coded by a second researcher and compared for interrater reliability. However, due to the exploratory nature of the study and the high consistency in the initial coding of the 3 transcripts, it did not seem necessary to independently code any further transcripts, and coding was consistently reviewed in supervision meetings to assure quality. Lastly, participants were asked to discuss their experiences of SDM in CAMHS. Due to the slight variations in how the participants defined SDM and the subjective nature of the question, participants may have selected to express their first or most recent recall of SDM, therefore neglecting other instances of SDM or lack thereof.

Conclusion

Previous research findings indicate that the involvement of parents in CAMHS promotes uptake and adherence to treatment. Although SDM is recognised as a person-centred approach for quality healthcare, this current study suggests that levels of involvement in decision-making vary and parents experience a spectrum of emotions that may influence their participation in SDM. Therefore, the importance of an affective appraisal approach to SDM in CAMHS cannot be underestimated, and this should be assessed and supported. In particular, parents may need assistance to be adequately involved or informed in relation to their desire to preserve the "best interest" of their child. Future studies should further investigate this phenomenon.

Brief summary

The study presented in this chapter informed the SDM definition and proposed affective appraisal approach SDM model for the thesis. The framework identifies key decision-makers (i.e. child or young person, parents and service providers) and considers the influence of parent's positive, negative and mixed emotions on the SDM process. Attitudes, beliefs and experiences, and support systems also emerged as key factors to SDM. The next chapter moves on to identify and evaluate how existing parent-targeted decision support tools support parents involved in SDM.

Chapter 7 A Scoping Review and Assessment of Essential Elements of Shared Decision-Making of Parent-Involved Interventions in Child and Adolescent Mental Health (Study 5)

The previous studies highlighted the need to support parents and carers involved in CYPMH decisions. The study described in this chapter aimed to identify available decision support resources for parents of CYP accessing MH care. Additionally, the interventions were assessed by the extent to which they addressed the nine essential elements of SDM. Makoul and Clayman (2006) highlighted that in order for SDM to occur the process should include nine essential elements: patient values/preferences, options, professional knowledge/recommendations, make or explicitly defer a decision, define/explain the problem, check/clarify understanding, explore benefits/risks, discuss patient's ability/self-efficacy, and arrange follow-up. Therefore, each included intervention was assessed based on the comprehensiveness of the intervention to demonstrate these elements of SDM. Consequently, barriers and facilitators to usage and evidence for usefulness and acceptability were highlighted. In line with the affective appraisal approach to SDM, an exploration of how existing interventions addressed the emotional needs of parents was also conducted. This chapter concludes with discussions on the implications of the current findings for the development of future resources.

Aims and research questions

This study aimed to conduct a systematic scoping review to identify parent-involved SDM interventions in CAMHS and assess essential elements of SDM in these interventions. A secondary objective was to explore the factors associated with implementing SDM interventions in CYPMH settings.

The following research questions were developed to address the aims of this study:

1. What decision support interventions are available for parents of CYP accessing CAMHS?

2. Which of the SDM elements are addressed in these interventions?

3. What are the barriers and facilitators to usage and implementation?

4. What is the evidence for usefulness and acceptability of these interventions?

5. How do these interventions address the emotional needs of parents when making decisions?

Method

The protocol for this review was developed a priori and guided by the standard review methodology (Khan et al., 2003) and those described by Arksey and O'Malley (2005).

Identifying relevant studies

The following electronic databases were searched until March 2018: PsycInfo, Embase (Ovid version), Medline (Ovid version), Web of Science and the Cochrane Library, in addition to reference lists and International Shared Decision Making (ISDM2017) conference materials. The three concepts driving the searches included "shared decision-making", "parents" and "children and adolescent mental health services".

In addition to the relevant databases, the PhD candidate searched the Ottawa decision aid list, Children's Hospital of Eastern Ontario (CHEO) website, Google, Google Play store and popular CAMHS websites. Upon completion, the empirical studies found were documented and references were imported into EndNote and all

other relevant records (i.e. interventions not associated with any research literature) were added to an Excel spreadsheet.

Selecting studies

The eligibility criteria (see Table 7.1) were developed alongside the research questions. The elements of SDM by Makoul and Clayman (2006) were used to assess the extent to which interventions included essential elements of SDM similar to other studies (Cheng et al.,2017).

Table 7.1 Inclusion/Exclusion Criteria

	Inclusion Criteria	Exclusion Criteria
Population	Interventions should target persons identified as being a parent/primary caregiver/legal guardian of a child with MH problems or currently accessing child and adolescent mental health services (CAMHS)	Studies with interventions that target the parents' illness (e.g. how a parent with breast cancer should disclose to their child who is at risk for depression). Studies/ Interventions where the parents/caregivers are not active participants in the decision-making process
Intervention	Any family/parent- targeted or parent –involved intervention tool (e.g. online decision aids, mobile applications and parent training) used by the selected population over any period of time. Interventions targeted at parents/caregivers but aimed at being beneficial to decisions around the child's MH.	The intervention is aimed only at patient medical records (e.g. databases to allow ease of access by the parents of children in CAMHS). Interventions aimed at groups with physical diagnosis (e.g. interventions for children experiencing anxieties of taking insulin). Papers where the interventions are targeted at the child and/or clinician only and excluded the caregivers.
Comparator	N/A	N/A
Outcome	Intervention should aim to change levels of parental/caregiver involvement in their child's treatment decision.	Evaluating other health issues or outcomes other than mental health only (e.g. diabetes).
Study Design	All study types (published and unpublished) that involve the development and testing of the intervention and reported in English.	

Firstly, the eligibility criteria were piloted on a random sample of five papers by the PhD cndidate and another independent reviewer (BP). This was necessary to refine and clarify the inclusion criteria and ensure that they could be applied consistently by more than one person and reduce the possibility of rejecting relevant reports (Edwards et al., 2002).

Stage 1: Once all duplications were removed, the remaining records were screened by title only and irrelevant records were excluded (i.e. records identifying physical health, e.g. asthma, or non-CAMHS settings, e.g. palliative care).

Stage 2: Abstracts were read and further records not meeting inclusion criteria were excluded.

Stage 3: The remaining full-text reports and records identified through the grey literature were screened for inclusion. The most frequent reason for exclusion at this stage was the intervention not meeting any of the essential elements of SDM. All the searching and screening was conducted by the PhD candidate, and the articles being considered for final inclusion were screened by BP to eliminate the possibility of paper selection bias. There were no major disagreements regarding inclusion/exclusion judgement and through discussion, a consensus was reached to include all selected records.

Data extraction process

The data extraction sheet was developed based on those used in similar systematic reviews (Cheng, Hayes, Edbrooke-Childs, et al., 2017; Feenstra et al., 2014; Gondek et al., 2017; Wyatt et al., 2015). The data were then extracted from all the records being included, by the PhD candidate and verified by BP. Extracted

variables included authors, year, target population, description of the intervention,

modality, barriers and facilitators identified, study design, emotive concepts and

outcome (where applicable). Disagreements between the two investigators SL and

BP regarding data extraction were resolved through discussions. Where differences

in opinions for data extraction arose, a consultation was sought from the PhD

supervisor (JEC). A difference in opinion occurred for 3 interventions (1%), mainly

around the identification of barriers and facilitators. The PhD candidate contacted

two of the interventions' authors (Brinkman, Froehlich, et al., 2013; Grant, 2016) and

obtained further information.

Assessment of essential elements of SDM

The assessment of essential elements of SDM was reported as per the

number of elements of SDM characteristics met. For example, in high-SDM

interventions, a higher number (7 to 9) of the essential elements were met, medium-

SDM interventions met 4 to 6 of the essential elements, and low-SDM interventions

met 1 to 3 of the essential elements. The assessments were conducted

collaboratively by SL and JEC and discussed in detail before any consensus was

reached. The nine elements defining SDM, according to Makoul and Clayman

(2006), have been used in previous studies to evaluate decision support tools

(Bouniols et al., 2016; Cheng, Hayes, Edbrooke-Childs, et al., 2017) and is one of

the most frequently cited SDM models. This model was developed based on a

synthesis of other SDM models and therefore provides a broad description of the

SDM process which allows for comparisons among the identified SDM interventions

(Makoul & Clayman, 2006).

Data synthesis

The limited number of eligible RCTs and heterogeneity in the intervention type, study design, and outcomes precluded the pooling of results for a meta-analysis (Hoffman, 2015). Therefore, a narrative synthesis approach (Popay et al., 2006) was used to address the research questions. For research questions 1 and 2, data was utilised from all the interventions identified (n=23). To address research questions 3, 4 and 5, it was only possible to include interventions that were evaluated (n=15).

Results

The database searching identified 20,112 records: PsychInfo = 3345, Embase = 7099, Medline = 5203, Web of Science = 3308 and Cochrane Library = 1157. An additional 14 records were identified through other sources in March 2018 and updated 14th December 2018: Ottawa decision aid list = 4, Reference trolling = 2, Children's Hospital of Eastern Ontario (CHEO) = 3, Google = 5. The preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow diagram (see Figure 7.1) depicts the flow of information through the different phases of this review and reported the number of records identified, included, and excluded.

Figure 7.1 PRISMA flow diagram of study selection (adapted from Moher et al., 2009)
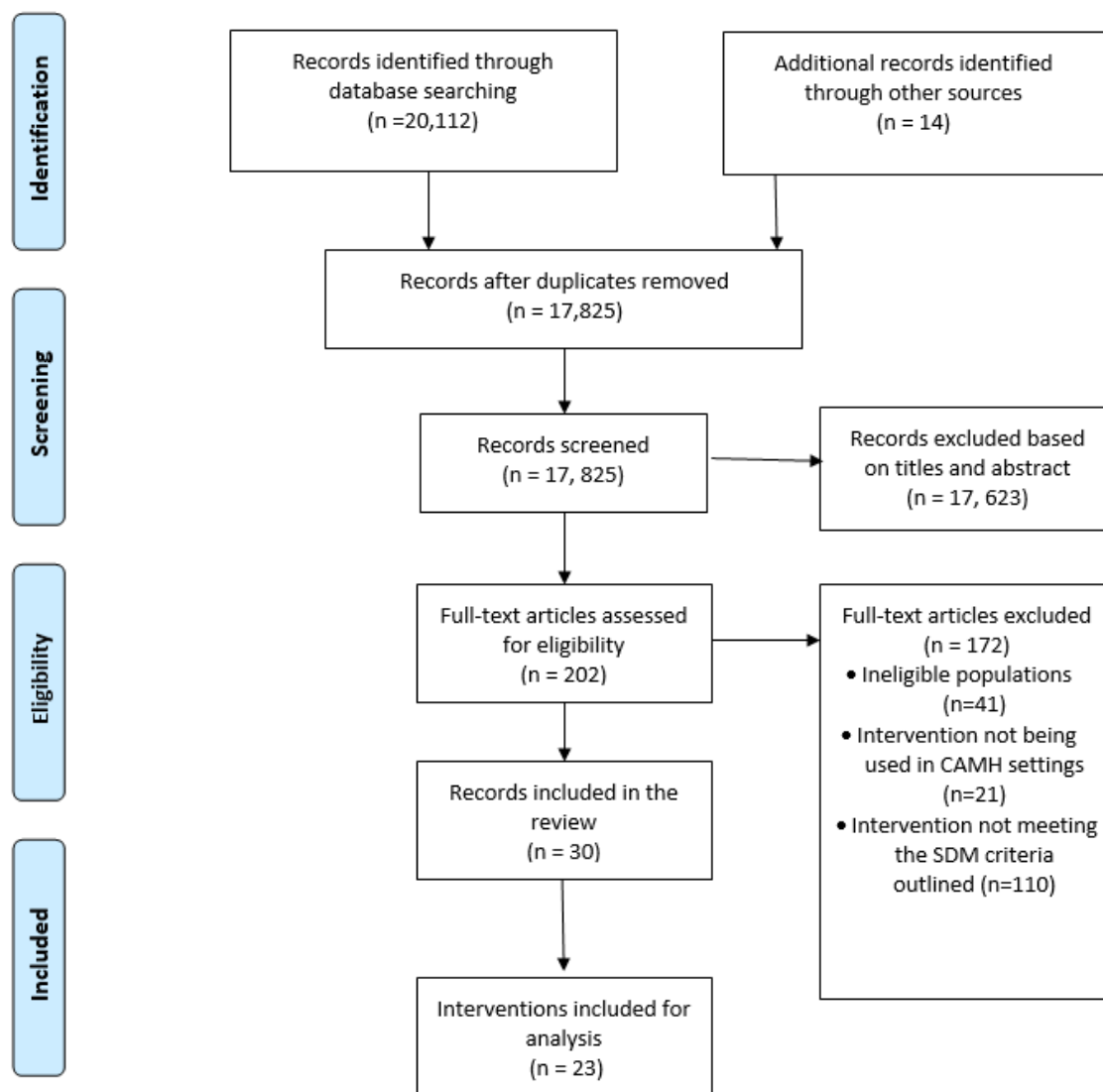
A total of 30 records were identified for inclusion. These included 24 research articles with publication dates ranging from 1994 to 2018 and six interventions without any associated research publication. The interventions with development dates were developed from 2010 onwards. The 30 records identified (inclusive of development and evaluation studies), map onto 23 interventions for use by parents of children with MH difficulties. Details related to the interventions are provided in Table 7.2.

What decision support interventions are available for parents of CYP accessing MH services?

The 23 interventions identified in this review were: 1) Asking Questions about ADHD-Question Prompt List (QPL), 2) ADHD SDM Intervention, 3) The Shared Decision Framework, 4) Preparing for the Appointment (PFTA) worksheet, 5) Counseling in Dialogue (CD), 6) Families First of Essex County, 7) Decision Aid for ADHD, 8) ADHD Preference & Goal Instrument, 9) Giving Parents a Choice, 10) ASD-Specific Medical Home, 11) Interactive Early Intervention Patient Decision Aid for Parents, 12) Coaching in deliberation, 13) i-THRIVE Grids, 14) Option Grid treatment decision aid, 15) Guided access DVD, 16) A checklist for parents with children with MH problems, 17) Autism: Should my Child Take Medicine for Challenging Behaviour?, 18) Depression: Should My Child Take Medicine to treat Depression?, 19) ADHD: Should My Child Take Medicine for ADHD?, 20) Goal progress/record/rating Charts, 21) Treatment Options for ADHD in Children and Teens: A review of research for parents and caregivers, 22) Is this guide right for the child in my care?, and 23) Ottawa Family Decision Guide.

Interventions were supported by various modalities and accessible by one or more of the following formats: 43% (10) paper-based, 39% (9) digital, 17% (4) multimodal, and 9% (2) face-to-face. The majority of the interventions were available online for print, web-use, or the contact details were available to seek authors' permission to use. The primary foci of the interventions were to support treatment decisions, highlight goals, choices and preferences, provide information, and facilitate overall doctor-client communication.

Of the 23 interventions identified, eight were targeted at services providing care for children with ADHD, five were targeted at services providing care for children with ASD, six were for services providing care for emotional and behavioural disorders (EBD), five were for universal MH care and one for self-harm. Table 7.2 summarises the characteristics of these interventions without any hierarchical order.

Table 7.2 Characteristics of included interventions

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
1	Agency for Health Care Research and Quality (2012)	USA	Treatment Options for ADHD in Children and Teens: A Review of Research for Parents and Caregivers	ADHD	Not reported	Digital	N/A	A summary of research for parents of a child with ADHD who may be wanting to know what the research says about ADHD. This tool addresses decision making questions.
2	Agency for Health Care Research and Quality	USA	Is This Guide Right for the Child in My Care?	ASD	Not reported	Digital	N/A	A guide created to help parents talk with their child's doctor, school administrator, social worker, or health insurance representative about available options for programs and therapies.

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
3	Ahmed et al. (2016) Ahmed et al. (2014) Ahmed et al. (2017)	Australia	Question Prompt List (QPL) Asking Questions about ADHD	ADHD	3 to 18	Paper-based	Delphi Method User-testing Pre/Post Trial	A question prompt list (QPL) to encourage parents to ask treatment-specific questions during consultations. It contains 88 questions about the diagnosis, treatment and management of ADHD.
4	Autism Speaks Autism Treatment Network (n.d)	USA	Autism: Should My Child Take Medicine for Challenging Behaviour?	ASD	Not reported	Digital/Paper-Based	N/A	A Decision Aid to help parents to choose a treatment that matches the needs and values of their child and family. This tool also includes general information about ASD and prompts parents to make a decision.
5	Barnett et al (2017)	USA	Option Grid treatment decision aid for complex behaviour problems in youth	Behavioural problems	Mean = 7	Paper-based	Pilot User Testing	A one-page Option Grid patient decision aid to facilitate shared decision-making for children's complex behavioural

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
								problems. This decision aid aims to help families and health care professionals talk about how to treat complex behaviour problems in youth ages 5 to 18.
6	Brinkman et al. (2013a) Brinkman et al. (2009)	USA	ADHD SDM Intervention	ADHD	6 to 10	Paper-based	Pre/Post Trial Qualitative	An intervention tool that includes pre-encounter cards and a booklet on ADHD treatment modalities, in addition to ADHD medication choice cards. The cards provide a brief overview of the treatment modalities including a description of the process to implement each treatment and the pros and cons of each option.
7	Brinkman et al (2013b)	USA	Coaching in deliberation	ADHD	Not reported	Face to Face	Randomized Crossover Trial	This involves an approach to strike a balance between medication benefit

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
								and side effects in addition to a decision aid that graphically depicts parent – and - teacher-reported symptoms and side effects for weekly and explicitly elicited parent preferences.
8	British Columbia HealthLink BC (n.d)	Canada	Depression: Should My Child Take Medicine to Treat Depression?	Depression	Not reported	Digital	N/A	A decision tool for parents/caregivers who may want to have a say in the decision. The information helps parents to understand what the choices are, so they can talk to the doctor about them.
9	Carlon et al (2017)	Australia	Guided Access DVD	ASD	1 to 5.5	Digital	Pre/Post Test	A DVD to provide support to parents accessing and interpreting information from websites. The DVD provide guidelines for choosing interventions and provide directions

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
								on how to access websites.
10	Children's Hospital of Eastern Ontario	Canada	Ottawa Family Decision Guide	Universal	Not reported	Digital/paper-based	N/A	An intervention for Families Facing Tough Health Decisions. This tool allows parents to list options, consider who is involved in the decision-making process and prompts to ask the right questions.
11	Crickard et al. (2010)	USA	The Shared Decision Framework	Universal	14 to 17	Multimodal	Preliminary User-testing	An SDM framework which includes (1) setting the stage for SDM, (e.g. training and orientation) (2) facilitating SDM (e.g. identifying decisional conflict areas) and (3) supporting SDM (e.g. process and peer support).
12	Evans et al. (1994)	USA	Families First of Essex County	Emotional & Behavioural problems	Not reported	Multimodal	Quasi-Experiment	A parent-driven change in the way that county services are provided to

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
								families. This service involves a range of activities, support groups & information resources to involve families in the services' decision-making process.
13	Fiks et al. (2012) Fiks et al. (2011)	USA	ADHD Preference & Goal Instrument	ADHD	6 to 12	Paper-based	Qualitative Qualitative	An instrument to assess parent's treatment preferences and goals. This includes 3 sections addressing preferences for behaviour therapy, medication treatment and goal items.

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
14	Golnik et al (2011)	USA	ASD-specific Medical Home	ASD	0 to 18	Multimodal	Pre/Post Test	A service focusing on providing coordinated, comprehensive, ongoing primary care for children and young people with autism. This involved ASD care plans, change monitoring logs and tools to coordinate and improve appointments.
15	Grant (2016)	Australia	Interactive Early Intervention Patient Decision Aid for Parents	ASD	Under 7	Digital	Pilot RCT	A patient decision aid for parents to assist in making informed decisions about early interventions for their recently diagnosed child with ASD. The website includes general information about ASD and an interactive 8-item questionnaire that asks how important it is that an intervention improves various

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
								functional areas (e.g. academic skills).
16	Hayes et al (2018)	UK	i-THRIVE Grids	Low mood/ADHD/self-harm	Not reported	Paper-based	Mixed method	The grids are grounded in the THRIVE framework. It covers getting advice, getting help, and getting more help. These 8 decision aids aim to improve SDM in children and young people's MH.
17	He et al. (2015) He (2016) He et al. (2018) Gewirtz et al. (2018)	USA	Giving Parents a choice	Behavioural problems	4 to 12	Face to face	Randomized Preference Trial	An approach offering parents a choice of preferred treatment for their child. The main aim is to incorporate parents' preferences into intervention decision-making.
18	Healthwise Staff (n.d)	Canada	ADHD: Should My Child Take	ADHD	Not reported	Digital	N/A	A decision tool to provide information to help parents

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
			Medicine for ADHD?					understand what the available choices are and to talk to the doctor about them.
19	Law et al. (2015)	UK	Goal progress /record / rating Charts	Universal	Not reported	Paper-based	N/A	A tool to identify and track agreed goals and monitor progress (Goal Based Outcomes). This tool allows the child/young person, parents/carer and the practitioner to discuss goals and track progress at each session.
20	O'Brien et al. (2014)	USA	Preparing for the Appointment (PFTA) worksheet	Universal	Over 10	Paper-based	Observational	This tool helps parents to identify pressing topics for discussion at the medication clinic appointment from both the parent and youth perspectives. The PFTA is designed to facilitate communication between clinician, parents and youths.

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
21	Ossebaard et al. (2010)	The Netherlands	Decision Aid for ADHD	ADHD	6 to 18	Digital	Pre/Post Test	An online decision aid tapping into relevant constructs of decision making; e.g. "Would you please rate your knowledge of ADHD and its treatment possibilities?" This intervention contains information on different treatment options for young people with ADHD.
22	Royal College of Psychiatrists	UK	A checklist for parents with children with MH problems	Emotional and behavioural problems	Not reported	Paper-Based	N/A	This leaflet is aimed at suggesting questions parents might ask at appointments to get information about their child's condition.

[#]	Reference	Country	Intervention	Target Area	*Age of child (years)	Format	Study Design	Intervention Description
23	Westermann et al. (2013) Westermann et al. (2009)	The Netherlands	Counseling in Dialogue (CD)	Universal	2 to 12	Multimodal	RCT Survey/ Delphi Design	A semi-structured, 3-part counselling session which involves retrospection, discussing of diagnostic findings and treatment and policy arrangements. CD aims to achieve intermediate outcomes (e.g. certainty, trusts) associated with treatment success.

Note: Age of the child is reported as the age of the children at the time the study was conducted. This do not reflect the

recommended age group for use of the intervention. Universal referred to general (i.e. non-specific) mental health care;

ASD=Autism spectrum disorder; ADHD= Attention-deficit hyperactivity disorder; SDM=Shared decision-making

Which of the SDM elements are addressed in these interventions?

The interventions met an average of 4.57 (SD=1.93) SDM elements. Of the 23 interventions, 61% (14) included the capacity to "explain the problem", 87% (20) to "present options", 83% (19) to "discuss pros and cons", 61% (14) to explore "values, goals and preferences", 22% (5) to check service user's "ability and self-efficacy", 61% (14) to allow professionals to "make recommendations", 39% (9) to "check understanding" of the available options, 39% (9) to allow users to "make or defer decision", and 4% (1) to "arrange follow-up" if unable to make a decision at the moment or to review the decision that was made.

All of the interventions included at least two of the SDM elements. Of the 23 interventions, ten were rated as low-SDM, eight were rated as medium-SDM, and five were rated as high-SDM based on the number of elements of SDM characteristics met. None of the interventions met all nine SDM criteria. Only 20% (1/5) of the interventions rated as high were evaluated, while 87.5% (7/8) of those rated as medium and 70% (7/10) of those rated as low were evaluated. The more comprehensive interventions (i.e. rated as high) included most of the elements of SDM except for "arranging follow-up". Interventions rated as medium mostly met "explain the problem", "make recommendation", "present options", "discuss pros and cons" and "explore values, goals and preferences" elements, with fewer opportunities to "discuss ability and self-efficacy", "check understanding", "make or defer decision" and "arrange follow-up". Interventions rated as low mostly met "explain the problem", "present options" and "discuss pros and cons" with some opportunities to "explore values, goals and preferences". However, these interventions less often provided opportunities to "discuss ability and self-efficacy",

"make recommendations", "check understanding", "make or defer decision" and

"arrange follow-up". Table 7.3 summarises the results of the SDM elements.

Table 7.3 Summary of SDM elements and quality assessment

Record	Intervention	Essential Elements of SDM									Assessment	
		Explain problem	Present options	Discuss pros and cons	Explore values, goals & preferences	Discuss ability and self-efficacy	Make recommendations	Check understanding	Make or defer decision	Arrange follow-up		
1	Asking Questions about ADHD (QPL)	✔	✔	✔			✔	✔		✔	6	Medium
2	ADHD SDM Intervention	✔	✔	✔	✔		✔	✔	✔		7	High
3	The Shared Decision Framework	✔	✔	✔	✔			✔			5	Medium
4	Preparing for the Appointment (PFTA) worksheet	✔		✔				✔			3	Low
5	Counseling in Dialogue (CD)	✔	✔		✔		✔	✔	✔		6	Medium
6	Families First of Essex County		✔		✔		✔				3	Low
7	Decision Aid for ADHD		✔	✔			✔		✔		4	Medium
8	ADHD Preference &		✔	✔	✔		✔		✔		5	Medium

Record	Intervention	Essential Elements of SDM									Assessment	
		Explain problem	Present options	Discuss pros and cons	Explore values, goals & preferences	Discuss ability and self-efficacy	Make recommendations	Check understanding	Make or defer decision	Arrange follow-up		
	Goal Instrument											
9	Giving Parents a choice		✔		✔						2	Low
10	ASD-specific Medical Home	✔	✔	✔	✔	✔	✔				6	Medium
11	Interactive Early Intervention Patient Decision Aid for Parents		✔	✔	✔		✔		✔		5	Medium
12	Coaching in deliberation			✔	✔		✔				3	Low
13	i-THRIVE Grids	✔	✔	✔							3	Low
14	Option Grid treatment decision aid for complex behaviour problems in youth	✔	✔	✔							3	Low
15	Guided Access DVD		✔	✔							2	Low

Record	Intervention	Essential Elements of SDM									Assessment	
		Explain problem	Present options	Discuss pros and cons	Explore values, goals & preferences	Discuss ability and self-efficacy	Make recommendations	Check understanding	Make or defer decision	Arrange follow-up		
16	A checklist for parents with children with MH problems	✔	✔	✔			✔				4	Medium
17	Autism: Should My Child Take Medicine for Challenging Behaviour?	✔	✔	✔	✔	✔	✔	✔	✔		8	High
18	Depression: Should My Child Take Medicine to Treat Depression?	✔	✔	✔	✔	✔		✔	✔		7	High
19	ADHD: Should My Child Take Medicine for ADHD?	✔	✔	✔	✔	✔	✔	✔	✔		8	High
20	Goal progress /record / rating Charts				✔		✔				2	Low
21	Treatment Options for ADHD in	✔	✔	✔							3	Low

Record	Intervention	Essential Elements of SDM									Assessment	
		Explain problem	Present options	Discuss pros and cons	Explore values, goals & preferences	Discuss ability and self-efficacy	Make recommendations	Check understanding	Make or defer decision	Arrange follow-up		
	Children and Teens: A Review of Research for Parents and Caregivers											
22	Is This Guide Right for the Child in My Care?	✔	✔	✔							3	Low
23	Ottawa Family Decision Guide		✔	✔	✔	✔	✔	✔	✔		7	High
Total		14	20	19	14	5	14	9	9	1		

Note. ADHD=Attention deficit hyperactivity disorder; ASD=Autism spectrum disorder

What are the facilitators and barriers to usage and implementation?

Findings of this review suggest that factors such as time (e.g. increase in session times), accessibility (e.g. easily available via the web), and appropriateness (e.g. easy to use and understand) of the intervention were common themes identified as influencing usage and implementation of SDM interventions. These themes are encompassed in the two categories: facilitators and barriers.

Facilitators

Factors influencing the usage of interventions varied across the different modalities (e.g. face-to-face vs. paper-based) and purpose (e.g. to provide information vs. to improve communication). For instance, parents expressed that they were interested in using the QPL (described in Table 7.2) because it was clear, easy to understand, and made it easier for them to ask questions. Most parents also indicated that the length of the QPL was "just right" and suggested that they would benefit most from the resource if it was provided soon after diagnosis (Ahmed et al., 2017). Additionally, for the ADHD SDM intervention, which involved using choice cards and booklets, not having an increase in the length of the appointments was another factor encouraging usage (Brinkman, Froehlich, et al., 2013). However, feedback from families and service providers suggested that web interventions can save time, increase the efficiency of the process (Crickard et al., 2010), and provide parents with information prior to sessions (Westermann et al., 2013). Parents involved in the Counseling in Dialogue study also appreciated the visualised form of information, which supported their understanding, and findings across studies highlighted that knowing parents' preferences may boost participant engagement and inform SDM (Gewirtz et al., 2018; He et al., 2016, 2018).

Clinicians highlighted that one factor encouraging the use of the intervention was the minimal training requirement. Similar to parents, clinicians were also happy with no increase in the duration of consultations. Therefore, clinicians were more inclined to use the intervention if it did not affect the flow of the consultation, or strain time or staff resources (Brinkman, Froehlich, et al., 2013). Additionally, clinicians who participated in the evaluation of the i-THRIVE Grids expressed the ease of use and not detracting from practice as facilitators (Hayes, Town, & Lemoniatis, 2018). Another influencing factor was the clarity and appropriateness of language as indicated by participants in the study of the Option Grid treatment decision aid. That article also highlighted that clinicians appreciated interventions including information that was credible and reliable, and like other interventions, if the resources did not result in any additional time burden (Barnett et al., 2018).

Barriers

The theme of appropriateness of the intervention was further highlighted in the article describing the Shared Decision Framework (Crickard et al., 2010). Families and service providers involved in that study expressed concerns about paperwork loads and power struggles arising from the involvement of youth in decision making. Similarly, the study on the PFTA worksheets highlighted (increased) disagreement among parent and child dyads (O'Brien et al., 2015). For example, dyads disagreed on topics of preference to be discussed during sessions. Findings also suggest that not giving parents a preference choice resulted in a higher chance of drop out of treatment (Barnett et al., 2018).

Similar to the Shared Decision Framework, accessibility was also important to clinicians using the i-THRIVE Grids, who preferred them to be electronic for ease of access, suggesting paperwork overload as a barrier to usage (Crickard et al., 2010; Hayes, Town, & Lemoniatis, 2018). Another barrier to the usage was highlighted in the Families First of Essex County study, which suggested that not having the availability of services and the capacity to coordinate services among their providers hindered its use (Evans et al., 1994). Findings from the evaluation of the Interactive Early Intervention Patient Decision Aid for Parents also suggested that clinicians feared there would be a chance of information overload for parents (Grant, 2016). Similar to parents' concerns, some clinicians expressed that the use of the i-THRIVE Grids and the Option Grid treatment decision aid added to the already packed schedule of service users, therefore, making them 'burdensome' and overwhelming (Barnett et al., 2018; Hayes, Town, & Lemoniatis, 2018).

What is the evidence for usefulness and acceptability of these interventions?
Usefulness

There is evidence for 11 of the 23 interventions reporting on whether users of the intervention found it helpful or useful. Descriptions of the 11 interventions (1-5, 7, 10, 11, 13-15) are provided in Table 7.2. Overall, the interventions were identified as useful. Users (n=17) of the QPL found it useful, and qualitative findings indicated that parents felt the QPL would address some difficulties they experienced during consultations. Parents also indicated that the booklet contained questions that were useful. Early feedback from implementing the Shared Decisions Framework tools and methods indicated that youths, parents, and service providers appreciated the value in SDM and the questions on the tools (Crickard et al., 2010; O'Brien et al.,

2015). Similarly, the evaluation of Counseling in Dialogue resulted in parents'

understanding of the information, participation in treatment planning, and promoted

an active role in decision making (Westermann et al., 2013) indicating positive

outcomes. Parents also described the i-THRIVE Grids as useful because the grids

provided reliable information that accurately covered the range of available

treatments and made them feel empowered.

Similar to parents, the clinicians also found the i-THRIVE grids helpful as a

reminder of available options. Users of the Option Grid treatment decision aid also

indicated that the information they received via the intervention was helpful.

However, parents suggested the time in which the interventions were received was

important as suggested in relation to the Guided Access DVD, which was described

as being useful for parents with a recent diagnosis (Carlon et al., 2017).

The usefulness of the interventions to help parents prepare for appointments

was a common theme across studies (Barnett et al., 2018; Crickard et al., 2010;

Hayes, Town, & Lemoniatis, 2018; O'Brien et al., 2015; Ossebaard et al., 2010) as

the interventions were seen as convenient, flexible, and valuable to parents' lifestyle

(Crickard et al., 2010; Westermann et al., 2013). Furthermore, the evaluation of the

Counseling in Dialogue intervention found that the visualization elements of the

intervention were helpful in supporting parents' understanding of the information, and

the Interactive Early Intervention Patient Decision Aid for Parents pilot study

highlighted that some parents found the intervention overall useful. The usefulness

of the interventions was further highlighted by parents in the evaluation of the ASD-

specific Medical Home intervention who reported experiencing fewer unmet needs,

and an improvement in SDM than the control group. However, that study reported

marginal statistical significance between the groups for unmet needs (Golnik et al., 2012).

Clinicians indicated that the QPL helped parents initiate discussions about difficult topics and helped (or will help) parents in making decisions. Overall, 71% of physicians in the evaluation of the ADHD SDM choice cards and booklets found the information extremely helpful and acceptable for use by parents (Brinkman, Hartl Majcher, et al., 2013). Similar to parents, therapists also considered the Counseling in Dialogue intervention to be a convenient and valuable method, and clinicians in the qualitative study of the i-THRIVE Grids suggested the grids were useful in the context of assessment clinics and 'intrinsically useful' to service users. Clinicians also found the Option Grid treatment decision aid useful in structuring the session and reducing the burden related to paper handouts.

Acceptability:

Eight of the 23 evaluated interventions reported on acceptability. Descriptions of the eight interventions (1, 2, 4, 7, 10, 13-15) are provided in Table 7.2. The interventions were generally acceptable by users. For example, the QPL was well-received by participants in the study and resulted in a mean satisfaction score of 9.5 on a 10-point scale measure. Results showed that all parents were very satisfied or satisfied with the use of the QPL. The paediatricians also agreed that the QPL was acceptable for use by families and indicated that they would be happy to use it as part of their practice. In the evaluation of the choice cards and booklets of the ADHD SDM Intervention, physicians indicated the resources were acceptable for use by families and 86% indicated that they would recommend it. Similarly, parents

responded positively to using the PFTA worksheets and despite some parents reporting moderate levels of satisfaction, some were eager to use it again for future appointments.

The Decision Aid for ADHD received average feedback ratings on whether users were satisfied with the decision aid itself and users reported moderate satisfaction with the information received via the tool (Ossebaard et al., 2010). Participants in the intervention group for the ASD-specific Medical Home study were more satisfied than those in the control group. Additionally, a parent in the qualitative study of the i-THRIVE Grids highlighted satisfaction with the intervention as it "allowed her to make the decision that was right for her family" (Hayes et al., 2018, p.3). All participants using the Guided Access DVD indicated that they would recommend the intervention to others and some of the parents highlighted that they were very likely to continue using the tool. Although interventions were acceptable, some parents and clinicians who used the Option Grid highlighted that the resources needed to be used during sessions because as a stand-alone intervention a parent may feel overwhelmed by the amount of information.

How do these interventions address the emotional needs of parents when making decisions?

Studies associated with six of the interventions highlighted emotional factors. Some researchers (Ahmed et al., 2014, 2017) measured anxiety scores before and after the use of the intervention and highlighted a significant decrease in mean anxiety scores from 32.4 to 28.2 on the Spielberger State Anxiety Inventory Form t (16) = 2.151, p<0.05. Similarly, findings from the evaluation of the ASD-specific medical home intervention suggested that family stress related to their child's

condition, was lowered after being involved with the programme. Another study by O'Brien and colleagues (2015)), surveying parents and youths, highlighted that *worries* about treatment side effects affected their decisions to accept medication. In line with this, the researchers reported that in 25% of the cases, parents wanted to discuss worries while teens did not. Additionally, clinicians involved in the implementation of the i-THRIVE grids expressed concerns that the grids seemed burdensome and "when parents are already feeling full, it's hard to have all these to add" (Hayes et al., 2018, p.4). However, only the Counseling in Dialogue intervention included retrospection as a component of the intervention, which was explicitly aimed at reducing stress.

Discussion

This scoping review was designed and carried out to identify and examine parent-targeted or parent-involved SDM interventions to inform practice and the development and implementation of future decision support tools. This study identified a total of 23 interventions for use by parents of CYP with MH difficulties. The findings of this review suggest that interventions targeting parents met on average 4.57 (SD = 1.93) out of a possible 9 essential elements of SDM and have received favourable responses to usage (acceptability and usefulness). The factors influencing usage and implementation of the interventions emerged as three overarching themes: time (e.g. increase in session times), accessibility (e.g. easily available via the web), and appropriateness of the intervention (e.g. easy to use and understand). In addition, only one intervention (i.e. Counseling in Dialogue) included emotional support for parents.

The review by Cheng et al. (2017), examining approaches used in SDM interventions for CYP, also identified twelve of the interventions that this study found, and conducted similar quality checks using the Makoul and Clayman (2006) elements which coincide with the current findings. However, it must be noted that the nine elements of SDM were developed based on the literature reviewed in adult physical health settings. Therefore, applying this model to CAMHS may require more involvement from service users within CAMHS to understand how to include these elements in the interventions. With the uniqueness of the triad in CAMHS, even more research is needed to ensure these elements can be included in the development of interventions to support the SDM process. Additionally, the higher number of interventions "presenting options" but fewer "arranging follow up" can be explained as an immediate approach to acute care decision making (described in Chapter 2), which is mostly required in physical health. With more chronic conditions in MH, the "arrange follow up" component may be quite useful for this population and developers can consider this going forward.

Interventions were targeted at services providing care for children with ADHD, ASD, EBD, universal CAMH problems, or self-harm. This finding is also consistent with previous reviews (Cheng, Hayes, Edbrooke-Childs, et al., 2017; Grist et al., 2017), highlighting that most interventions in CAMHS target these disorders. This is not surprising due to the prevalence statistics reported in Chapter 2. Therefore, it is noted that parents of children with these MH difficulties will be faced with making a wide range of decisions.

Previous research in this area highlighted barriers and facilitators to person-centred care in CAMHS (Gondek et al., 2017). However, this review aimed to

investigate further, to discover if there were any factors specific to the use of SDM interventions by parents. Findings were consistent with the previous literature in both physical and MH regarding the general importance of information sharing (Bee et al., 2015) as a facilitator and parents appreciated having information from a variety of sources in order to help make decisions (Brinkman, Hartl Majcher, et al., 2013; Jackson et al., 2008). However, as this review also highlighted, the information should be appropriate, for example in a language that is jargon-free and understandable for service users (Bee et al., 2015; Gondek et al., 2017). Knowing the types of information parents need and how to use the right media to effectively communicate the relevant information can aid parents in decision making (Allen & Varela, 2015; Allen, 2014; Brinkman et al., 2009).

Another facilitator highlighted was time efficiency, for example in being able to prepare for appointments ahead of the session. This can be favourable to parents as they are usually faced with long waiting times and time-consuming evaluations (Kalb et al., 2012). Therefore, the time spent waiting will be occupied with preparations for upcoming appointments. Additionally, accessibility of the interventions were important, for example some parents found web-based interventions to be appealing. Although there is growing evidence to support technology in CYPMH care settings (Hollis et al., 2017; Montague et al., 2015), more evidence is needed to investigate parents' preference for using digital interventions as a stand-alone or integrated into face-to-face sessions to support their child. From the clinician's perspectives, SDM support interventions were likely to be used if they required minimal training and had no increase in the duration of the consultations. Therefore, having interventions that can be used during and within sessions can impact both clinicians' and parents' satisfaction with services by increasing efficiency (Dugdale et al., 1999).

In line with previous findings from similar reviews, not all interventions identified were evaluated (Cheng, Hayes, Edbrooke-Childs, et al., 2017; Wyatt et al., 2015). This study found that 15 (65%) of the included interventions had associated research publications. Therefore, reporting on usefulness and acceptability for all interventions is limited, and it is therefore difficult to recommend their use. The increase in commercially developed interventions leaves empirical studies lagging behind. This is concerning, given the emotional state of this population (discussed in Chapter 3), and therefore, caution should be taken when implementing new interventions to ensure sufficient support is given throughout the decision-making process. Rigorous and ecologically valid empirical studies should be conducted to test these interventions before implementing into practice.

Service users and service providers found interventions to be useful for the decision-making process. This is consistent with existing literature as SDM has been widely advocated across health settings, patient populations and policy (National Institute for Health and Care Excellence, 2019; Wolpert et al., 2012). One reason highlighted for the usefulness of the interventions was the ability to provide or facilitate information sharing. This again corroborates previous findings that information seeking is a primary element of the journey parents undergo post-diagnosis of a child or young person with a MH disorder (Grant et al., 2016). However, it is noted that information needs may change at different periods (Grant, 2016) and information only may not be sufficient for parents (Jackson et al., 2008). Therefore, additional support needs should be offered at various stages.

Similarly, clinicians found interventions to be useful as it facilitated discussion. In pediatric health settings, health professionals welcomed additional resources that

provide access to information at the convenience of parents, and outside of the clinical session (Delany et al., 2017). As a result of this, parents can be better prepared for appointments allowing for further discussions between parents and clinicians. In CYPMH settings, similar findings indicate that keeping reports and tracking progress leads to shared work between the therapist, young person and family, which can lead to better agreement and working alliance in therapy (Law et al., 2015).

Eight interventions had supporting evidence to indicate overall satisfaction with the use of the intervention. This is supportive of previous studies that highlight parents' need for additional support (Ahmed et al., 2014; Fiks et al., 2012) to make informed decisions. Therefore, the findings of this review confirm that parents were satisfied with receiving more information through SDM interventions. These findings suggest that once parents are provided with the right kind of support, they will feel more included by services and their own anxieties of not being informed will decrease (Association of Young People's Health (AYPH), 2016). Clinicians also responded favourably to using SDM interventions suggesting that services have a willingness to implement person centred care as recommended by policy guidelines for health care (Department of Health, 2015; Institute of Medicine, 2001; Levinson et al., 2005).

Researchers agree that parents of CYP with MH difficulties experience anxiety (Chapter 3), and this anxiety may emerge from multiple factors associated with parenting a child with additional needs. Consistent with these concerns, researchers in six of the identified studies monitored anxiety levels of parents. The interventions, in most instances when assessed, decreased anxiety or worry in

parents, indicating that by providing parents with appropriate decision support tools their level of anxiety diminishes. These results are reflected in the broader literature highlighting that decisions around CYPMH care can be difficult for families, and adequate information is a significant source of support to parents (Jackson et al., 2008). On the other hand, concerns of the increase in burden or worry when using the intervention is also consistent with previous findings indicating that potentially anxiety-provoking information (e.g. diagnostic test results) can increase anxiety levels, and therefore should be discussed simultaneously with a health professional (Gekas et al., 1999). These findings highlight a significant gap in the current evidence base, indicating that parent-targeted SDM interventions may benefit parents if both emotion and information sources of support are included.

Future directions

There is an urgent need for adequately powered and rigorously designed RCTs to evaluate the effectiveness and efficacy of parent-targeted SDM support interventions. Conducting such studies can support researchers in identifying and comparing specific elements that best support the SDM process in future review studies. Based on findings from this review, some broad key recommendations are suggested to develop and implement SDM support interventions. Firstly, it is recommended that interventions not reaching International Patient Decision Aids Standards (IPDAS) criteria report on elements of SDM involved in the intervention, so end users can obtain additional support to supplement the intervention if needed. Secondly, as identified by some service users and service providers, interventions should be web-based or online to avoid paperwork overload. Just as important, it is recommended that new interventions require minimal training for both providers and users of the interventions and that the interventions be made accessible via an open

access repository of SDM interventions. Another recommendation is that the content and usage of the interventions be easy to understand. It is also recommended that service providers receive the necessary support and knowledge to be confident in recommending or using decision support tools with service users. Finally, intervention developers could ensure consideration is given for parents with additional support needs (e.g. emotional support), and therefore adopt the affective appraisal approach to SDM model as an underpinning theory.

Strengths and Limitations

This review has major strengths, such as, including a very broad search strategy similar to those already published (Cheng, Hayes, Edbrooke-Childs, et al., 2017;Gondek et al., 2017) and a comprehensive concept-specific tool for assessing essential elements of SDM (Makoul & Clayman, 2006). However, there are some limitations to be considered when interpreting the findings of this scoping review. Firstly, of the 23 interventions, only 9 were identified through the database searching. This can be due to the lack of a standardized definition (e.g. decision aid, decision support tools, and decision support interventions) used for SDM tools. Although this review used a very broad search strategy and two independent reviewers, it was possible that some records may have been missed. Secondly, not all the interventions identified were evaluated and those that were evaluated lacked homogeneity in terms of study design, SDM outcome measure, mode of delivery, and target population making it difficult to synthesize.

For this review, the essential elements of SDM in the identified interventions was examined using the framework by Makoul and Clayman (2006) . Although these guidelines are useful in providing an overall sense of whether the intervention is

achieving its purpose, the behaviours associated with each criterion may differ making it difficult to standardize (Towle & Godolphin, 1999). Additionally, the lack of detail and heterogeneous study designs made it difficult to objectively conduct assessment using this tool as it was uncertain how the intervention was used within the client-clinician interactions. An alternative assessment tool that can be considered in future studies is the International Patient Decision Aid Standards (IPDAS), which provides a minimal set of standards for qualifying as a decision aid, and for judging the quality of decision aids (Ottawa Health Research Institute, 2005). However, the IPDAS may not have been suitable for the current study as the PhD candidate aimed to assess the presence of essential elements of SDM in relations to the SDM process and not the quality of the intervention itself. Assessing the quality of the evidence underlying the interventions, including development and evaluation, may have required contacting the interventions' developers, which was beyond the scope of this review. Nonetheless, it is believed that this scoping review provides important information, and it is the most rigorous in the area of parent-targeted SDM in CYPMH settings that the PhD candidate is currently aware of.

Conclusion

In conclusion, this scoping review provided a broad overview of parent-targeted decision support interventions used in CAMHS. It was noted that further research is needed to evaluate and compare parents' preferences for decision support interventions. This review was essential to inform guidelines for the development, implementation, and usage of new interventions adopting the affective appraisal approach to SDM.

Brief summary

This chapter identified 23 interventions meeting an average of 4.57 (SD = 1.93) essential elements of SDM. The interventions generally received favourable responses to usage (acceptability and usefulness). One face-to-face intervention (Counselling in Dialogue) offered additional emotional support to parents, highlighting that interventions rarely adopt an affective appraisal approach to SDM. The next chapter was informed by the learnings of the current study, and the studies described in previous chapters, and describes the development of a novel digital intervention (Power Up for Parents) underpinned by the affective appraisal approach to SDM.

Chapter 8 Development of Power Up for Parents

The previous chapters identified a need to support parents making CYPMH decisions (Chapters 1-7). Chapter 7 identified 23 existing interventions and assessed those interventions against the nine essential elements of SDM. Results highlighted that the currently available interventions met on average 50% of the number elements of SDM and common themes such as time (e.g. increase in session times), accessibility (e.g. easily available via the web), and appropriateness of the intervention (e.g. easy to use and understand) emerged as factors influencing usage and implementation. Only one face-to-face intervention (Counselling in Dialogue), described in the review, offered additional emotional support to parents, and that study expressed parents' appreciation for additional support to be better prepared to engage in the SDM process (Westermann et al., 2013). As a result, the need to develop an intervention informed by the affective appraisal approach to promote SDM among parents making CYPMH decisions emerged. This chapter describes the process of designing and developing an evidence-based intervention called Power Up for Parents (PUfP). A logic model for the intervention, various theories and models used to inform content, and how end-users were involved in the process are discussed. Consequently, the resulting prototype is presented and next steps outlined.

Rationale for the digital intervention

Digital health interventions emerged in the early 2000s, and have been increasingly used in CYPMH to provide evidence-based interventions (Grist et al., 2017; Hall & Bierman, 2015; Hollis et al., 2017; Pennant et al., 2015; Lucassen et al., 2018). For example, Power Up, a mobile phone app to support young people in SDM

(Chapman et al., 2017) has shown some evidence of promise that young people who received Power Up reported greater levels of SDM after the intervention period (Edbrooke-Childs et al., 2019). Power Up is a mobile app to enable young people to record their questions, plans, decisions and diary entries to promote communication in therapy. The intervention was owned and managed by the child and encouraged the child, as the primary service user, to be part of the SDM process. Similarly, LGBT+ youths highlighted pros and cons of online resources and expressed interest in e-therapies (Lucassen et al., 2018). Further to this, parents also report feeling excluded from services (Chapter 3) and therefore, may also benefit from receiving additional support. A systematic review highlighted that parents' decision support needs include information, talking to others, and feeling a sense of control over the decision-making process, which could be influenced by their emotion (Jackson et al., 2008).

Chapter 6 supported an affective appraisal model of SDM in CYPMH. However, as highlighted in the previous study, exiting interventions rarely addressed this concern, and only one face-to-face intervention (i.e. Counseling in Dialogue) included such support. Moreover, concerns about stigma and confidentiality, shame or embarrassment in attending services, financial costs, time, appropriateness and/or limited access to services are usually among the many barriers to accessing help in this population (Anderson et al., 2012; Bidargaddi et al., 2017; Liverpool et al., 2020; Tillfors et al., 2011). As a result, existing efficacious face-to-face interventions are adopting digital technology as a means of addressing these barriers (Silfvernagel et al., 2015).

Mobile technology (i.e. mobile phones, tablets, laptops) can incorporate multiple features, and have been on the increase and estimated to reach 6.1 billion users by the end of 2020 (Ericsson, 2015). Also, technology may help parents overcome barriers (e.g., anxiety) and communication that is reliant on face-to-face visits only, endorsing advantages such as: accessibility, a high degree of anonymity, prompt feedback and applicability in real-life contexts (Alvarez-Jimenez et al., 2014; Diehl et al., 2012; Donker et al., 2013). Additionally, easily accessible interventions help to promote preparation for visits and overall communication (Ahmed et al., 2017; O'Brien et al., 2015).

There is evidence of technology-assisted strategies being incorporated into parenting interventions. For example, recent reviews have described innovative technological applications in parent management training programs (Baumel et al., 2016; Breitenstein et al., 2014), and programs to promote child health (Nieuwboer et al., 2013). The reviews highlighted their usefulness to increase availability and accessibility by parents who are geographically isolated. They also have the potential to provide increased access to information, advice and supportive networks (Hall & Bierman, 2015). Although, research is showing great efficacy for the use of parent targetted technology in child health care (Kahn & Moore, 2010), to the best of my knowledge, there are presently no mobile apps designed for and tested in CAMHS that supports the affective-appraisal SDM process for parents of CYP with MH problems (Chapter 7).

Aims and objectives

The overall aim of this chapter is to describe the development of an evidence-based digital intervention for use by parents of CYP with a MH problem, to promote SDM in CAMHS. Consequently, the following sub-objectives were addressed:

1. Develop a logic model outlining how the intervention is proposed to work.

2. Consolidate evidence-based content to support the affective-appraisal model of SDM.

3. Involve end-users in the design and development of an SDM intervention to be used in CAMHS

Method

Framework for intervention development

Decision aids are described as "tools to prepare people to participate in making treatment choices" (IPDAS Collaboration, 2019) and "a means of helping people make informed choices about healthcare that take into account their personal values and preferences" ("An introduction to patient decision aids," 2013, p. 90). Decision aids are usually complex by nature (Lenz et al., 2012) and therefore, the UK Medical Research Council (MRC) which offers guidelines for developing and evaluating complex interventions (Craig et al., 2011) was adopted. Other "user-based" frameworks, embedded in Human-Computer Interaction (HCI), such as the multiphase optimization strategy (MOST) framework (Collins, 2018) were also considered. However, HCI frameworks have been criticised for focusing mainly on specific details of the interventions resulting in multiple iterations of development (Blandford et al., 2018).

The MRC guidelines encompasses four phases: development, feasibility/pilot testing, evaluation and implementation (see Figure 8.1). The current intervention is described as complex, in line with the conventional definition describing complex interventions as interventions with several interacting components (Craig et al., 2011). Therefore, the MRC framework was used as the overarching guide to inform the development process. The framework proposes that during the development stage it is important to: identify the evidence base, identify theory and model the process and outcomes. The process describing how these key elements are addressed are incorporated into the steps outlined by O'Connor & Jacobsen (2003) on how to develop and evaluate a decision aid. This workbook proposes the seven following steps:

1. Assess need

2. Assess feasibility

3. Define the objectives of the aid

4. Identify the framework of decision support

5. Select the methods of decision support to be used in the aid

6. Select the designs and measures to evaluate the aid

7. Plan dissemination

Figure 8.1 MRC Framework for development and evaluation of complex interventions
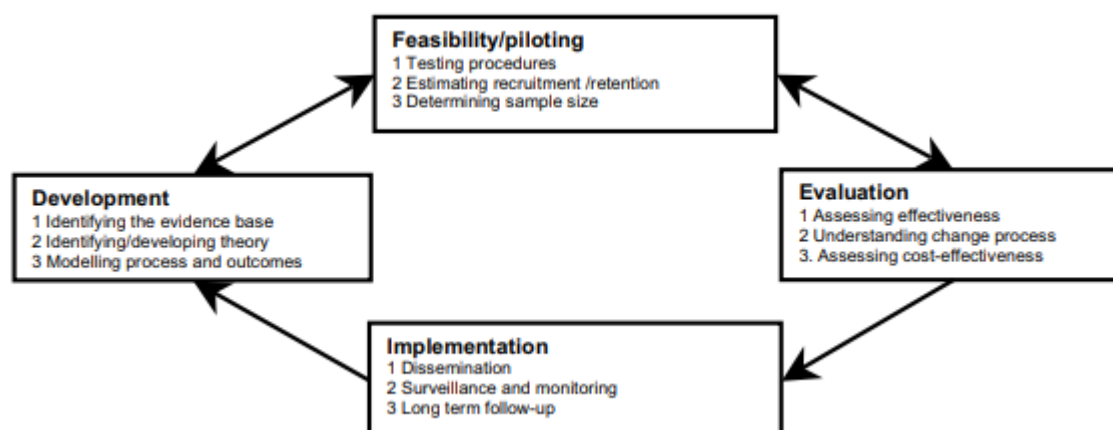
Note. Reprinted from (Craig et al., 2011)

Assessing need

Several empirical studies consisting of 2 systematic reviews, 2 quantitative studies and a qualitative study were used to justify the need for the development of the current intervention. Additionally, an overview of the literature explored existing evidence for CYPMH prevalence, influencing factors to decision-making in CYPMH, SDM and impact on the family (Chapter 2). The first systematic review aimed to better understand the emotional experiences of having a child with MH problems and explored how those experiences may influence parents' involvement in care and treatment decisions (Chapter 3). The second review aimed to identify and examine the existing decision support interventions available for parents of children with MH problems (Chapter 7). The first quantitative study explored primary carers' decision to seek help for CYP's MH in a representative sample of school-aged children (Chapter 3). Further, a realist perspective was adopted to quantitatively explore parents' experience of SDM in CAMHS and discussed associations with MH difficulties, additional problems and impact on the CYP (Chapter 5). Lastly,

qualitative interviews were conducted to obtain insight into how HCPs and parents perceived and described experiences of SDM and provided an opportunity for participants to identify support systems used (Chapter 6).

Assessing development feasibility

Firstly, the 3-year timeline for the PhD was deemed appropriate to develop and evaluate an intervention. Secondly, the pre-existing relationship with the app company (Create Health) made it suitable to undertake the development of a digital intervention. Additionally, the financial resources necessary to develop the intervention was available through the PhD project funding. Furthermore, preliminary evidence from the original Power Up for CYP (Edbrooke-Childs et al., 2019) suggested that is was feasible to develop and evaluate a new digital intervention to be used in CYPMH settings.

Defining the objectives of the decision aid

Based on the results of the studies described in this thesis and feedback from parents, practitioners and researchers (described later in this chapter), the following primary objectives were considered necessary to guide the intervention's development process:

1. Encourage discussion (i.e. Three talk model proposed by Elwyn et al., 2017)
2. Allow parents to ask questions during sessions or seek further information within sessions.
3. Provide a space for parents to identify their own feelings/moods and receive support.
4. Allow service providers (i.e. healthcare professionals) to tailor the SDM process to accommodate the needs of the parent and child (i.e. informed vs involved)

Identifying the framework of decision support

In general, the development process of the intervention was conducted in line with the IPDAS quality dimensions as it is intended to be used as part of the SDM process (Elwyn et al., 2006; Ottawa Health Research Institute, 2005). The guidelines encourage using a systematic development process; providing information about options; presenting probabilities; clarifying and expressing values; using patient stories; guiding/coaching; disclosing conflicts of interest; internet delivery; balanced presentation of options; using plain language and basing information on up to date evidence. However, more specifically, the Youth SDM model (Crickard et al., 2010), the Ottawa Decision Support Framework (ODSF) (O'Connor A et al., 2011), the integrative model of SDM in medical encounters (Makoul & Clayman, 2006) and the affective appraisal SDM model (Chapter 6) informed the content of the intervention.

The Youth SDM model highlights three key SDM functional areas: setting the stage for youth SDM, facilitating youth SDM and supporting youth SDM. Setting the stage for youth SDM involves providing an introduction to the concept of SDM and inviting and acknowledging the service user's preference for involvement. To facilitate this, a co-design process to develop a webpage, to define and explain SDM in CYPMH settings, was undertaken. The PhD candidate, as the primary applicant of the UCL Public Engagement grant, secured funding (see Appendix L) to work alongside parents and young people to develop a SDM resource (discussed later in the chapter). Consequently, the webpage became the welcome screen of the intervention to "set the stage" for SDM.

Secondly, the nine essential elements of SDM were used to "facilitate the SDM process". Researchers conducted an in-depth review of the SDM literature and

proposed that in order for SDM to occur service users and service providers should work together to define and/or explain the problem, review options, discuss pros and cons, explicate service users' values and preferences, discuss self-efficacy, obtain clinician's recommendations, clarify service user understanding, make or defer decision and arrange follow-up (Makoul & Clayman, 2006). The current intervention was designed to incorporate all nine elements of SDM outlined in that review.

In line with the affective appraisal approach to SDM (described in Chapter 6), the ODSF was used to inform "support" for the SDM process. The framework proclaims that *participants'* decisional needs will affect decision quality which in turn affects actions or behaviour (e.g. delay), health outcomes, emotional state (regret, blame) and appropriate use of health services (Murray et al., 2004). This framework was pertinent to the intervention as previous research highlighted the potential impact of parents' emotions on the SDM process (Chapters 2 and 6).

Selecting the methods, designs and planning for the feasibility and pilot study

Stakeholder Involvement

The remaining 3 steps outlined by O'Connor & Jacobsen (2003) were collapsed under the overarching heading stakeholder involvement. There is an overarching consensus that involving end-users in the development of health interventions is critical to successful implementation (Bagley et al., 2016). Developers and researchers converge on the understanding that PPI can benefit uptake and usage of interventions. More specifically, the involvement of end-users is known to improve idea generation and creativity (Blackburn et al., 2018; INVOLVE, 2017). The following sections describe how various stakeholders were involved in the development of the intervention.

Steering Committee

From conception, a steering committee was formed consisting of the PhD candidate's primary supervisor (JEC), the former digital lead at AFNCCF (Helen), 3 parents with experience of having a child with a MH problem and chaired by the PhD candidate. The parents were appointed as part of the steering committee after expressing interest in the study at various presentations undertaken by the PhD candidate. The committee was ideal for consensus forming and was mainly responsible for ensuring the development process was transparent and unbiased. The steering committee also guided the feasibility and pilot study for the intervention by offering strategies to promote recruitment and received quarterly updates on recruitment figures.

Patient and public involvement

The overall objective of the PPI consultations was to obtain parents' expert advice on the research and intervention design. However, gaining insight into how parents may use digital health interventions and obtaining input on how to improve the intervention before the study began was necessary. A three-step approach described below was undertaken to achieve these aims.

First, an email consultation was conducted with the Family Research Advisory Group (FRAG) at the National Children's Bureau (NCB). Information about the aims of the study and plans for an intervention with specific questions to generate ideas were shared with the research team at the NCB. The team contacted 9 parents who provided input on the value of the intervention, what support might be needed and which group of parents we should target for recruitment. Prototype development began based on input received.

Second, the study design and an example of how the intervention might be used were presented to the group at a scheduled meeting. The pros and cons of digital versus other formats of decision-making tools were discussed along with general thoughts and concerns on the study/intervention design. The prototype was refined and updated before the final meeting.

At the final meeting, a group discussion, including a presentation of the prototype was conducted, to examine the penultimate version of the intervention and the study design. There were further discussions on how parents could use and benefit from the intervention in practice. Further refinement of the prototype was carried out based on feedback received.

Showcase Pollinator event with Clinicians and Researchers

At a showcase pollinator event, which was held in Austria at the Technology Enabled Mental Health (TEAM-ITN) Summer School, the prototype was presented to clinicians, researchers and intervention developers who were asked to provide feedback and specifically provide input to improve the interactivity of the intervention. Three round table discussions followed, and input was obtained from a total of 12 experts in the area of CYPMH. Attendees at the event had a specific interest in digital interventions to prevent, treat and promote policy for CYPMH.

Public engagement

A collaborative approach was taken to develop and design a webpage to promote SDM in CYPMH settings. Firstly, a survey to elicit the public's opinion on the preferred mode of delivery for an SDM resource was conducted via social media. Responses from clinicians, parents, CYP, school staff and others were in favour of a

web resource. Consequently, three Parent Champions and four Young Champions from the AFNCCF attended two workshops and provided email feedback on two versions of the webpage before agreeing on the final version. At the first workshop participants explored what SDM meant and a consensus was reached for a family-friendly definition that could be displayed on the webpage. At the second workshop participants were involved in designing paper prototypes of the webpage. The former digital lead at AFNCCF (Helen) and the PhD candidate conducted these workshops. Consequently, the webpage was designed, and content updated based on feedback received from the two rounds of email input. The communications team at AFNCCF were then involved to ensure the content and design was in line with the Centre's standards. The webpage presented as the welcome screen for parents upon accessing the intervention.

App developers

The app developers at Create Health were responsible for the technical development of the intervention. However, design specific components such as swipe versus touch features or the labels for the settings menu of the app were proposed by the developers and included only after it was agreed by the PhD candidate. Based on feedback from the steering committee, PPI sessions and parent experts, a series of paper prototyping and digital designs were developed before the final version was adopted.

Results

Evidence-Base

The general affective appraisal theme arising from Chapters 1-7 of this thesis highlighted a need for an intervention targeting parents of CYP with MH problems, to

promote SDM. Chapter 2 reported the high prevalence of CYPMH problems, several

decision-making opportunities, barriers and facilitators to SDM and positive

outcomes when SDM was adopted in care. Chapter 3 revealed that parents are

expected to, but not always able to be involved in CYPMH decisions and identified a

wide spectrum of emotions that may affect the decision-making process. The results

of Chapter 4, suggested that parental worry was negatively associated with the

decision to seek CYPMH support.

Nonetheless, chapter 5 highlighted a large number of parents reporting

involvement in SDM, and illuminated a framework describing an affective appraisal

approach to SDM that is essential to CYPMH SDM. Chapter 6 highlighted the

importance of including parents in the decision-making process, as expressed by

parents and service providers, and provided support for the theory that 'parents are

expected to, but not always able to be involved in the SDM process'. Chapter 7 then

identified 23 existing parent-targetted decision support tools that met an average of

4.57 SDM elements out of a possible 9. Furthermore, time, accessibility and

appropriateness of the intervention emerged as factors influencing usage and

implementation of interventions providing additional support for a digital intervention.

Table 8.1 presents an overview of how the research studies informed the

intervention's design objectives and key features.

Table 8.1 Overview of the intervention's objectives and key features

Research Evidence	Intervention design objective	Key features of the intervention
Recognising the need for help can be challenging as parents' perceptions of their child's MH difficulties differ from that of their child's, teacher's and health professionals (Cleridou, Patalay, & Martin, 2017; Fält, Wallby, Sarkadi, Salari, & Fabian, 2017; Hawley & Weisz, 2003). These disagreements are reflected in parents reporting not feeling listened to or respected, further adding to frustrations and disappointment (Andershed, Ewertzon, & Johansson, 2017; Hart, Saunders, & Thomas, 2005) (Chapters 2,3 and 6).	Encourage discussion. Allow parents to ask questions during sessions or seek further information within sessions.	Decisions/Goals Decisions/Resources

Findings suggest that parents are 'expected to, but not always able to' engage with CAMHS due to the 'emotional roller coaster' they experience (Chapters 3 and 6).	Provide a space for parents to identify their feelings/moods and receive support.	Support/Journey
Findings suggest the triad relationship is unique and can be challenging in CAMHS settings. Recommendations are made to explore opportunities for varying levels of involvement such as "informed" versus "actively involved" parent (Chapters 2, 5 and 6).	Allow service providers to tailor the SDM process to accommodate the needs of the parent and child (i.e. informed vs involved)	Decisions/Resources
Findings indicated that time, accessibility and appropriateness of the intervention emerged as factors influencing usage and implementation of parent-targeted SDM interventions (Chapter 7).	Be suitable and accessibility to parents	Digital mode of delivery

Logic Model

The above evidence was explored in detail and presented in a logic model to outline the purpose of the intervention. Figure 8.4 provides an overview of the EBPU logic model, consisting of four parts that describe the intervention and the target audience. The logic model also highlighted the aims of the intervention and expected outcomes once implemented. Additionally, a list of potential moderators that may influence usage and implementation were reported.

Figure 8.2 Logic model outlining the intervention process (Adapted from Wolpert et al., 2016)
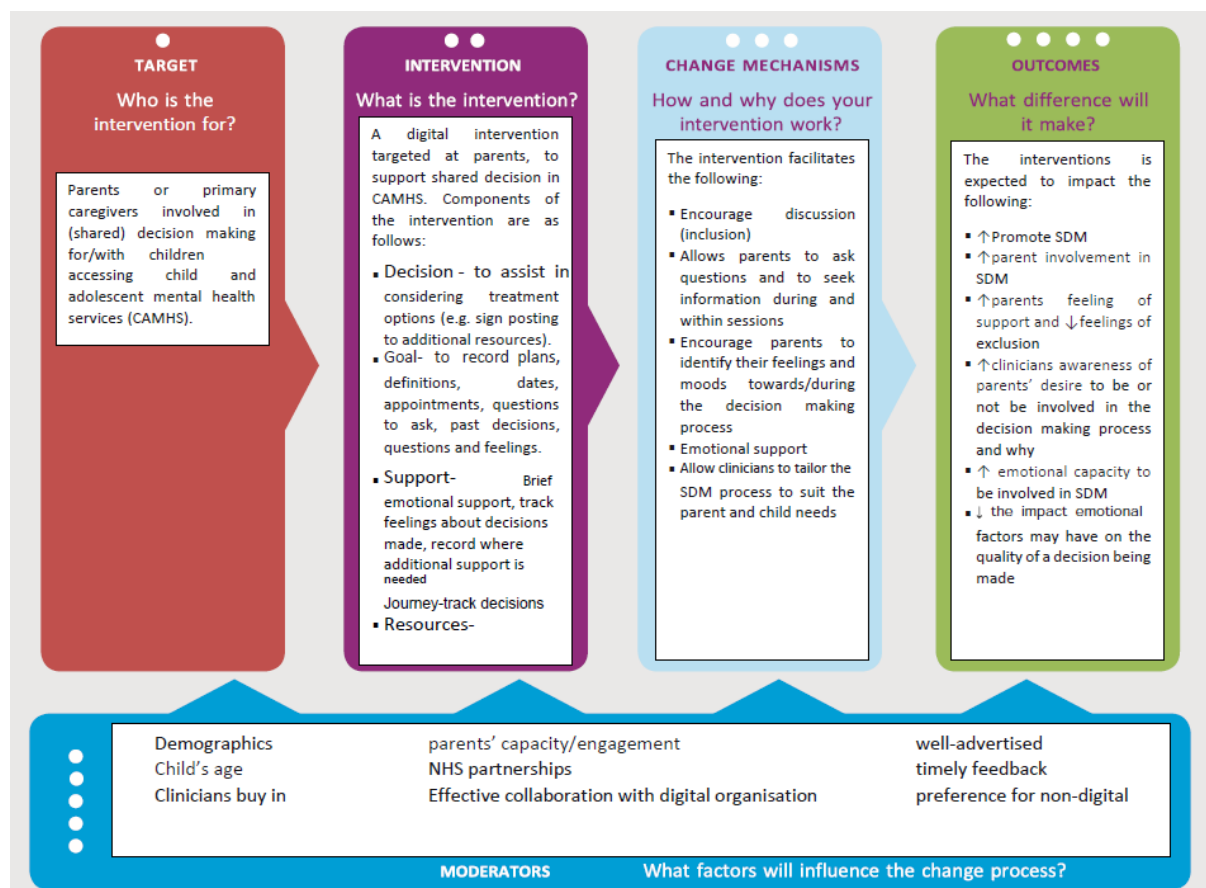
Outline of the intervention (i.e. Power Up for Parents)

This section summarises the key features of the resulting prototype and user manual (see Appendix M). The Power Up for Parents title was adopted as this

project was an amended version of the original Power Up intervention for CYP that supports and promotes SDM in CYPMH settings (Chapman et al., 2017). Although the current prototype is being referred to as Power Up for Parents, the feedback from PPI sessions indicated that non-biological parents may feel excluded. In response to this, the prototype included a customisation feature to change the word "Parents". Therefore, it can be labelled "Power Up for Rob" to reflect the child's or parent's name (see Figure 8.5). The overall structure of the app's content is as follows:

Decision

This is a decision support feature that guided users to seek information about treatment options, to review the benefits and risks of each option, to track decisions, and to record where more information or support was needed (see Figure 8.3). Additionally, as the research focused on the triad relationship, parents were encouraged to involve others in the decision-making process by seeking preferences from the clinicians, their child, or other relevant persons. This section uses the 9 essential elements of SDM to "walk" users through the decision-making process prompting users to answer questions such as: "Do you have sufficient information about the options available to you?" and " Do you feel ready to make this decision?". The other sections below provide additional support throughout the decision-making process in line with the affective appraisal model of SDM.

Figure 8.3 Example of the home screen and decision tab
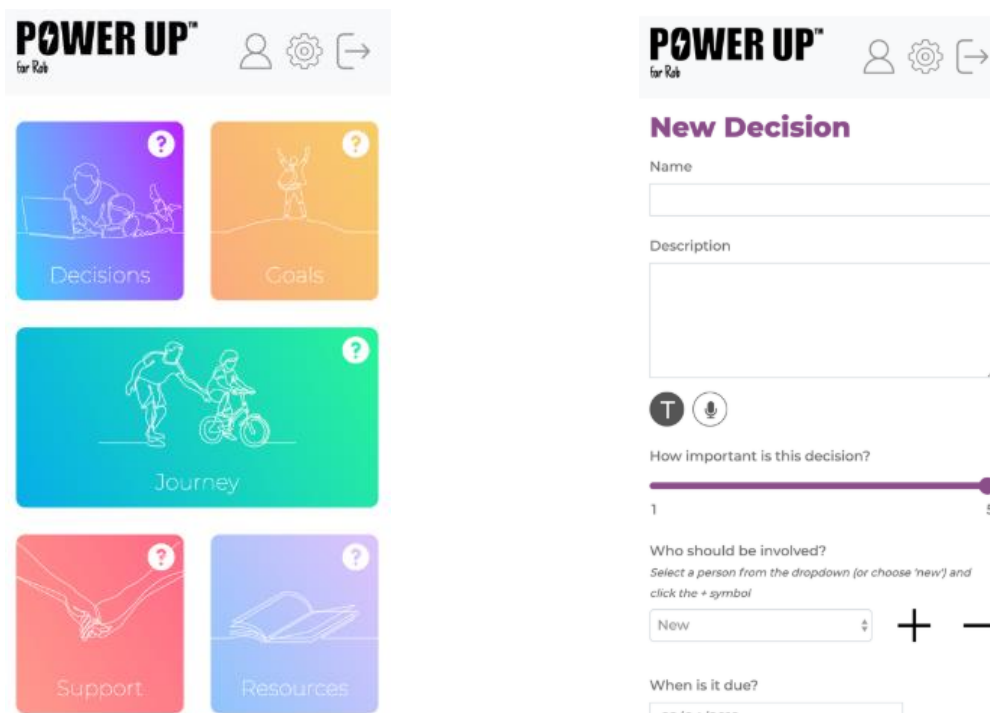
Goal

This feature is expected to be used in sessions or between sessions to record and track goals as they were discussed with healthcare professionals and the child. It is expected to allow users to set individual or consensus goals and explore plans to achieve these goals (see Figure 8.4). Additionally, parents could record any questions or concerns they had so that they could address them at the following session. Research findings suggest that goal-setting and tracking progress is associated with self-efficacy (Chang et al., 2017) and is one approach to promoting SDM in CYPMH (Cheng et al., 2017).

Figure 8.4 Example of the goal tab
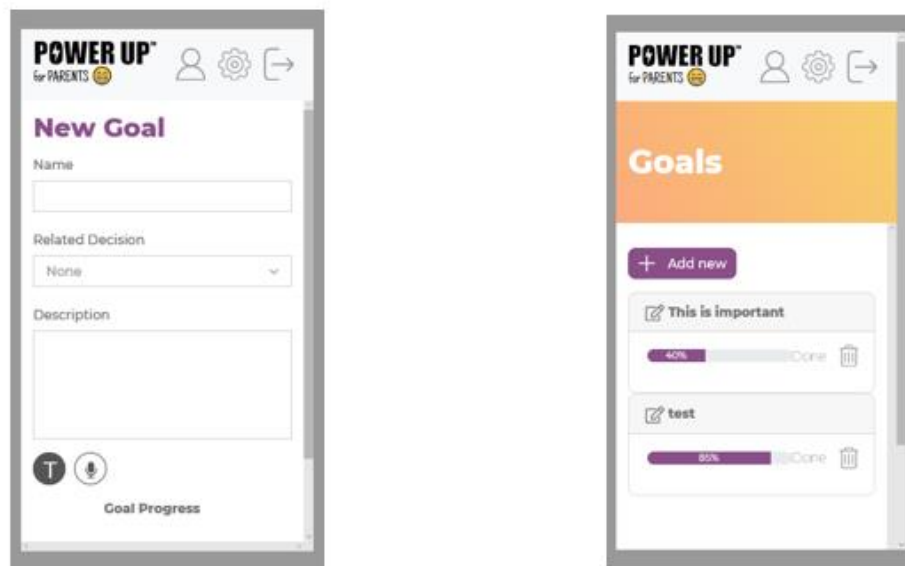
Journey

This feature allows parents to reflect on their emotions or issues that may

have affected the decision-making process. A parent could decide to share the

content with the child and the clinician, and it could be used during and within

sessions to keep track of the decision-making journey from user readiness to

outcomes. Expectations, experiences, and reflections are recorded here using the

diary function (see Figure 8.5). The usefulness of implementing case-tracking and

the documenting of client journeys have been highlighted in previous research

(Barton et al., 2019). Although previously explored in primary care services, the

authors highlighted its importance in monitoring the comprehensiveness of service

responses and the experiences of clients.

Figure 8.5 Example of the journey tab
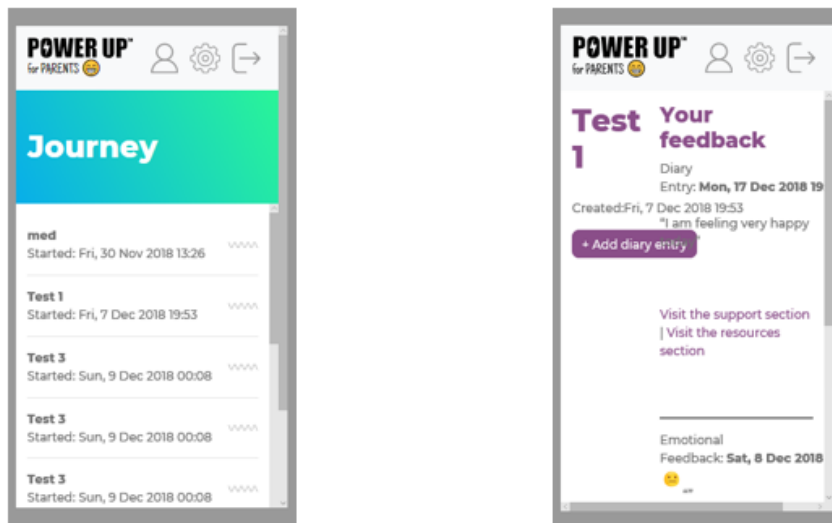
Support

This section hosted a tool to allow parents to identify and express their views about various stressors affecting the decision-making process. Users were encouraged to think about things that are stressful and explore ways to manage them. They were able to track feelings about decisions and explored where additional emotional support was required (see Figure 8.6). The stress bucket concept has been endorsed across health care and well-being settings with positive feedback across age groups (Brabban & Turkington, 2002).

Figure 8.6 Example of the support tab
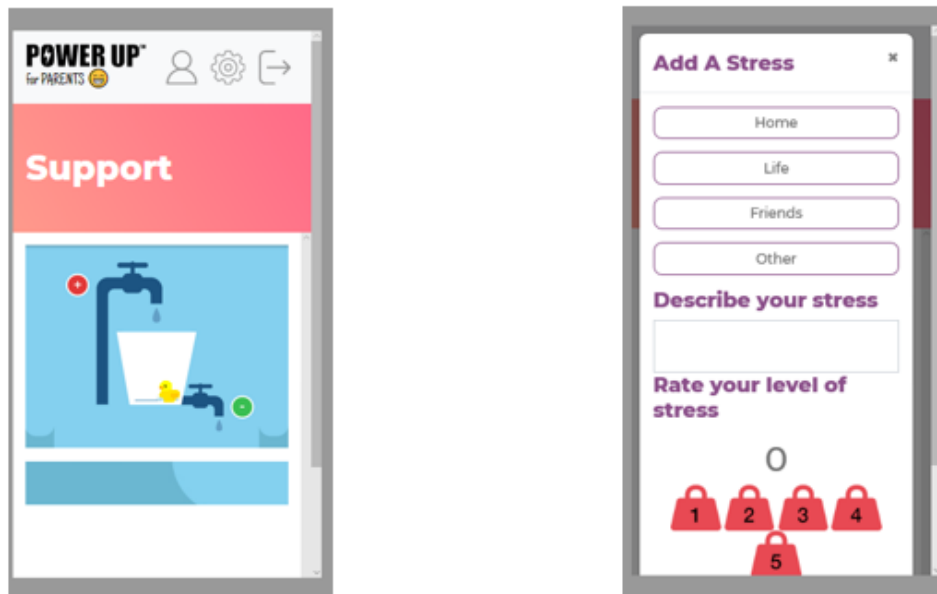
Resources

This section included useful contact details that signposted users to further support and guidance. Parents could have uploaded their own resources to help with the decision-making process and included contacts that they found most helpful (see Figure 8.7). Parents involved in previous CYPMH research indicated the benefits of receiving information and expressed feeling more included when provided with adequate evidence (Association of Young People's Health (AYPH), 2016). However, parents reported feeling overwhelmed when too much information was given at once (Chapter 3) and therefore, this section allowed parents to work with the service provider to identify and obtain specific resources that are directed at them.

Figure 8.7 Example of the resources tab
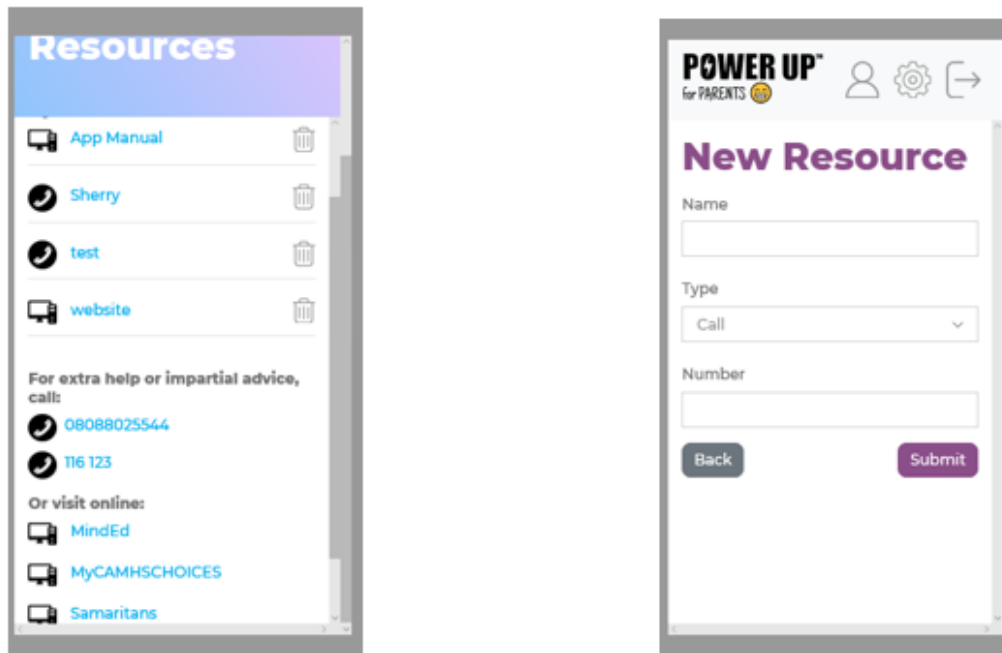
Discussion

This chapter described an evidence-based process to the development of a complex intervention, referred to as Power up for Parents, based on the MRC framework (Craig et al., 2011) and guided by the workbook for developing and evaluating decision aids (O'Connor & Jacobsen, 2003). The intervention's objectives were based on five empirical studies and a narrative literature review described in this thesis (Chapters 1-7). Additionally, stakeholder input from parents, clinicians, researchers and CYP informed the design and content of the intervention. The intervention was developed in accordance with the IPDAS guidelines (IPDAS Collaboration, 2019) and grounded in four main SDM models: the Youth SDM model (Crickard et al., 2010), The Ottawa Decision Support Framework (O'Connor et al., 2011), the integrative model of SDM in medical encounters (Makoul & Clayman, 2006) and the affective appraisal SDM model (Chapter 6). The findings from studies included in this thesis and the existing literature highlighted a need to provide

additional support for those parents who are involved in CYPMH decisions. The resulting prototype aimed to encourage discussion, allow parents to ask questions during sessions or seek further information within sessions, provide a space for parents to identify their own feelings/moods and receive support, in addition to allowing service providers to tailor the SDM process to accommodate the needs of the parent and child. To address the design aims 5 key sections were embedded into the intervention. These features were: "Decisions", "Goals", "Journey", "Support" and "Resources".

Comparison with existing literature

The development process described in this chapter is consistent with the development process described in other parent-targetted SDM interventions identified in Chapter 7. Developers generally reported utilising end-user feedback, literature reviews, established guidelines, and empirical studies to inform the intervention (Ahmed et al., 2014; Brinkman et al., 2013; Grant, 2016; Hayes, Town, & Lemoniatis, 2018). Some developers also reported using the IPDAS and ODSF guidelines or being informed by the Behaviour Change Theory or Theoretical Domains Framework . Overall researchers reported adopting one or a subset of these approaches to inform the intervention development process. However, only Hayes et al. (2018) reported using the MRC guidelines to inform the development of the i-THRIVE Grids. Of the 15 interventions with associated literature (Chapter 7), three were considered digitally accessible, of which two targeted parents of children with ASD (Carlon et al., 2017; Grant, 2016) and one targeted parents of children with ADHD (Ossebaard et al., 2010). Additionally, only one face-to-face intervention explicitly offered additional emotional support through Counselling in Dialogue to support the SDM process (Westermann et al., 2013). Recently, recommendations to

develop digital interventions that promote well-being factors in addition to the
targeted behaviour change have been proposed (Calvo & Peters, 2015; Person-
Centred Care Team and Coalition for Collaborative Care, 2015). In line with this
recommendation, PufP targetted parents of children with any MH problem, to
promote SDM and offered additional emotional support.

Strengths and limitations

The main strength of this development process is the adoption of participatory
design methods, where researchers, app developers, clinicians, parents and children
were involved as partners at various stages to determine the content and design of
Power Up for Parents. Secondly, adhering to the MRC framework and following the
workbook for developing decision aids provided a solid foundation for an evidence-
based intervention. Additionally, the theoretical underpinning of the affective
appraisal approach to SDM, and the evidence-base informing the content of Power
Up for Parents provided a basis for potential success when the intervention is tested
for effectiveness. Another strength is the dynamic nature of web-application platform
to integrate into electronic health record systems or embedded in NHS websites if
found to be effective. Lastly, incorporating all 9 elements of SDM, instead of the
average 4.57 contained in similar interventions identified in the scoping review
(Liverpool et al., 2020) was viewed as a major strength.

However, the complexity of the intervention and the comprehensive approach
taken to inform development resulted in a process that lasted almost 28 months.
Although this may be viewed as a time-consuming process, developers aiming to
develop similar interventions can utilise fewer empirical studies and incorporate rapid
prototyping techniques (McGurk et al., 1997). In hindsight, another possible limitation

could be the selection and combination of SDM models and theories. Other researchers in the field of SDM may criticise the chosen models and may have a preference for alternatives. However, for the purpose of this research project, they seemed appropriate, and because they overlap in some areas were readily combined. Similarly, the parents and CYPs involved in the PPI sessions could represent a biased sample of persons who volunteer their time and expertise to inform research (Rashid et al., 2017; Staniszewska & Denegri, 2013). Therefore, they may not provide a broad representative view of families having a child with MH problems. Lastly, it can be costly to develop digital interventions. For that reason, it is recommended that cost-effectiveness be integrated into future study designs when evaluating the intervention. Once proven effective the cost can be justified as digital interventions have the ability to be scalable, affordable, and easily accessible for users (Alvarez-Jimenez et al., 2014; Diehl et al., 2012; Donker et al., 2013).

Implications for implementation science

Interventions addressing MH concerns or SDM could replicate this development process if the intervention is found to be effective in later studies. Digital interventions have the potential to offer support, endorsing advantages such as accessibility, a high degree of anonymity, prompt feedback, cost-effectiveness, applicability in real-life contexts and high treatment fidelity. With the high prevalence of CYPMH problems (Chapter 2) and the need for emotional support for parents (Chapters 3 and 6), CYPMH setting could benefit from offering virtual support to parents in the absence of the resources to facilitate face-to-face sessions with such large numbers of families. Additionally, developing an intervention that encourages service users to collaborate with service providers can be empowering for service users.

Conclusion

A multidimensional process was adopted, including an in-depth exploration of existing literature, empirical studies, theoretical underpinnings and patient and public input, to develop an evidence-based intervention to support parents. The resulting intervention demonstrated and confirmed that it is possible to use input from end-users, integrated with theory and research evidence to create digital health interventions to be used in CAMHS. The following chapter enters a pilot phase (Chapter 9), aimed at obtaining end-users input for further development, views on acceptability, and explores the feasibility for conducting a randomised control trial. This is in line with the MRC recommendations for next steps before proceeding to a full-scale evaluation and implementation.

Chapter 9 Acceptability and Feasibility Pilot Study of a Digital Intervention to Support Parents of Children with Mental Health Problems (Study 6)

Previous chapters highlighted that the prevalence of CYPMH can be a burden on the NHS, and therefore supporting large numbers of families at face-to-face sessions can be a challenge (Knapp et al., 2011; M. Knapp et al., 2015). Secondly, (shared) decision-making within this population can be challenging for many reasons, such as individual, professional, service and policy level barriers. One understudied individual factor in the area of CYPMH is the emotional state of the parents as an influencing factor on SDM. Chapter 3 explored this concept and reported that although parents are expected to be involved in the decision-making process, they are not always able to. Chapter 4 discussed the negative association between parents' decisions to seek help and their state of 'worry'. Chapter 6 further built on this line of argument by focusing on how emotions may potentially affect SDM. Chapter 7 then examined how the existing decision support interventions offer the necessary support to assist with involvement in SDM.

Consequently, Chapter 8 described the development of an evidence-based and evidence-informed 'complex' intervention to support parents involved in CYPMH decision-making. This chapter focused on testing the feasibility of conducting a prospective RCT to examine the impact of Power Up for Parents on families accessing CAMHS. The protocol for the study described in this chapter was published in the Journal of Medical Internet Research (Liverpool et al., 2019) and registered with an International Clinical Trials Registry (ISRCTN39238984) (Liverpool, 2018).

The rationale for this study

Based on the review of existing decision support tools for parents (Chapter 7), to date, there has been no RCT that has examined the effectiveness and acceptability of an interactive parent-targeted mobile digital decision support intervention for universal CYPMH problems. Previous research has either explored the use of other modalities (e.g. face-to-face, paper-based, or static digital tools) or within specific populations (e.g. ADHD or ASD) or utilised non-RCT study designs (e.g. pre/post, qualitative or pilot trials) (see Table 7.2, Chapter 7). The findings of that review also highlighted a large number of interventions that were developed and implemented without being tested for effectiveness. Researchers and clinicians agree that poorly designed studies to test these interventions can result in false-positive findings and loss in research investments (i.e. researchers' time and funding) (Deaton & Cartwright, 2018; Gillies et al., 2019).

The evidence-based approach to evaluating effectiveness recognises RCTs as the "gold standard" for generating the highest level of evidence. Researchers agree that RCTs are the most rigorous when it comes to determining cause-effect relationships between treatment and outcomes and are also very useful for assessing the cost-effectiveness of a treatment (Akobeng, 2005; Hariton & Locascio, 2018). However, to ensure a successful RCT is conducted, it is highly recommended that pilot and feasibility studies are first conducted. Feasibility studies help to answer the question "Can this study be done?" and pilot studies focus on whether the components of the study work well together (Arain et al., 2010; Thabane et al., 2010). Additionally, the MRC guidelines highlight that assessing the feasibility allows the researchers to examine important components of the research such as testing the procedures, estimating rates of recruitment and retention of participants and

determining the sample sizes for the future trial (Craig et al., 2011) which researchers agree is crucial to successful RCTs. Therefore, acknowledging the relevance of pilot and feasibility studies and in keeping with the MRC guidelines for developing, evaluating and implementing a complex intervention, this study was deemed an important next step.

Aims and research questions

The primary research aim for this pilot feasibility study was to develop and investigate whether it is feasible to conduct a prospective RCT of an evidence-based mobile application to promote SDM in families accessing CAMHS. In addition, this study assessed the perceived usefulness and acceptance of the intervention to determine if end-users would engage with it.

The following research questions were addressed:

Quantitative research questions

1. What is the eligibility, consenting, adherence and engagement rates of participants using Power Up for Parents?

2. Are the outcome measures appropriate and acceptable for a prospective RCT?

3. What are the potential barriers and enablers to conducting a prospective RCT?

4. Which data collection procedures are appropriate and acceptable?

5. What is the scope of the pilot data collected from users and non-users of PUfP?

Qualitative research questions

6.   Is Power Up for Parents acceptable and useful for parents and healthcare professionals?

7.   Can the feedback from users be used to further refine the prototype for the prospective RCT?

Methods

Study design

A two-stage research study was undertaken involving a qualitative study (also see Chapter 6) to inform the further development of Power Up for Parents (Stage 1) and pilot feasibility testing (Stage 2). Stage 1 involved user-testing by HCPs and parents to obtain feedback on acceptability, usefulness and suggestions for further development and upgrading of the prototype to a full app. The second stage of the study included: 1) a multi-centre, three-arm, cluster randomised controlled, pilot feasibility trial with parents accessing CAMHS, and 2) an online individually randomised trial with a community sample of parents to inform recruitment strategies for the full trial. A multi-site, cluster randomised approach was piloted to explore efficiency and eliminate possible study contamination. In addition, Chapter 5 highlighted the potential for service-level influence on parents' experience of SDM which may be controlled for when adopting cluster randomization.

Study setting

NHS sites were identified through consultations with supervisors and other researchers at the AFNCCF and UCL. Eighteen NHS Trusts throughout England were identified as potential sites to participate in the study. Nine London sites, and nine outside of London were selected. Six of these sites were sites that expressed interest in participating in the Power Up for Young People trial (Chapman et al., 2017) but were not involved because that study had ended. The remaining 12 were

randomly selected from the list of all CAMHS in the UK (NHS, 2019). CAMHS was used as a broad term for all services that work with children and young people who are experiencing MH difficulties. However, the focus was centred around, but not limited to, specialist CAMHS, where CYP received services from a multidisciplinary team that included psychologists and psychiatrists. Additionally, a community sample was obtained with participants from across England who were recruited online through social media advertising. Parents in the community sample accessed the study via a link to the recruitment software Gorilla (www.gorilla.sc).

Intervention: Power Up for Parents (PUfP)

The development and evidence base for the prototype was described and outlined in Chapter 8.

Participants

Identifying Potential Participants

Healthcare Professionals

A contact person (site collaborator) circulated information about the study to all HCPs. Then all HCPs at the selected NHS sites were invited to an information session at the CAMHS site. The PhD candidate gave a brief 7-minute introduction to the study and answered any questions that arose. At that session, an opportunity for staff to provide input to further assist in developing inclusion criteria for parent participants was offered to inform the recruitment process. Any HCP who identified as being in contact with the families accessing care when making care and treatment decisions were eligible to be part of the study.

Parents

Based on the inclusion/exclusion criteria agreed at the information session, staff identified suitable participants under their care. At a subsequent meeting with the families, staff solicited interest in participation by sharing information about the aims of the study. If the family expressed interest in taking part, their contact details were added to the site's database of potential participants and after consent, the site collaborator shared the contact details with the PhD candidate. Posters and flyers were also placed at participating NHS sites. To obtain a community sample, the study was advertised on the AFNCCF website between June and August 2019 and promoted through social media platforms (i.e. Facebook and Twitter). Additionally, a blog post was written on the Association of Child and Adolescent Mental Health (ACAMH) website to further advertise the study (ACAMH, 2019). The recruitment process was guided and informed by the PPI participants (Parent partners) and the study's steering committee.

All parents were screened against the following eligibility criteria:

Inclusion criteria

1. Over the age of 18

2. No known diagnosed MH issues

3. Ability to speak and understand English

4. Parent of at least one young person attending CAMHS.

Exclusion criteria

1. Concurrent and/or involvement in other research that was likely to interfere with the intervention

2. Parents or guardians in cases where the child/young person was being treated under a section of the Mental Health Act (1983).

Procedure and materials

Stage 1 (Development Stage)

Semi-structured interviews and FGDs were conducted. All participants (i.e. HCPs and parents) were sent information sheets and consent forms in advance of the interviews and FGDs. In addition to gathering parents' experiences of decision-making in CAMHS, an existing prototype of Power Up for Parents was presented, and suggestions for content and prototype upgrades were obtained. The interview guide also aimed to capture the perceived usefulness and acceptability of the intervention. At the end of the FGDs and interviews, participants were debriefed and advised to contact researchers with any further questions or suggestions via the contact details provided on the information sheets.

Stage 2 (Pilot and Feasibility Testing Stage)

The 18 sites identified were randomly assigned to either control or one of two intervention groups. Intervention group 1 (IG1) received the prospective version 1 of intervention which included the "Support" and "Resources" features. Intervention group 2 (IG2) received version 2 of the intervention without these two features. In line with the affective appraisal approach to SDM the additional features provided emotional and knowledge support. The cluster randomization for the NHS sample, was completed independently of the research team, using the R software programme guided by the balance algorithm (Carter & Hood, 2008). For the community sample, participant level randomization was conducted using the online recruitment software (Anwyl-Irvine et al., 2018). Therefore, any parent at any

CAMHS coming in contact with the study information had a chance to participate in the study.

Participants in the clinical sample met with a researcher at a time convenient to them and completed a battery of baseline and follow-up questionnaires, which consisted of demographic details, SDM measures, the experience of service questionnaire, decisional conflict measures and an anxiety questionnaire. Participants had the choice to complete these online or using paper and pencil. Participants in the community accessed questionnaires via an online link. Depending on which group the participants were recruited into (i.e. IG1, IG2 or Control), they received help to access the app and were given a guided tour of the app. The parents were then encouraged to go away and use the app as much as they needed to. Participants completed follow-up measures at three months after or at drop out/discharge (whichever came first).

HCPs working with the families participating in this cluster randomised study also completed an adapted version of The Control Preferences Scale to highlight observer changes in the amount of parental involvement in the child's care and treatment decisions. At the end of the pilot testing phase, participants were asked to share opinions on the study and more specifically on the intervention used before being debriefed and thanked for their participation.

Outcome Measures

Stage 1 (Development Stage)

Demographic Characteristics

Participants' demographic information were collected, including categorical (e.g., gender, ethnicity, first language, relationship to child) and continuous (e.g., age) characteristics.

Interview Topic Guide

To obtain end-users' views, a comprehensive topic guide (see Appendix N) was used which allowed participants to review the current prototype of and provide feedback on all aspects of the prototype. The participants' answers provided preliminary qualitative input on acceptability, improvements and usefulness of the intervention.

Stage 2 (Pilot Testing Stage)

Demographic Characteristics

Again, participants' demographic information was collected, including categorical (e.g., gender, ethnicity, first language, relationship to child) and continuous (e.g., age) characteristics.

Participation rates

The number of sites that were approached and the number of sites agreeing to take part were recorded, in addition to the number of participants consenting and participating in the overall study. The proportion of participants completing various parts of the study (i.e. consent, pre-test, intervention, post-test) was also recorded.

The prototype usage rates were also collected and reported using data from Google Analytics software (analytics.js).

Parent-reported decision-making preferences

The Control Preferences Scale for Paediatrics (CPS-P) (Pyke-Grimm et al., 1999) is an adaptation of the Control Preferences Scale (Denger et al., 1997). This tool was originally developed to measure "the degree of control an individual wants to assume when decisions are being made about medical treatment" (Denger et al., 1997, p. 21). This CPS-P consists of five different scenarios (e.g. I prefer to leave all decisions about my child's MH care and treatment to my child's practitioner), describing different levels of control preference in decision-making (see Appendix M). The scenarios ranged from "I prefer to make the final decision about which treatment my child will receive" to "I prefer to leave all the decisions about my child's treatment to the clinician". The original scale has been tested in a variety of populations, ranging from the general public to highly stressed groups. The CPS has proven to be a clinically relevant, easily administered, valid, and reliable measure of preferred roles in healthcare decision-making (Degner & Sloan, 1992).

Healthcare provider-reported observed parent decision-making involvement

Permission was obtained to modify and reproduce the Control Preferences Scale-Paediatrics. Therefore, the questionnaire was also adapted to obtain HCPs' perspectives on how parents preferred to be involved in the decisions. Providers were asked to select 1 of 5 statements on whether "the parent left all MH care and treatment decisions about the child to the practitioner" or "the parent shared responsibility for the MH care and treatment decisions about the child with the

practitioner" (see Appendix O). The aim of this measure was to assess parents'

actual (rather than hypothetical) decision-making roles.

Parent-reported SDM

The 9-item Paediatric Shared Decision-Making Questionnaire (modified)

measured the extent to which parents were involved in the process of decision-

making from the perspective of the parent (parent version PSDM-Q-9) (see Appendix

M). The measure was developed for use in research and clinical practice and

includes statements such as "My child's MH practitioner made it clear that a MH care

decision needs to be made". This tool is commonly used for the purposes of

evaluation and quality improvement in health care. This measure has shown face

validity, high acceptance and internal consistency with a Cronbach's alpha of 0.94 in

test samples (Kriston et al., 2010). The nine statements on the measure are rated on

a six-point scale from "completely disagree" (0) to "completely agree" (5). All items

were summed to give a raw total score between 0 and 45 where 0 indicated the

lowest possible level of SDM and 45 indicated the highest extent of SDM (Doherr et

al., 2017).

Parent-reported anxiety

The Spielberger State Anxiety Inventory Form for Adults (STAI-AD) is a 40-

item self-report questionnaire commonly used as a measure of trait and state anxiety

(see Appendix M). Each type of anxiety (i.e. state or trait) has its own scale of 20

different questions that are scored. Each item was rated on a 4-point scale for State-

anxiety as: not at all (1), somewhat (2), moderately so (3) and very much so (4). The

4-point scale for Trait-anxiety was: almost never (1), sometimes (2), often (3) and

almost always (4). This measure is commonly used in research as an indicator of

caregiver distress and include statements such as "I feel anxious" and "I feel like crying". The STAI-AD internal consistency coefficients ranged from .86 to .95 and test-retest reliability coefficients have ranged from .65 to .75 over a 2-month interval in previous research (Spielberger et al., 1983). In addition, test-retest coefficients for this measure in another study was also rated as highly significant with an intraclass correlations coefficient ranging from 0.39 to 0.89 (Quek et al., 2004). Scores range from 20 to 80, with higher scores correlating with greater anxiety. A cut point of 39–40 has been suggested to detect clinically significant symptoms for the State-Anxiety scale (Knight et al., 1983).

Parent-reported decisional conflict

The 16-item Decisional Conflict Scale (DCS) was originally developed to elicit information concerning the decision maker's: 1) uncertainty in making a choice; 2) modifiable factors contributing to the uncertainty, such as lack of information, unclear values, and inadequate social support; and 3) perceived effective decision making. This 16-item scale quantifies factors which contribute to uncertainty both during the process and at the outcome (see Appendix M). Each item was rated on a 5-point scale as: strongly agree (0), agree (1), neither agree or disagree (2), disagree (3) and strongly disagree (4) in response to statements such as "I know which options are available to me". Total scores ranged from 0 (no decisional conflict) to 100 (extremely high decisional conflict). Previous studies have shown that the psychometric properties of the scale are acceptable, and this measure is feasible and easy to administer (O'Connor, 1995).

Parent-reported satisfaction

The Experience of Service Questionnaire (ESQ) measures service satisfaction and is widely used in CAMHS in the UK. The ESQ consists of 12 items and three free text sections looking at what the respondents liked about the service, what they felt needed improving, and any other comments (see Appendix M). For example, the satisfaction with care construct was obtained by summing items 1 to 7,11 and 12 (Brown et al., 2014). The constructs in this tool were important to the current study as the SDM process and outcome may impact parents' perception of service satisfaction. Based on literature reviews of SDM (Makoul & Clayman, 2006) and similar research (Edbrooke-Childs, Jacob, Argent, et al., 2015), it was agreed that statements on the ESQ: "1) I feel that the people who have seen my child listened to me"; "2) It was easy to talk to the people who have seen my child"; "4) My views and worries were taken seriously" and "6) I have been given enough explanation about the help available here", assessed the key components of SDM. Each item had 4 possible responses: don't know (0), not true (1), partly true (2) and certainly true (3). The higher the score obtained, the better the respondents' SDM experience with service.

Usability and acceptability

The Post-Study Usability Questionnaire (PSSUQ) is a 19-item usability quantification survey (see Appendix P) developed in 1992, by the IBM Design Centre. The PSSUQ is generally used to quantify the usability of websites, apps, or any software or hardware that users interact with. The instrument presents a series of statements describing the app, which users agree or disagree with using a Likert scale (Lewis, 2002). PSSUQ follows a 7-point Likert scale starting from 1 (strongly agree) to 7 (strongly disagree). Participants are usually asked to rate statements

such as "It was simple to use the system" or "Overall, I am satisfied with the system".

For this study, the more general term "system" was replaced with the word "app" and

therefore questions were more targeted, such as "I was able to complete the tasks

and scenarios quickly using this app." This measure aimed to further assess

usability, appropriateness, acceptability and feasibility of the intervention within a

CYPMH context. Coefficient alpha for this measure has shown to be .97 and .91 to

.96 for the three subscales. The mean of the ratings was computed and the lower the

score represented the better performance and satisfaction. The subscales assessed

usefulness (questions 1 to 6), information quality (questions 7 to 12) and interface

quality (questions 13 to 15) (Lewis, 2002).

The SPIRIT figure illustrates the pathway through the trial, based on the trial

protocol approved by the NHS REC and, the Health Research Authority (HRA) (see

Appendix I.1) and the UCL REC (see Appendix I.2).

Figure 9.1 SPIRIT figure for stage 2 of the Power Up for Parents feasibility trial (Adapted from Chan et al. 2013)

	STUDY PERIOD				
TIMEPOINT	Enrolment	Pretest	Intervention	Posttest	End of Study
Eligibility screen	X				
Informed consent	X				
Allocation	X				
INTERVENTIONS:					
Intervention Group 1			●————————●		
Intervention Group 2			●————————●		
Control Group			●————————●		
ASSESSMENTS:					
Feasibility outcomes*	X	X	X	X	X
CPS-P[a]		X		X	
PSDM-Q-Parent[b]		X		X	
STAI-AD[c]		X		X	
DCS-P[d]		X		X	
ESQ[e]		X		X	
PSSUQ[f]				X	

[a]Control Preference Scale for Pediatrics, [b]Pediatric Shared Decision-Making

Questionnaire, [c]State-Trait Anxiety Inventory for Adults, [d]Decisional Conflict Scale –

Parent, [e]Experience of Service Questionnaire, [f]Post-Study System Usability

Questionnaire

Data analysis

Stage 1: Development Stage

All interviews and FGDs were audio-recorded and transcribed verbatim. Data collected were analysed using thematic analysis (Braun & Clarke, 2006). Data were coded using a combination of a priori themes as categories, and any emergent themes (Silverman, 2001). The coding process involved moving backwards and forwards between the data and the emerging concepts. The first step generated initial codes from open coding in which units of meanings were derived from line-by-line analysis followed by axial coding to integrate and differentiate among subcategories. The computer package NVivo was used as the qualitative data management software (QSR International Pty Ltd, 2015). An independent investigator (JP, an experienced applied psychology data analyst) independently reviewed 3 random transcripts and generated codes. Codes were compared and discussed to reach a consensus before inclusion.

Stage 2: Pilot Testing Stage

A quantitative evaluation was carried out to examine the feasibility and acceptability of the intervention as a useful decision support tool for parents. Descriptive statistics were calculated for participant characteristics at baseline. Consenting, questionnaire completion and study dropout rates were recorded and described as percentages. Google Analytic estimates were used to report engagement with the prototype. To address the aims of the feasibility study, the main focus was on the descriptive data. However, some exploratory significance testing was conducted on within and between-group mean differences at the 2 time points (i.e. baseline and follow-up) on the SDM measure using the "as-per-protocol" approach and therefore accounting for all missing data. The ICC was also calculated

in order to prepare information for sample size calculation within a clustered randomized trial. Analyses were conducted using the Statistical Package for Social Sciences (SPSS) software (IBM Corp., 2016). Owing to the importance of engagement for the success of digital interventions, outcomes were tested against the following progression criteria for proceeding to a full RCT upon completion of the feasibility trialClick or tap here to enter text.:

1. Recruitment of at least 6 CAMHS (2 sites per condition) within the first 6 months of recruitment
2. Ability to recruit at least 60 eligible participants during the recruitment period
3. >50% of consenting participants completing baseline measures and entering the intervention phase (minimum 10 per condition)
4. >50% of participants completing follow-up measures
5. Intervention use (>70% account registration and <30% bounce rate)

Recording adverse events

Adverse events were identified as any untoward medical occurrence in a patient or trial participant, which does not necessarily have a causal relationship with the intervention involved. Any adverse event arising during the study period was assessed for severity, causality, seriousness and expectedness (i.e. relating to the information provided by the intervention).

Trial management and monitoring

Overall, the trial was managed by the PhD candidate. However, the PhD candidate was supervised and guided by the PhD supervisors. The steering committee which was convened during the development of the prototype also

received quarterly updates on recruitment and offered strategies to promote recruitment. There were site collaborators and Principal Investigators at each of the participating CAMHS site to oversee the daily recruitment process.

Data management

All digital information about participants in the trial was stored securely in the password-protected Data Safe Haven and was only accessible by the PhD candidate and JEC (PhD Supervisor). Any other documents relating to the study that could not be stored electronically were securely stored in a locked cabinet in a locked room and accessible only by the PhD candidate. Identifiable information about research participants was kept for 3 months after the study ended, and all data will be securely stored and destroyed in accordance with UCL guidelines.

Ethical approvals and research governance

The study was ethically reviewed by the London Surrey Research Ethics Committee (REC) and approved by the Health Research Authority (IRAS 236277) for NHS CAMHS recruitment (Appendix I.1). Recruitment for the community sample was approved by UCL REC (Appendix I.2). The study was guided by the Declaration of Helsinki (2008), the International Conference on Harmonisation Good Clinical Practice (ICH-GCP),and conducted in accordance with the Department of Health Research Governance Framework for Health and Social Care (April 2005) and the Data Protection Act (2018).

Results

Overall, recruitment began in October 2018 and was scheduled to last for 1 year. The necessary NHS REC approvals were received in December 2018, and therefore recruitment from NHS CAMHS began in January 2019. The PhD student approached 18 NHS CAMHS. Twelve (67%) sites expressed interest and were recruited to take part in the study. For the online study, the online advertising reached an audience of 37,255 and resulted in 387 unique visitors to the study webpage. Data collection for the entire study was terminated on October 1st 2019.

The results section of this chapter is structured according to the study's research questions and assessed against the progression criteria defined prior to the start of data collection. Due to the feasibility nature of this study, where possible, data from the clinic and community samples were pooled to address the research questions. The criteria for proceeding to a full RCT were informed by the key areas of focus for evaluating a feasibility study (Arain et al., 2010; Thabane et al., 2010).

Changes to protocol

During the initial stages of the study, it was explored in supervision that the intervention may be applicable to settings beyond the NHS CAMHS. Parents in the PPI sessions confirmed this by expressing that the intervention was something they could use with limited guidance. In addition, typical service users accessing CAMHS are below the age of 18. The current research interest extended to parents of young people up to age 24. Therefore, to obtain more feedback and usage data during the feasibility and pilot testing of the intervention the PhD candidate added a second recruitment strand (Community sampling). It also became clear at the later stages of the study that recruitment from CAMHS was slower than anticipated and therefore

the second recruitment strand assisted in increasing the study's sample size. This change also strengthened the study by allowing further exploration of different recruitment strategies to address the aims of the feasibility study.

What is the eligibility, consenting, adherence and engagement rate of participants in the trial?

Through consultation with site collaborators and service providers, the eligibility criteria were considered clear and straightforward. However, one site expressed difficulties in recruiting parents due to the high percentage of parents at that site with a MH diagnosis which met the exclusion criteria. Consequently, that site withdrew from the study within 3 months of confirming capacity and capability.

Stage 1

Parents

For stage 1, forty parents in total consented to be part of the study (i.e. 36 from NHS CAMHS and 4 from community recruitment). The 36 parents from CAMHS were recruited from 7 of the 12 sites (58%). The remaining five sites not recruiting for stage 1 included the site that withdrew from the study, one site that wished to take part in stage 2 only and three sites that stated the parents were too busy to commit to an interview or focus group. Consequently, a total of 24 parents participated (60%): 14 parents were interviewed, and 10 participated in FGDs. For the remaining participants who consented but did not attend a FGD or interview, it was either not possible to contact them on the email or phone contact provided by the site collaborator or not possible to arrange a convenient time for an interview.

The sample included n=22 mothers and 2 fathers with a mean age of 44.88 (SD=6.76). The majority of the sample (96%) identified as White or White British ethnicity and the remaining (4%) identified as Asian. The mean age of their children was 13.88 (SD=2.8) and experiencing a range of MH problems. Of their children, seven (29%) were boys, sixteen (67%) were girls and 1 (4%) identified as other. Table 6.3 in Chapter 6, pp179 presents the characteristics of the parents who participated in stage 1 of the study.

Healthcare professionals

For stage 1, thirty-three HCPs from eight sites consented to be part of the study. Nineteen of the 33 were interviewed, and twelve participated in FGDs, accounting for 94% of the total HCP sample. For the remaining 2 HCPs (6%), it was not possible to arrange a time that was convenient during the recruitment period. HCPs represented a broad range of clinical expertise, worked with CYP from ages 0-25 years in an outpatient capacity and had an average of 7.54 (SD=6.24) years working experience in CAMHS. Table 6.4 in Chapter 6, pp181 presents the characteristics of the clinicians who participated in stage 1 of the study. For stage 2, any HCP who worked with the families that were participating in the study completed the observer Control Preference Scale at baseline and follow-up.

Stage 2

For stage 2, a total of 63 parents met eligibility criteria and consented to be part of the study (i.e. 30 from NHS and 33 from the Community sample). There were no significant demographic differences in the parents accessing the trial through community recruitment and those accessing through the NHS CAMHS (χ^2 (8)

=8.272, p=407). However, a higher number of missing values were observed for the community sample. Of the 63 parents, 42 (67%) parents completed baseline measures (i.e. 30 from NHS and 12 from the Community sample) and were randomly assigned to control (n=12), IG1 (n=11) or IG2 (n=19). Of the 42 parents, 16 (40%) completed follow-up measures (i.e. 12 from NHS and 4 from the Community sample). Two parents expressed not having time to complete the follow-up measures and the remaining parents could not be reached. There were no significant differences between the parents who consented and completed baseline measures and those who consented but did not complete baseline measures ($\chi^2$2(8)=8.766, p=.362). Similarly, there were no significant differences between the parents who completed follow-up measures and those who did not (χ^2(8)=8.015, p=.432).

Only 50% (6/12) of CAMHS sites were able to recruit parents into stage 2 of the study with an ICC of .042 on the PSDM-Q-9 measure. Of the remaining 6 sites, one withdrew from the study reporting difficulty to obtain HCPs support for the study and difficulty to recruit parents due to high levels of parental MH problems at that site. One site reported insufficient clinical staff to assist in identifying potential parents. The other 4 sites entered the study within the last 3 months of recruitment and reported insufficient time to participate in both stages of the study. The total randomised sample (N=42) were predominantly White British, English speaking mothers, with a mean age of 45.98 (SD=6.45) years. The majority of the sample were primary carers of teenage girls with a mean age of 14.31 (SD=2.14) years. Table 9.2 presents the demographic characteristics of the stage 2 sample and Figure 9.2 illustrates the flow of all parents throughout the study.

Table 9.1 Demographic characteristics of parent participants in stage 2 of the feasibility trial

Variable	Clinic n=30	Community n=12	Total N=42
	Mean ± SD or n (%)	Mean ± SD or n (%)	Mean ± SD or n (%)
Relationship to child			
Mother	24 (80)	12 (100)	36 (85.71)
Father	4 (13.33)	0	4 (9.52)
Other	2 (6.67)	0	2 (4.76%)
Parent's age in years	46.10 ± 6.85	45.67 ± 5.66	45.98 ± 6.45
Ethnicity			
White	28 (93.33)	11(91.67)	39 (92.86)
Black	1 (3.33)	0	1 (2.38)
Asian	1 (3.33)	0	1 (2.38)
Mixed-race	0	1 (8.33)	1 (2.38)
English as 1st language: Yes	28 (93.33)	11(96.67)	39 (92.86)
Child's age in years	14.6 ± 2.16	13.58 ± 1.98	14.31 ± 2.14
Child's gender			
Male	7 (23.33)	4 (33.33)	11 (26.19)

Variable	Clinic n=30	Community n=12	Total N=42
	Mean ± SD or n (%)	Mean ± SD or n (%)	Mean ± SD or n (%)
Female	22(73.33)	8 (66.67)	30 (71.43)
other	1 (3.33)	0	1 (2.38)

Note. SD=Standard deviation

Figure 9.2 CONSORT flowchart of participants in stage 2 of the Power Up for Parents feasibility trial (Adapted from Moher et al., 2001)
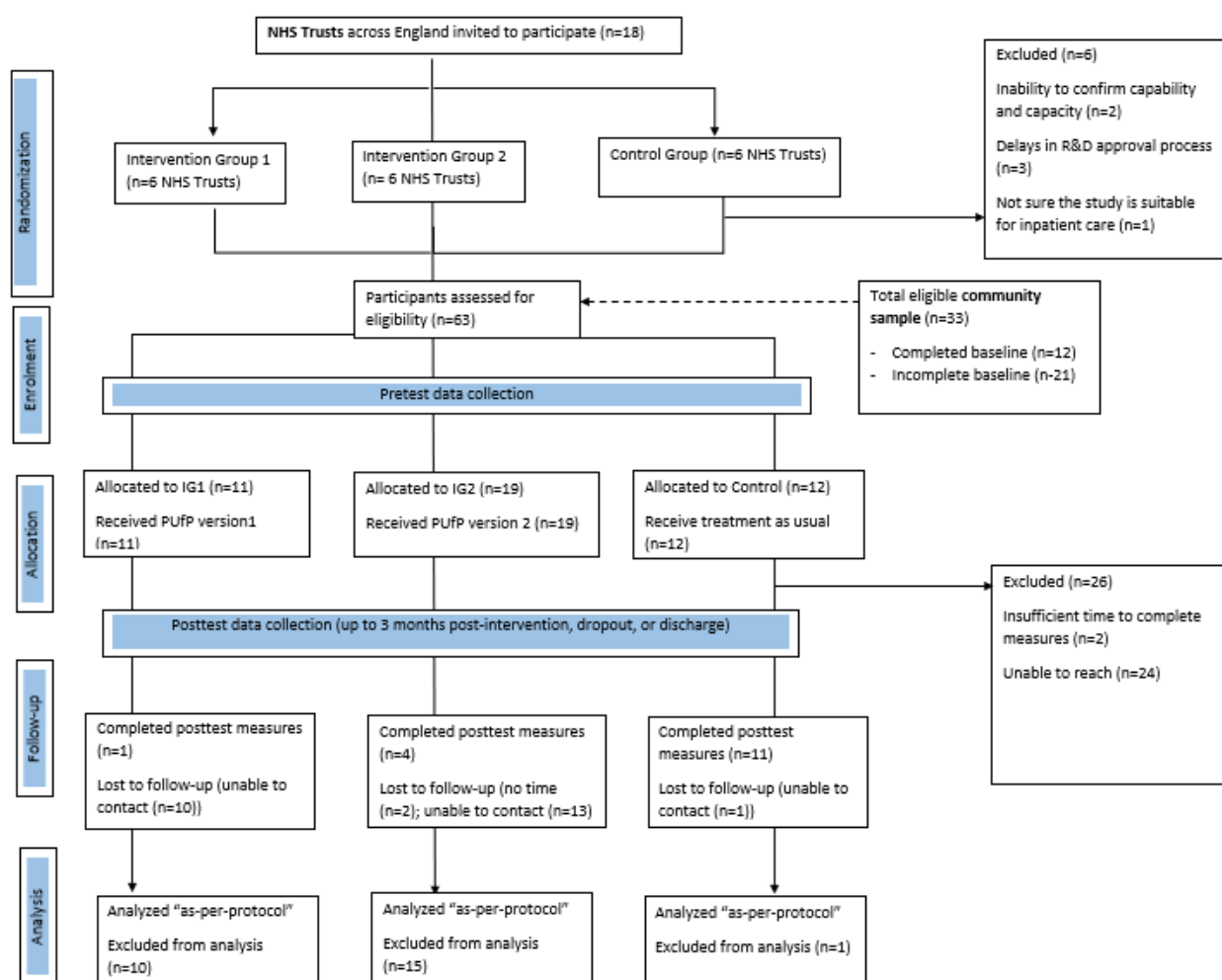
Engagement with the intervention

Google Analytics were used to examine app usage data during the period January 2019 and October 1st, 2019, which coincides with the recruitment of the first participant to Stage 2 of the study and the last day of data collection. App usage data were made anonymous to comply with GDPR and research ethical guidelines. Overall, 117 users cumulatively accessed version 1 and 2 of the app and 72 registered an account. It was estimated that a number of these users (~30) were

non-study participants (i.e. HCPs, parents not participating in the study and members of the research team/ steering committee and app developers). In total users visited the app 288 times at an average duration of 5 minutes and 59 seconds. Less than 33% of the users visited the app and left immediately without viewing any of the features (bounce rate = 32.99). An average of 3 active users were recorded for each 28 day-period during the study. The decisions feature was accessed 330 times, followed by the journey at 163 times, goals at 160 times, resources at 146 times and support at 103 times. All parents recruited via the NHS were guided through the setting up of the app, and online participants had to download the app before clicking next to indicate completion of baseline.

Are the outcome measures appropriate and acceptable for a prospective RCT?

For parents who completed baseline measures (N=42), the majority (40/42) had no missing data at baseline. The two cases with missing data failed to complete the PSDM-Q-9 and the Decisional Conflict Scale. For parents completing follow-up measures (n=16), all measures were completed by all parents except the PSSUQ. Only parents belonging to the intervention groups were required to complete the PSSUQ, and all 5 completed it. At baseline, 53% (16/30) of the NHS cases had completed HCP observed preference measures. At follow-up, 58% (7/12) of the NHS cases had completed HCP completed observed preference measures. Healthcare professionals completed observed measures were required only from parents recruited via CAMHS.

Overall, the majority of parents (n=26) participating in the study preferred to be involved in SDM. However, clinicians reported that based on observations, parents left the final decision to the HCPs after sharing views (n=6), involved in SDM

(n=5) or preferred to make the final decision themselves (n=4). The average PSDM-Q-9 score reported at baseline was 26.54 (SD=10.98) and increased to an average of 28.8 (SD=10.98) at the end of the study. The average DCS score increased from 35.44 (SD=17.85) to 38.18 (SD=19.22) during the study. Additionally, the average overall satisfaction with care decreased from 20.62 (SD=5.74) to 19.63 (SD=6.93) by the end of the study. The average overall anxiety scores for the sample showed scores that were above cut off (38) at both time points indicating that the parents in the sample were moderate to highly anxious. The PSSUQ had a mean score ranging from 3 to 3.4 overall and on all the subscales.

The outcome measures provided valuable information on parents' anxiety levels, decision-making preference and experience of SDM. Data from the outcome measures were summarized and descriptively presented in Table 9.3.

Table 9.2 Summary of outcome data

Outcomes measure	All participant		IG1		IG2		Control	
	Mean(SD) or n(%)		Mean(SD) or n(%)		Mean(SD) or n(%)		Mean(SD) or n(%)	
	Baseline N=42	Follow-up n=16	Baseline n=11	Follow-up n=1	Baseline n=19	Follow-up n=4	Baseline n=12	Follow-up n=11
[a]CPS_P								
[b]HCP-lead	5 (11.9%)	2 (12.5%)	2(18.18%)	0	1(5.26%)	0	2 (16.67%)	2(18.18%)
[c]SDM	26 (61.9%)	10 (62.5%)	8 (72.72%)	1	10 (52.63%)	2 (50%)	8 (66.67%)	7 (63.64%)
Parent-lead	11 (26.2%)	4 (25%)	1(9.09%)	0	8 (26.32%)	2 (50%)	2 (16.67%)	2 (18.18%)

Outcomes measure	All participant Mean(SD) or n(%)		IG1 Mean(SD) or n(%)		IG2 Mean(SD) or n(%)		Control Mean(SD) or n(%)	
	Baseline N=42	Follow-up n=16	Baseline n=11	Follow-up n=1	Baseline n=19	Follow-up n=4	Baseline n=12	Follow-up n=11
Observer								
HCP-only	1 (2.38%)	1(6.25%)	0	0	0	0	1(8.33%)	1 (9.09)
HCP-lead	6 (14.29%)	1(6.25%)	3(27.27%)	0	0	0	3(25%)	1 (9.09)
SDM	5 (11.9%)	4(25%)	3(27.27%)	3	0	0	2(16.67%)	1 (9.09)
Parent-lead	4(9.52%)	1(6.25%)	1 (6.25%)	1	3(15.79%)	0	0	0
Missing data	16 (38.1%)	7(43.75%)	4(36.36%)				6(50%)	8 (72.72)
[d]PSDM-Q-9	26.54 (0.98)	28.81(10.48)	28.45(9.23)	33	24.28(12.62)	26.25(13.28)	28.17(9.62)	29.36(10.36)

[e]STAI-AD

Outcomes measure	All participant Mean(SD) or n(%)		IG1 Mean(SD) or n(%)		IG2 Mean(SD) or n(%)		Control Mean(SD) or n(%)	
	Baseline N=42	Follow-up n=16	Baseline n=11	Follow-up n=1	Baseline n=19	Follow-up n=4	Baseline n=12	Follow-up n=11
STATE	40.85(14.12)	44.25(16.10)	43.18(9.88)	58	38.37(17.67)	46.5(22.35)	42.67(12.59)	42.18(14.61)
TRAIT	45.9(13.4)	48.88(11.63)	47.55(9.85)	60	43.26(15.97)	53.5(17.17)	48.58(12.06)	46.18(14.61)
Total [f]DCS	35.44(17.85)	38.18(19.22)	35(21.59)	31.25	39.14(18.6)	45.31(26.03)	29.95(12.46)	36.22(17.91)
Uncertainty	41.67(25.69)	43.75(21.62)	40.83(28.72)	58.33	48.68(25.8)	50(29.66)	31.25(20.76)	40.15(19.66)
Informed	36.59(21.48)	38.54(20.15)	29.17(19.35)	25	43.42(24.15)	50(24.53)	31.94(16.22)	35.61(18.67)
Values	27.5 (19.81)	31.25(23.27)	29.17(23.98)	25	27.78 (21)	29.17(33.68)	25.69(15.26)	32.57(21.56)
Supported	40.24(26.41)	41.67(24.72)	43.33(28.27)	25	46.93(27.68)	56.25(36.24)	27.08(18.84)	37.88(19.85)
Effective	32.77(18.74)	36.45(18.73)	33.13(25.86)	25	32.57(19.61)	45.83(25.91	32.81(10.02)	34.09(16.44)
[g]Satisfaction								
Care	20.62(5.74)	19.63(6.93)	23.27(3.85)	26	20.11(6.01)	15.5(8.06)	19(6.32)	20.55(6.38)

Outcomes measure	All participant Mean(SD) or n(%)		IG1 Mean(SD) or n(%)		IG2 Mean(SD) or n(%)		Control Mean(SD) or n(%)	
	Baseline N=42	Follow-up n=16	Baseline n=11	Follow-up n=1	Baseline n=19	Follow-up n=4	Baseline n=12	Follow-up n=11
Service	27.05(27.05)	26.79(7.64)	30.18(4.21)	33	26.47(7.03)	21.75(8.81)	25.08(6.89)	27.18(7.12)
SDM	9.1(2.45)	8.56(3.1)	10.18(2.14)	12	8.87(2.51)	6.5(3.79)	8.33(2.46)	9(2.65)
[h]PSSUQ		3.15 (0.63)						
Usefulness		3.13 (0.66)						
Information		3.0 (0.54)						
Interface		3.42 (1.17)						

Note: IG = Intervention Group; SD= Standard Deviation; [a]Control Preference Scale for Paediatrics; [b]Healthcare Professional; [c]Shared Decision-Making; [d]9-item Paediatric Shared Decision-Making Questionnaire; [e]Spielberger State Anxiety Inventory Form for Adults; [f]Decisional Conflict Scale; [g]Experience of Service Questionnaire; [h]Post-Study Usability Questionnaire

What is the scope of the pilot data collected from users and non-users of

PUfP?

       Since the PSDM-Q-9 for the overall sample changed in a positive direction by the end of the study, this measure was investigated further to gain insight of the SDM outcome. The CI around estimated differences in mean scores were too wide to indicate any potential significant differences between groups (Cousineau, 2017). However based on observed data, at baseline, there was a small observed difference between the control (M=28.12; SD=9.17) and intervention groups (M=25.86; SD=11.46) on the PSDM-Q-9 (i.e. SDM measure) (2.3 points, 95% CI=-5.31,9.92). At the end of the intervention period, there was also a small observed difference between control (M=29.36; SD=3.12) and intervention groups (M=27.6; SD=11.89) on the PSDM-Q-9 (1.76 points, 95% CI=-10.75, 14.28). Based on observations both the control and intervention group may have increased in behaviours of SDM over time.

       For participants completing both baseline and follow-up, it was observed that the control group at baseline (M=28.91; SD=29.36) showed very little change at follow-up (M=29.36; SD=10.36) on the PSDM-Q-9 (.45 points, 95% CI= -4.75, 3.84). The intervention group also showed a small difference from baseline (M=22.2; SD=10.62) to follow-up (M=27.6; SD=11.89) on the PSDM-Q-9 (5.4 points, 95% CI=-26.56, 15.76). Again, the CI around the estimated differences in mean scores were too wide to indicate any potential significant differences over time. These findings suggest that if the change over time was ignored, parents in the control and intervention group may have had similar scores on the PSDM-Q-9 measure at this preliminary stage of the research (Cousineau, 2017).

What are the potential barriers and enablers to conducting a prospective RCT?

Potential barriers observed or reported by site collaborators included insufficient time for recruitment and site set up as indicated by the challenges some sites faced to recruit participants for stage 2 within the final 3 months of the study. Second, including a criterion that excluded parents with a diagnosed MH problem decreased the number of potential participants. This was confirmed by the withdrawal of one site which expressed challenges with recruitment as most parents reported having a MH difficulty. Another potential barrier is the high attrition rate (>50%) observed which limits analysis of the outcome data in the future trial.

Although this feasibility study highlighted potential barriers that can affect recruitment in a full RCT, overall, the study highlighted no reports of adverse effects in both stages of the study. It was also possible to recruit a satisfactory sample (n=31) across 6 CAMHS within 9 months, and 33 participants within 3 months of community sampling. No other barriers to upgrading to a full RCT were observed or identified. Input from PPI sessions and guidance from the study's steering committee were highlighted as beneficial to the intervention development and recruitment strategies.

Which data collection procedures are appropriate and acceptable?

The majority of the parents preferred to complete baseline (30/42), and follow-up (10/16) measures online. Although there was no online option for HCPs completing observed CPS for parents in the study, many HCPs requested to have the measure emailed to them or to receive a reminder email to prompt them to complete the measure. Additionally, both forms of randomization worked smoothly and accumulated participants to each comparison groups.

Qualitative Results

Is Power Up for Parents acceptable and useful for parents and healthcare professionals?

Data obtained from qualitative interviews and FGDs were examined to address the final two research questions. Feedback from parents and HCPs revealed feasibility categories that represented acceptability, (perceived) usefulness and scope for improvement (Arain et al., 2010; Barton et al., 2019). Participants described the "appearance and functionality" of the intervention as essential to acceptability. "Perceived need and general helpfulness" of the intervention, and "accessibility and appropriateness" of the intervention emerged as two further themes describing the perceived usefulness. Figure 9.3 provides a brief overview of the themes emerging from the qualitative data highlighting important influencing factors.

Figure 9.3 An overview of the themes emerging from qualitative data

Acceptability

Appearance and functionality
attractive (+)
age-appropriate (+)
suitable(+)
unclear (-)

Accessibility and appropriateness
easy to use (+)
mobility (+)
added burden (-)
lack data security (-)

Perceived need and general helpfulness
information (+)
promoted SDM (+)
keep record (+)

Wish list for improvement
usability (+)
easy implementation (+)

(Perceived) Usefulness

Scope for improvement

Acceptability

Theme 1: Appearance and functionality of the interface

Parents' feedback on the intervention was mostly positive. The majority (79%; or 11/14) of parents participating in the interviews expressed satisfaction with the intervention. Parents generally described the appearance of the intervention as attractive. Additionally, parents appreciated the layout and functionality of the

intervention and described it as age-appropriate and suitable to their busy lifestyle. There was a general sentiment that the images and graphics were suitable for parents.

> *I find it much easier on the eye. It gives a soothing vibe kinda thing.*
> *(Parent, age 47)*

> *Yeah, it looks good, colourful. (Parent, age 40)*

> *It's not overly childlike. Yeah, I think it looks very user friendly. (Parent,*
> *age 53)*

Healthcare professionals also expressed satisfaction with the appearance and the majority (79%; or 15/19) of HCPs in the sample provided favourable comments on the way in which the intervention was presented. They also expressed positive comments and endorsed specific components of Power Up for Parents, and its suitability. They highlighted that the layout and colours drew attention to the relevant features within the app.

> *I like the layout, in terms of the different sections. I think that's really good.*
> *(HCP, 2.5 years' experience)*

> *It's nice and clear in terms of the graphics. It tells you what it is, and the*
> *tabs are really nice. (HCP, 7 months experience)*

Although parents and HCPs were generally satisfied with the intervention, some expressed dislike with some of the features. Additionally, not all participants understood all the features. Dislikes centred around preferring specific colours and wording. Although parents were able to find their way around the app after "clicking

around" or browsing the user-manual, participants expressed clarity or further instructions are needed to guide users.

> *I would say, I don't like question mark boxes, because I think the text should maybe be in the main box itself, because it's just another thing to click on (HCP, 6 years' experience)*

> *So, it's not altogether clear what that [Support section] does... here I've got a plus and a minus...(Parent, age 51)*

Usefulness

Theme 2: Perceived need and general helpfulness

The majority (93%; or 13/14) of the parents participating in the interviews provided feedback highlighting that the intervention was useful. The intervention was well-received by parents and they generally indicated the intervention was or would be useful for them and may help with various aspects of accessing CAMHS. Parents generally echoed the potential value of the intervention to keep records, promote involvement in SDM, and signpost to useful resources.

> *…and if it worked and it worked well, I'd be using it. It's really good to have all your appointments in one place as well. And the notes section, things that you think, "Oh, I need to talk to the doctor about that." Yeah, I think it sounds really good. (Parent, age 39)*

> *This definitely looks like something I would use. (Parent, age 47)*

Similarly, many professionals (84%; or 16/19) expressed that the intervention was useful and would be relevant to their practice. They provided insight on the

potential application and benefits with the majority expressing that it should make it easier to signpost families to useful resources that can support their practice.

> *It might also be helpful in terms of just understanding CAMHS. That's often one of the first hurdles that I have to get over with parents and young people is they don't really understand our service and they don't really understand CAMHS. I think that could be quite helpful in this. (HCP, 13 years' experience)*

> *I think this can be used with any diagnosis. This is kinda helpful. With any kinda parents, this is helpful. (HCP, 15 years' experience)*

Theme 3: Accessibility and appropriateness of the intervention

The concept of an app received mixed views from parents and professionals mainly around usability. However, participants highlighted positive reasons for using an app and expressed that an "easy to use" and "easily accessible" app may motivate parents to at least try the intervention. Participants generally thought a digital resource provided that "instant" support and because of its dynamic nature may also help the parents themselves by providing feedback and signposting. Participants also expressed appreciation that the intervention had the potential for use "on the go".

> *I think even if there were parents with learning difficulties or struggled with using a bit of technology, I think, as long as they obviously had a phone, you know, that they brought with them and we were able to help guide them through it, I think that could still work as well. (HCP, 2.5 years' experience)*

> *I think I'd probably use it more on my phone because that's constantly with*
>
> *me. So, if something happened, like panic attack in McDonalds, like we've*
>
> *had before, something like this will be quite handy. (Parent, age 36)*

Although many participants highlighted that the intervention presented limited potential for harm, there were genuine concerns around specific groups of parents, suggesting the intervention may be an additional burden to parents. Generally, a sense of excluding some users based on their comfort with technology or level of literacy was expressed. Similarly, data security and privacy were also highlighted as a concern. Participants expressed that generally sensitive data would be entered into the app and therefore reassurance of trustworthiness and safety would be needed.

> *Just thinking about culture and ethnicity and language, and whether or not*
>
> *this would available in different languages, for those that don't read*
>
> *English, basically. (HCP, 2.5 years' experience)*

> *As long as I'm assuming, it's obviously all secure with the data that you put*
>
> *on there and everything. As long as I was confident that what I was putting*
>
> *on there was all secure. (Parent, age 39)*

> *Well, I have a few illiterate parents so they may struggle with this. (HCP,*
>
> *16 years' experience)*

Can the feedback from users be used to further refine the prototype for the prospective RCT?

Theme 4: A wish list for improvement

Parents and HCPs appreciated that their input could potentially help further develop and improve the prototype for future research and before implementation. They suggested improvements that could enhance usability and facilitate easy

implementation into practice. Feedback was either in line with refining what already existed (e.g. attaching the user-manual to the home screen), or adding new features that were seen as vital (e.g. emergency help) or features that could promote usage of the app (e.g. options for emotional support such as mindfulness). The overarching theme emerged as "a wish list of improvements" for informing the development and refinement of PUfP.

A section on mindfulness, for themselves... (HCP, 2.5 years' experience)

Sometimes a brief video of how to use the app can be useful, or testimony of another parent or carer talking about themselves can be helpful. (HCP, 5 years' experience)

I think if there was under resource, if there was things like, "If this happens, do this." Maybe that would help. (Parent, age 47)

Maybe having the manual where it is fine, but maybe there could be a smaller, I don't know, more compact, sorry, more compact version within the app itself to just remind people what each of the particular areas are for. (Parent, age 39)

Statement of feasibility and acceptability findings

Based on this preliminary pilot study , the findings suggest that there is some evidence for the acceptability of Power Up for Parents. However, the findings also suggest some adjustments to the study recruitment protocol is critical before proceeding to an appropriately powered trial. Based on the criteria set a priori, the study recruited more than 6 CAMH sites, over 60 eligible participants and obtained baseline data from more than 50% of eligible participants (i.e. at least 10 per

conditions). Based on the available usage data, it is possible that >70 of the study's

participants registered an account and fewer than 30% did not interact with the

intervention. However, the study fail to obtain follow-up data from at least 50% of the

participants, with only 5 participants from the intervention groups completing follow-

up measures. Therefore, it is not yet feasible to upgrade to a full scale RCT.

Discussion

This study was a preliminary investigation to pilot a novel digital evidence-based web application (Power Up for Parents) to promote SDM among parents of CYP with MH difficulties. This study aimed to assess the acceptability and usefulness of the intervention and examine the feasibility of proceeding to a full RCT. To my knowledge, this is the first randomised controlled feasibility study to pilot test an interactive parent-targeted digital SDM tool in CAMHS. This two-stage research project and its findings can inform the development and testing of an SDM web application to be used in CAMHS. The intervention was designed in consultation with end-users and developed according to the MRC framework for developing and evaluating complex interventions as described in Chapter 8.

Summary of the findings

For stage 1 of the study, it was possible to recruit an adequate sample of parents and HCPs. The sample participated in semi-structured interviews and FGDs with a preference for phone interviews and FGDs attached to existing meetings at the CAMHS site. Thematic analysis of the transcribed data highlighted "appearance and functionality" as contributing to the overall acceptability of the intervention. Two themes emerged "perceived need and general helpfulness" and "accessibility and appropriateness" of the intervention to inform end-users perceived usefulness of Power Up for Parents. Additionally, a final theme centred around "a wish list" provided valuable information to inform future development and refinement of PUfP.

For stage 2, 63 persons met eligibility criteria and consented to participate in the study. However, 42 completed baseline measures and only 16 completed follow-up, suggesting that some modifications should be applied to increase recruitment to

ensure target numbers are met for a fully powered RCT. The majority of the sample displayed a preference for online completion of outcome measures. Of the 18 sites that were approached, 12 expressed interest and were recruited into the study. However, 1 site withdrew after three months and the remaining 11 sites were able to recruit participants for stage 1 and/or stage 2 of the study suggesting that site-level recruitment is feasible. Although, both forms of randomisation (i.e. cluster randomisation and person randomisation) worked well, and accrued participants for the trial, more incomplete data were observed from the online sample, and one site withdrew from the study which can affect recruitment in the future trial. Additionally, including the presence of a parent's MH diagnosis as an exclusion criterion for participation was highlighted as a potential barrier for recruitment. Careful consideration could be given to this eligibility criterion in the future trial.

The outcome measures provided valuable information on parent's anxiety levels, decision-making preference and experience of SDM. A high average state anxiety level was observed among parents. Generally, parents reported a preference for SDM and reported experiencing some level of SDM throughout the trial. Finally, a satisfactory amount of engagement with the app was observed with 288 visits at an average duration of 5 minutes and 59 seconds, an average of 3 active users for each 28 day-period during the study and less than 33% of the users visiting the app and leaving immediately without viewing any of the features.

Results in context with other research

This study incorporated interviews and FGDs data from a sample of 24 parents and 31 clinicians in stage 1. This sample size is acceptable for qualitative research, allowing for data saturation, as indicated in previous literature (Guest et al.,

2006). Stage 2 identified 63 eligible parents and obtained consent. This sample size is also comparable to other studies exploring decision aids in CAMHS (Ahmed et al., 2017; Hubner et al., 2018; Ossebaard et al., 2010) and higher than recommended sample size for feasibility and pilot studies (Lancaster et al., 2004). Previous research also identified a similar demographic sample of mostly Caucasian mothers.

Over 50% of participants were lost to follow-up. This is consistent with research on web-based interventions reporting high attrition rates (Murray et al., 2016). However, the fairly large number (n=33) of eligible participants identified through social media when compared to the NHS sample is consistent with other studies reporting social media as beneficial to recruitment rates (Murray et al., 2016). In contrast to previous studies indicating challenges to recruiting HCPs (Bower et al., 2009; Brinkman, Hartl Majcher, et al., 2013), this study identified a fairly large number (n=33) of interested participants in stage 1. A possible explanation for this might be that the topic resonated with the clinical care agenda or is in an area of special interest to CAMHS (Wolpert et al., 2012).

Parents generally completed the outcome measures. This is of great importance to evidence-based practice and useful for interpreting the current findings as well as those of the future RCT. The majority of the parents in the sample reported a preference to be involved in SDM. However, HCPs reported that some parents in their care, displayed behaviours in line with a preference to be engaged in SDM or left the decision up to the HCP or made the final decision themselves after sharing their views or listening to the HCP's recommendations. These preliminary findings are in agreement with other academics suggesting that although SDM is preferred, not everyone may want (Degner & Sloan, 1992; Levinson et al., 2005), or it may be

too challenging to implement (Boland et al., 2019; Gondek et al., 2017). Additionally, this finding also highlights that within triad relationships as identified in Chapter 6, varying levels of "shared" decision-making may exist. Usage data also demonstrated the feasibility and acceptability of using the intervention. Similar findings have been reported in the original Power up for young people tested in schools and CAMHS (Edbrooke-Childs et al., 2019). However, caution should be taken when interpreting these findings.

Regardless of power, the observed mean scores for the PSDM-Q-9 measure increased in a positive direction suggesting more experiences of SDM over the course of the study. However, the DCS score also increased which suggested an increase in decisional conflict These contradictory findings observed in different measures were also present in other studies (Hong et al., 2016) and discussed in studies exploring differences across the various constructs included in the SDM measures (Scholl et al., 2011). These researchers also agree that there is a need for a consistent definition and understanding of SDM if measurements are to be valid. Further investigations of the PSDM-Q-9 data utilising confidence intervals resulted in no significant findings within- and between groups. This is not surprising due to the small sample size obtained and the "per-protocol" analytic approach chosen (Sedgwick, 2015). Notably, a high average anxiety level was found for this study's sample. This in line with other research suggesting parents of children with MH difficulties report higher stress levels than those with physical health or typically developing children (Peters & Jackson, 2009).

The main potential barrier identified for the future trial centred on recruitment. This is not uncommon among researcher recruiting in medical settings (Bower et al., 2009). However, this trial explored other methods of recruitment (i.e. online community sample) with input from parent partners which proved to be partly beneficial. Other methods of recruitment can also be considered for the future trial. Although concerns surrounding parents' level of literacy was raised as a potential factor influencing the adoption of the digital intervention, participants expressed a willingness to try. This, in addition to concerns about sensory impairment, limited financial resources and other cognitive and language problems are generally of concern to researchers and app developers (Rahimi et al., 2018). Therefore, the current study further highlights that user-centred designs and PPI approaches are crucial to the study of digital interventions in this population.

The majority of the sample (>80%), including parents and health professionals, provided feedback consistent with acceptance and (perceived) usefulness of the intervention. These findings demonstrate that additional support is generally well-received in CYPMH settings, as indicated in other studies (Ahmed et al., 2017; Brinkman, Hartl Majcher, et al., 2013; Hayes, Town, & Lemoniatis, 2018). Three themes emerged that identified the appearance and functionality of the interface, perceived need and general helpfulness, and accessibility and appropriateness of the intervention were important to end-users and may promote usage. These themes fit with previous research on the broader Technology Acceptance Model (TAM) highlighting perceived usefulness and perceived ease-of-use as influencing usage (Rahimi et al., 2018). Qualitative findings also highlighted "a wish list" of features and improvements to the intervention that can potentially increase acceptability and usefulness. Incorporating these feedbacks is in line with

the Human-Computer Interaction approach for designing technological interventions and reinforces an opportunity for involving end users in the development of interventions. Researchers generally agree that this approach to co-designing improved usability and subsequent outcomes (Blandford et al., 2018).

Strengths and limitations

The primary strength of this study was that the intervention was acceptable by parents and healthcare professionals at CAMHS. Second, recruitment figures for stage 2 were improved by including the online community sampling. The online advertising was able to reach a very wide audience and resulted in the identification of 33 eligible parents interested in participating in the trial. The study was only advertised over a 2-week period via the AFNCCF's social media platforms, and over one week when the blog was shared on social media but remained available online for 3 months. This figure was comparable to recruitment figures from the NHS where it was possible to recruit over a 9-month period. The future trial should consider these forms of recruitment going forward, however, careful considerations to account for the possible high proportion of incomplete data via the online platform versus the slow recruitment process via the CAMHS is necessary.

Another strength of this trial was the consideration for respondent burden by providing the participants with options for interviews in stage 1 (i.e. phone or face-to-face) and options from completing outcome measures in stage 2 (i.e. online or paper-based). This flexibility was possibly responsible for the satisfactory recruitment figures in both stages of the trial. This may be necessary moving forward as both parents and health professionals sometimes rescheduled interviews, and in two instances, parents reported not having time to complete follow-up outcome

measures. However, having only one form of contact (i.e. phone or email) made it difficult to reach some of the parents and resulted in a small number of parents completing follow-up measures.

Themes emerging from the interviews and FGDs suggested a high degree of acceptability and perceived usefulness of the intervention. However, these themes were informed by views taken from a non-representative sample that included majority White British, English-speaking, mothers of teenage girls. A more representative sample, including fathers and other ethnic groups, can provide deeper insight. In addition, individual qualitative and quantitative data were not matched limiting explorations of associations between satisfaction and actual usage. Although mixed feedback was received from participants, generally there existed some willingness to try the intervention suggesting some level of interest from both parents and service providers to use a digital intervention. This in itself is a strength of the study as digital interventions have been promoted for their accessibility, affordability and scalability. Therefore, if this intervention is accepted and found to be effective in a future RCT, it has potential to reach a large audience.

This study focused on developing an engaging intervention and exploring justifiable administration procedures to inform a full RCT. On one hand, a multi-site, cluster randomised approach was used to maximise efficiency and eliminate possible study contamination. This approach was considered a major strength and did not incur additional cost to the intervention development. However, potential contamination of the control group could be considered if the participants came in contact with the online study (i.e. community recruitment) information. This may present some obstacles for the research team if the clinic sample's control group

gained access to the intervention. Additionally, a web app was chosen over a native mobile app as it does not require downloading or installation from an app store and therefore does not occupy space on the user's phone. It functioned as a website that is suitable for a smartphone and is usually cheaper to build, maintain and update than native mobile apps (Charland & LeRoux, 2011). Funding provision was appropriate for a developmental project and further cost savings can be explored when refining the app. It may also be useful to explore economic evaluation of the prototype, and with limited changes to the study design, this can be undertaken as part of the full trial.

The ability to gather usage data is a major strength to the study of digital interventions, so researchers do not only rely on self-report. However, due to GDPR regulations, and the usage data available via Google analytics explorations of individual usage (e.g. number of visits per user) were limited. Further, although, the PhD candidate attempted to share the intervention only to CAMHS sites in the intervention arm, it was possible that site collaborators, HCPs and parents could have shared the link with non-study participants. This may have affected the accuracy of the usage data, and therefore, caution should be considered when interpreting this type of data. The future study may need to collect both usage and self-report data to present a more reliable picture.

Lastly, a mixed-method, two-stage study design was viewed as a strength at this feasibility phase of the intervention. Outcome measures provided valuable information that is of importance to a future trial, providing a basis on which to estimate sample size calculations and to select appropriate measures. Additionally, it provided estimates on time required to complete outcome measures and gain access

to the intervention. However, although recruiting participants for both stages of the study was feasible, this approach may potentially add burden to parents who wish to participate in both stages. Although not necessary, some minor changes to the study design can be made. The future trial may consider post-trial interviews at which point the control will gain access to the intervention and provide new insight on perceived usefulness and acceptability, and the intervention group will provide insight on the actual usefulness and post-use satisfaction with the intervention. Nonetheless, the mixed-method approach can provide a better understanding of efficacy and efficiency and strengthen the findings of the future RCT (Regnault et al., 2018). This is especially important in light of recent debate questioning the potential of RCTs to evaluate digital interventions, given the speed at which technologies advance (Michie et al., 2017)

Implications for clinicians and policymakers

The findings of this feasibility and pilot study suggest potential areas of clinical application. First, the main clinical implication is that the intervention is an acceptable and useful intervention, as suggested by parents and health professionals in the current sample. This study highlighted that it is possible to develop and implement an intervention that can support families involved in CYPMH care and treatment decisions. Furthermore, the positive feedback surrounding the theme of perceived need and general helpfulness of the prototype highlighted a desire to obtain support if SDM is to be successfully applied. Taken together, these findings suggest that policy guidelines should be considered to support parents of young people who report feeling uninformed and excluded from services (Wolpert et al., 2012). Notwithstanding the acknowledgement of the "Gillick competency" principle ("Gillick v West Norfolk and Wisbech Area Health Authority.," 1984), the policy

guidelines specific to MH care in CAMHS could be informative for practitioners working with families of adolescents and young persons who are still considered being "under the care" of their parents. Lastly, these preliminary findings, highlighting high levels of anxiety among parents, can provide practitioners with a knowledge base and basic understanding of the parents accessing care.

Future directions

The study's findings suggest that the intervention has potential to be acceptable for use in CAMHS, subject to further upgrading and refining. First, it is recommended that the prototype is upgraded and refined in line with suggestions provided by participants in the current sample before being tested further. These suggestions can impact usefulness and usability of the intervention. For example, incorporating mindfulness techniques or other techniques can provide additional support to parents during difficult moments. Just as important are the suggestions to include a crisis section and features to facilitate optional communication between providers, CYP and parents or parent-to-parent interactions. These improvements should also be made in collaboration with end-users to ensure suitability of the components are considered as appearance and functionality of the features were important to parents.

This feasibility and pilot trial also provided important findings that can be used to inform future testing of the intervention. In terms of the study design, it is recommended that the future trial maintain a multicentre randomised controlled study design. However, a two-arm approach may be sufficient as opposed to the 3-arm tested in this feasibility trial as it was clear from the findings in this thesis (Chapters 3 and 6) that parents involved in CYPMH decisions may benefit from additional support

(e.g. emotional support). Therefore, if a 3-arm study design is to be maintained the existing body of knowledge may benefit from insight into using a different modality of the intervention, for example, paper-based or face-to-face or combination. Additionally, clustered randomisation is recommended to control for site-level activities that can impact family involvement in SDM (Chapter 5). However, if community recruitment is also utilised comparisons can be made between samples to strengthen the findings, or considerations can be made to stratify the community sample into existing clusters (e.g. area of residence or area accessing care).

Furthermore, this study did not collect data specific to the CYPMH diagnosis or family type. The future trial may benefit from obtaining such data as the previous study (Chapter 5) highlighted that parents having children with conduct problems and those where both parents were involved in the decision-making experienced lower levels of SDM. An alternative will be to test the intervention only among a sample with a behavioural diagnosis and explore possible generalisability to other CYPMH disorders. Another recommendation is the exclusion criteria identifying and excluding parents with an existing MH diagnosis not be carried to the future trial. These parents may actually benefit from the additional support and therefore future trials can control for and benefit from these statistical comparisons. It is also recommended that the future trial adopt an "intent-to-treat" analytic approach to draw accurate (unbiased) conclusions regarding the effectiveness of the intervention (Sedgwick, 2015). This approach will also be beneficial in light of the retention rates observed in this trial.

Additionally, this study benefitted from the input of enthusiastic parent partners who contributed to the intervention design and study recruitment strategies. Future studies could utilise this PPI approach as it possibly contributed to the smooth

running of this pilot feasibility study. Future trials can also explore extending an invitation and training to parent partners so they can be part of the research process as interviewers or the identification and recruitment process at CAMHS, in line with PPI recommendation to support research. Finally, the findings suggest that it is possible to identify non-recurrent and recurrent costs associated with developing, upgrading and implementing Power Up for Parents. It may also be possible to estimate NHS provider cost for usual care and other interventions, in addition to parent-reported costs to access services. Taken together, these costings can be explored to fully capture any savings to be estimated if the future trial incorporates economic evaluation to explore cost-effectiveness of the intervention.

Conclusion

This feasibility pilot trial was designed and conducted to test important aspects of the research design and acceptability of the intervention to examine the potential for conducting a future fully powered RCT. Despite evidence suggesting the acceptability of Power Up for Parents, the findings also suggest that recruitment modifications are needed to enhance the feasibility of collecting follow-up data, before scaling up to a full RCT to test the effectiveness. Nonetheless, findings from the development and feasibility phases provide valuable data to help inform the future research.. One important recommendation is that the future RCT may benefit from incorporating a mechanism to explore the cost-effectiveness of implementing Power Up for Parents. Furthermore, in recognition of age and capacity of CYP, and the promotion of standards of care to empower young service users, considerations to refine the prototype to interact with other versions of Power Up (e.g. Power Up for CYP) may be valuable. If future research is able to show proof of concept for a digital intervention among parents in the CYPMH population, applicability to other health

conditions can be explored. The next chapter provides a general discussion of the findings throughout the thesis and final conclusions.

Chapter 10 General Discussion and Conclusions of the Thesis

The overall aim of this research project was to understand the role of parents' emotional experiences in CYPMH decisions, explore possible associations, and develop and test the feasibility and acceptability of an intervention to support parents and promote involvement in care and treatment decisions. However, chapter-specific aims were necessary to inform the development and pilot/feasibility chapters. The preceding chapters (Chapters 2-7) reported on findings that contributed to the overall understanding of parents' experience of decision-making in a CYPMH context, described the development of a novel evidence-based SDM intervention (Chapter 8), grounded in a affect appraisal approach to SDM, and discussed the feasibility and acceptability of the intervention for a prospective RCT (Chapter 9). This final chapter presents a summary of the studies conducted to inform this thesis, the overall strengths and limitations of the thesis and discusses implications for future intervention development, research, policy and practice.

Recap of the research questions for this thesis

A comprehensive development process was undertaken, including two systematic reviews (Chapters 3 and 7), two quantitative studies (Chapters 4 and 5), a qualitative study (Chapter 6) and a mixed-method study (Chapter 9), guided by the following research questions to address the aims of the thesis. In so doing the findings provided a learning loop that highlighted the need for an affective appraisal approach to SDM.

1. How do emotions (e.g. anxiety) affect parents' experience and involvement in CYPMH decisions? (Study 1)

2.	What are the associations between CYP psychosocial difficulties, parental worry and parental help-seeking? (Study 2)

3.	Do parents in the UK experience SDM at CAMHS, and are there associations with clinical characteristics? (Study 3)

4.	How do parents and healthcare professionals view SDM, and how do they describe the impact of parental emotions on the SDM process in clinical practice? (Study 4)

5.	What are the existing decision support tools for parents and carers of CYP with MH problems? (Study 5)

6.	Is a novel intervention (Power Up for Parents) accepted by parents and healthcare professionals, and is it feasible to upgrade to a full RCT to test its effectiveness? (Study 6)

Summary and interconnection of findings and contributions to knowledge

Decision-making in CYPMH is a complex non-linear process that is affected by several factors, such as, parental emotional states and service level variables. An affective appraisal approach to SDM emerged highlighting an interaction between information and emotional arousal in shaping CYPMH decisions. Although, digital interventions that are acceptable and feasible with this population may offer support to manage the complex triad SDM process, further research is needed to test its effectiveness. While there is more to investigate in the field of emotions and SDM in CYPMH, this thesis has raised awareness about this topic by showing possible emotional influences along the SDM process. This is an important finding as it may help our understanding of parents making CYPMH decisions and help to answer a variety of questions on SDM implementation strategies and usage of decision support interventions.

Study 1

The main finding of the systematic review suggested that parents are 'expected to, but not always able to' engage in effective CYPMH decision-making. Consistent with previous studies in child physical and MH, the results confirmed that parents do experience an 'emotional roller-coaster' (Corcoran et al., 2017; 2015) and this may influence engagement with care and treatment decisions (Boland et al., 2019; Lipstein et al., 2012). Similar to previous reviews and qualitative studies, the study identified seven aggregated subcategories describing parents' emotional experiences. The identified emotional states, represented in various models of emotions, were found to either promote active involvement in decision-making or hinder involvement. More specifically negative affective states, such as: 1) anxiety and frustration; 2) isolation and powerlessness; 3) blame, guilt and shame; 4) exhaustion and overwhelm, and 5) distress and sadness, were generally identified as barriers to effective involvement in CYPMH decisions. Positive affective states, such as: 1) empowerment and respect, and 2) relief and hope were identified as promoting parental involvement in CYPMH decisions. The current findings and how it influences the decision-making may provide a general understanding of the parent population accessing CAMHS, and inform clinical practice, policies, research and intervention development.

Study 2

The second study in this thesis (Chapter 4) aimed to evaluate the themes arising in study 1 and in so doing add to the existing knowledge on parents' help-seeking for CYPMH. Findings suggested that parents' perceptions about the child's MH and their state of worry play an important role in their decision to seek CYPMH support. White British mothers of children with higher emotional, conduct, impact and

peer problem scores were more likely to worry about their child MH. These findings broadly support the existing literature indicating that parents of CYP with MH conditions experience enhanced emotional states (e.g. worry) (Bonis, 2016; Lipstein et al., 2016) and therefore may benefit from additional support. Further investigations indicated that fathers, families where the impact of the psychosocial difficulties on the child was low and parents who were worried were less likely to seek help. These findings are essential to highlight that parents' perception of CYPMH may influence help-seeking which is critical to early identification and treatment. Additionally, this study revealed a need to further investigate the difference on the influence of severity, presence and impact of the child's psychosocial difficulties on help-seeking as early identification and treatment can lead to better health outcomes (Falissard, 2016). The findings highlighting that worried parents are less likely to seek help contributes to the general health literature reporting that persons generally avoid seeking help for various reasons such as worrying about wasting GPs time, worrying about the diagnosis and the associated treatments, and other practical reasons (Coogle & Hanline, 2016; Simmons et al., 2011). The CYPMH literature generally agrees with the broader health literature and identifies additional specific reasons such as stigma and shame, and fear and anxiety of not knowing what to expect (Andershed et al., 2017). Therefore, these findings are key to distinguishing and understanding parents' worry. In so doing, factors that may help inform efforts to allay undue worry (e.g. ongoing MH screening and assessment), in those who are deterred by them, from engaging with prevention and early detection, may surface. This further strengthens the argument for a need to incorporate emotional support at crucial decision-making time points throughout the help-seeking journey for CYPMH care.

Study 3

The third study aimed to explore the frequency of parents' experience of SDM in CAMHS, in addition to examining associations between parental reported experience of SDM and clinician's perceptions of the CYP's MH, additional complex problems and the impact of the MH problems on the CYP. In light of the limitations highlighted in study 2 (Chapter 3) concerning the usage of self-report measures and the parents' perception of the CYPMH problems, this study was conducted utilising a clinical sample and using objective observations (i.e. HCPs report of CYPMH problems). The results of this study indicated that almost 70% of parents reported experiencing higher levels of SDM at CAMHS. This high proportion of self-report SDM was also represented in the previous literature. However, this prevalence of SDM was lower than parents reporting SDM in families accessing care for physical health conditions and comparable to other chronic health conditions (Fiks et al., 2011; 2012). Furthermore, although parents in the current study reported high levels of SDM, it highlighted a further need to understand the complex nature of SDM in a triad, since observational and qualitative research suggested otherwise (Chapter 2). Notably, this study added to the CAMHS literature since previous studies usually represented specific decisions, for example, parents facing challenges during medicinal decision-making in CYPMH (Brinkman et al., 2009; Brinkman, Froehlich, et al., 2013). Ethnicity, learning difficulties, relationship to the child and conduct disorders were the only potential service user level factors that predicted parental SDM in a simple logistic regression and the presence of conduct disorders remained the only significant predictor variable when accounting for service level variation. This highlights the importance of service level variables and its influence on SDM in CAMHS. Discussions also highlighted that attention should be given to supporting

parents of CYP with behavioural problems, and areas for future research that could include further investigations into service level variables and clinician-level variables to develop a three-level model.

Study 4

The study provided insight into the experiences of parents involved in CYPMH care and treatment decisions from the perspective of both HCPs and parents. Although previous researchers investigated the experiences of families, including barriers and facilitators to SDM, little research had focused on the emotional experience of parents in the UK and how the various emotional states may be a barrier or facilitator to involvement in CYPMH care and treatment decisions. The limited findings from previous research suggested emotions as an influencing factor to SDM in CAMHS (Chapter 2) and in primary care (Dicé et al., 2016). The findings of this study provided evidence for the transferability of the proposed theory that revolved around parents being "expected to but not always able to" be involved in CYPMH care and treatment decision-making (Chapter 2). Additionally, the study provided evidence to triangulate quantitative findings in the previous study (Chapter 3). The emerging affective-appraisal framework captured the influence of emotions on parental active involvement in SDM. These findings further highlighted the need for additional support and identified existing support mechanism and a valid definition of SDM specific to CYPMH that could be used to inform future research.

Study 5

The scoping review was designed and carried out to identify and examine parent-targeted SDM interventions to inform practice and the development and implementation of future decision support tools. The study identified 23 interventions

for use by parents, of which one face-to-face intervention (Counselling in Dialogue) offered additional emotional support to parents. Therefore, a significant gap in the current evidence base was identified, indicating that parent-targeted SDM interventions may benefit parents if both emotion and information sources of support are included. When assessed against the nine elements defining SDM, the findings suggested that interventions targeting parents met on average 4.57 (SD = 1.93) essential elements. Nonetheless, interventions received favourable responses to usage (acceptability and usefulness). However, factors influencing usage and implementation emerged as three overarching themes: time (e.g. increase in session times), accessibility (e.g. easily available via the web), and appropriateness of the intervention (e.g. easy to use and understand). The study was somewhat novel in that very few studies have used the assessment of the elements of the SDM approach to evaluate decision support tools (Bouniols et al., 2016; Cheng, Hayes, Edbrooke-Childs, et al., 2017). However, this model is one of the most frequently cited SDM models. Therefore, one main contribution to the body of knowledge is the methodology used to assess parent-targetted SDM interventions. Another key contribution was the identification of available interventions that can be used in CAMHS. In addition, the identification of time, accessibility and appropriateness as important themes to consider when developing new interventions are important findings for researchers and intervention developers going forward. Lastly, this study highlighted tha lack of interventions underpinned by an affective appraisal approach to SDM which crucial to successful SDM in parents accessing CAMHS.

Study 6

The final study piloted a novel digital evidence-based web application to promote SDM among parents. Based on the progression criteria set a priori, for

proceeding to a full RCT, the findings suggest some adjustments to the study recruitment protocol is critical before proceeding to an appropriately powered trial. Thematic analysis of the transcribed data highlighted "appearance and functionality" as contributing to the overall acceptability of the intervention. Two themes emerged "perceived need and general helpfulness" and "accessibility and appropriateness of the intervention" to inform the usefulness of the prototype. Additionally, a final theme centred around "a wish list" for improving the intervention, provided valuable information focusing on usability and easy implementation to inform future development and refinement of the intervention. These are important findings that may contribute to the acceptability of the intervention in the future trial. The mechanisms important for the full trial (e.g. recruitment process) appeared to be thoroughly investigated and highlighted the feasibility of adopting randomisation (i.e. cluster randomization and person randomisation) in the future study. In addition, including parent's MH diagnosis as an exclusion criterion for participation was highlighted as a potential barrier for recruitment. Therefore, this can suggest that careful ethical considerations should be given to this eligibility criterion in the future trials and similar as a high average state anxiety level was observed among parents.

However, parents generally reported a preference for SDM and reported experiencing some level of SDM throughout the trial. This was emphasized by the interest in using the intervention, and a fair amount of engagement with the app was observed. These findings provide a wealth of information that can inform the development and testing of SDM web applications to be used in CAMHS. The findings also confirmed that careful considerations are needed before proceeding to the next step (i.e. RCT) according to the MRC guidelines (Craig et al., 2011) suggesting it is not yet feasible.

Overall strengths and limitations of the thesis

Strengths

The combination of the parents' and health professionals' views, various study designs and methodologies, theoretical underpinning and PPI were considered a significant strength to this thesis. Obtaining input from end-users of the intervention in qualitative studies to inform further development and implementation of the intervention was also valuable to this thesis. PPI, which is generally acceptable and advocated across many research settings (Bagley et al., 2016), further complimented this thesis by informing the development of the intervention and the recruitment process for the feasibility study (Chapter 9). Additionally, the development of Power Up for Parents adopted a multidisciplinary approach incorporating aspects of HCI and user-centred design. This unique field contributed to the area of CYPMH by allowing the PhD candidate to not only focus on the design of the technology but more broadly, the interaction between the users and the technology (Blandford et al., 2018).

The ability to incorporate multiple study designs and methodologies further strengthened this thesis. As described in Chapter 1, the dialectic stance the PhD candidate adopted encouraged a "respectful conversation between differing perspectives" and focused on the learning and deeper understanding of the viewpoints that emerged. No study was identified as contributing more or less insight, but instead, each study contributed equally to help understand the phenomenon and address the thesis aims.

Furthermore, previous studies highlighted a lack of theory underpinning the majority of interventions (Waldron et al., 2020) despite recommendations that

appropriate theory enhances development (Groot et al., 2017). The development of Power Up for Parents was informed by the MRC framework and guided by the workbook for developing and evaluating patient decision aids which may be considered a strength to this thesis. Additionally, the affective appraisal model (Chapter 6), Youth SDM model (Crickard et al., 2010), DSF (O'Connor et al., 2011) and the elements of SDM (Makoul & Clayman, 2006) were important in designing the various components and content of the intervention.

Another main strength of this thesis was the exploration of the concept that parents are 'expected to, but not always able to' be actively involved in CYPMH decision-making (Chapters 2,3,6). Although previous research has extensively identified parents of CYP with MH problems as experiencing an *emotional roller coaster*, little research has explored how these emotions affect active involvement in general CYPMH care and treatment decisions. More specifically research on interventions that incorporate emotional support is yet to be fully explored. Researchers have identified that providing information only is not sufficient to facilitate SDM and therefore, additional support should be considered (Jackson et al., 2008). Consequently, due to the dynamic nature of digital interventions to be efficient, endorsing advantages such as accessibility, a high degree of anonymity, prompt feedback, cost-effectiveness, applicability in real-life contexts and high treatment fidelity, Power Up for Parents was able to provide tools to support both informational and emotional support (Chapters 8,9).

The opportunity to develop and test the feasibility of a digital intervention that was acceptable by parents was also considered a major accomplishment in this thesis. The parents in the overall sample of the feasibility trial had a mean age of

45.98 (SD=6.45) years and therefore, are described as *digital immigrants*. Digital immigrants are born before the 1980s and are generally fearful of using technology (Cut, 2017). The testing of a digital intervention also allowed for the collection of objective usage data using google analytics.

The final strength highlighted in this thesis was the development of a working definition of SDM, unique to parents in a CAMHS setting, that emerged from interviews and FGDs with parents and HCPs (Chapter 6). The key contribution to the existing SDM literature is the varying level of involvement due to the uniqueness of the triad usually determined by the age and capacity of the child. Despite the age and capacity of the child, it was also emphasized that parents are important to the SDM process and considerations can be made for "informed" versus "involved" in the SDM process. Therefore, the definition used in this thesis was recorded as follows:

> *SDM is a process involving key-decision-makers (i.e. parents, HCPs and*
> *CYP), as developmentally appropriate, sharing information and views and*
> *all parties taking steps (informed or involved) to build a consensus about*
> *the preferred care and treatment option.*

Limitations

Although the findings of this thesis have potential to advance empirical and practical knowledge on parent involvement in CYPMH SDM using an affective appraisal approach, the thesis acknowledges several limitations. The main limitation of this thesis was the lack of in-depth CYP input. Although the intervention was developed for general use by parents, the intervention itself may have benefitted from the voices of CYP. However, CYP were given information sheets with information about the feasibility and qualitative studies (Chapters 6,9) and

participated in the PPI sessions that informed the welcome screen for the intervention. If suggestions to connect the original Power Up for CYP and the current intervention (Chapter 8) are considered, input from CYP would be considered crucial before upgrading to a full RCT. Another limitation of this thesis was the underrepresentation or fathers and ethnic minority groups in some of the included studies. The ages of the children also varied, mean 9.85 in study two to a mean of 14.33 in study six. As a result, generalisability and interpretations of the findings from these studies must be considered with caution. This is also important as it may affect usage if some subpopulations are not involved in the design and development of the intervention. The preponderance of parents of children with ADHD and ASD in some of the included studies may also influence decisions arising out of this research project.

Similarly, the secondary analysis of existing data (Chapters 4 and 5) and reliance on voluntary participants or participants identified by site collaborators and practitioners may have invited common researcher and participant biases (McCambridge et al., 2014). For example, in secondary data analysis, data may not be collected from all population subgroups of interest, or variables that may be important in the intended analysis (e.g. no emotion variables for parents in study 4) may not be present. In addition, obtaining voluntary participants or participants identified by site collaborators may attract acquiescence bias or participants with an existing interest in SDM or digital interventions.

Just as important, attention needs to be given to field testing of recruitment and retention strategies as there are many instances where trials of mHealth interventions are inconclusive because of poor recruitment and high rates of loss to

follow-up (Marcolino et al., 2018). Although every effort was made to include end-users in the design and development of the intervention (i.e. PPI and steering committee), the final decision on various components of the prototype was left to the PhD candidate's and the app developer's judgment and included only if it was within a pre-specified budget. Another limitation was the potential of the measurements used to capture parents' SDM experience. Throughout this thesis, reference has been made to the lack of consensus definition on SDM which questions the ability of existing measures to capture SDM. However, with permission, existing measures were modified, where applicable, and both self-report and observer reports were obtained to triangulate findings. Lastly, the intervention still needs to be audited using the IPDAS criteria to ensure it meets the internationally agreed standards to be officially labelled as a patient decision aid (IPDAS Collaboration, 2019).

Overall implications of the thesis

Further intervention development

The results of the feasibility and acceptability study provided rich data upon which to further develop and refine the intervention. Generally, participants in the study were satisfied with the appearance of the app (Chapter 9). However, some participants suggested changes to the colours and the images. Although not explicitly stated in the interviews, it can be assumed that providing the option to include further personal customisation of the app can facilitate a variety of preference for colours and images. Additionally, the participants expressed an additional need for a "safety plan" or "crisis section" on what to do or whom to call in times of distress which can potentially be facilitated via the app. This is an important contribution to consider as the information can be constantly updated once new strategies and contact details surface. The findings in Chapter 6 suggest that parents seek out support from

Charities, online services, family members, other parents and practitioners. This finding has an important implication for further developing and refining of the app to allow connectivity and communication between parents (i.e. the app owner) and other members of their support network. Considerations for chat rooms and discussion platforms moderated or facilitated by Charities or CAMHS may be acceptable. However, further investigations would need to be conducted to ensure GDPR and ethical standards are adhered to. Lastly, based on the experience of working with parent partners and the valuable input obtained throughout this research, a continued person-centred approach to development, involving end-users, can promote positive user-experience and satisfaction with the intervention.

Research

Future RCT

Chapter 9 reported that the intervention was acceptable, but the recruitment protocol needs further exploration before upgrading to an RCT. Therefore, the next step according to the MRC guidelines is to utilise the data from the feasibility study to design and carry out further research to inform the evaluation Power Up for Parents. Since, the main purpose of the RCT would be to test effectiveness, attention should be given to recruitment before conducting the full trial. This may require a modified or micro RCT further testing recruitment strategies. Also, in line with the MRC guidelines, it is recommended that cost-effectiveness be evaluated as part of the trial. The future study should also give continued attention to implementation to ensure the intervention can be easily implemented into practice and be acceptable to encourage uptake and continued use. However, outcomes and learning from the RCT may also be used to inform an implementation trial at a later date (Brown et al., 2017). Findings within this small sample for the pilot feasibility trial indicated low retention.

With upgrades to the current intervention and a larger scale recruitment drive, the future trial could include long-term follow-ups or multiple follow-ups to capture prolonged usage over time. Additionally, due to the identification and potential influence of emotions (Chapters 2,3,6) on parents' involvement in CYPMH care and treatment decision-making, it is recommended that the future trial include outcome measures to gather data on multiple emotional states as opposed to anxiety only.

Other research

Further exploration of parents' affective states and influence on the SDM process in CYPMH will make a valuable contribution to the body of literature. The current direction of the literature suggests that if the service, professional and other practical level barriers are rectified, it is expected SDM will increase across health settings. However, this may not be the case if individual-level barriers, such as emotions, continue to influence involvement. The current findings (Chapters 2,3,6) are preliminary and further qualitative and quantitative research on more representative samples or utilising purposive sampling strategies to identify ethnic minority groups and male caregivers of boys could broaden the scope of our understanding of the phenomenon.

Furthermore, there are still some unanswered questions. There is more to be investigated about the preference for the various modalities of interventions and perceived ease of use. Usability studies can help further inform the RCT and implementation trials. Data from beta testing studies can inform adjustments and refinement alongside the trial. Additionally, studies to help identify and address research on "Who should make the "final" decision in CYPMH?", "At what age parents should adopt an "informed" instead of "involved" approach to SDM in

CYPMH?" and "How to accurately measure SDM in a triad context" are needed. Future research utilising observational study designs, self-report measures and usage data can be conducted to explore further and address these research questions.

Practice

The overall findings of this thesis highlighted potential areas of clinical application. Firstly, the majority of parents reporting a preference for SDM (Chapter 9), the importance of parental involvement in the SDM process (Chapter 6) and high prevalence (~70%) of parents reporting experiences of SDM in CAMHS (Chapter 5) suggests that parents may appreciate additional support to be included in the SDM process. Although information and emotional needs of the families may vary at different times post-diagnosis (Grant, 2016), support efforts could be offered to all parents at the point of accessing services and targeted to those with identified needs. Importantly, the findings within this thesis describe parents as experiencing high anxiety levels (Chapters 6 and 9) among other states of arousal (Chapter 3) that warrant support and attention. Previous research in primary health care suggests that parents' emotional states are sometimes not acknowledged during the clinical encounter (Dicé et al., 2016). Clinicians within CAMHS may appreciate additional training on how to support parents, without giving priority over the child, and without affecting session times or requiring additional sessions.

Additionally, given the digital nature of the intervention, the link to access the intervention can be easily provided on flyers, websites or via barcodes displayed on posters at the CAMHS. Therefore, service providers would not require extra time during sessions to facilitate access to the intervention. Help and tech support could

also be accessible through the app to avoid any burden to services. However, with the suitable upgrade and refinements to the intervention, parents and clinicians may be able to send notes ahead of sessions. This approach has been shown to be favourable among services users (O'Brien et al., 2015).

Policy

With the high prevalence of CYPMH problems (Chapter 2), the uniqueness of the triad involved in the decision-making process (Chapters 5,6), and the promotion of active involvement of young service users in their own care and treatment decisions (Chapman et al., 2017), there is an increasing need for CAMHS to effectively implement SDM into practice. Evidence suggests that involvement in care and treatment decisions can be empowering to service users and lead to better health outcomes (Chapter 2). Consequently, the views of service users and service providers are important in informing policy guidelines to guarantee the successful implementation of SDM in CAMHS. As a result, the implications of the findings of this thesis for the development and modification of existing policy guidelines specific to CAMHS were considered.

Common themes were identified across the six studies included in this thesis. These were interpreted to develop a list of eight recommendations for policy guidelines. The recommendations were based on a synthesis that went beyond the individual studies, and as such should be taken with caution, as it was dependent on the PhD candidate's judgement and knowledge of relevant literature, and insights from four independent reviewers (JP, BM, MP & BP) and the PhD supervisors. The recommendations were initially developed by the PhD candidate and reviewed by the four independent reviewers (i.e. 2 practitioners, 1 child development policy officer

and 1 researcher). The PhD supervisor (JEC) then checked and commented on the recommendations, then revisions were made, and consensus to include was reached. In 2010, a gathering of 58 experts from 18 countries produced the Salzburg Statement on Shared Decision Making (Salzburg Global Seminar, 2011) that included a call for clinicians to recognize SDM as an ethical imperative, stimulate two-way flow of accurate and tailored information, and give patients and their families resources that help to reach decisions. The statement also exhorted action by researchers, editors, journalists, patients (to speak up, to expect to be an equal partner, to seek and use high-quality information) and policymakers. In line with the Salzburg statement on SDM, the following eight perceived implications for policy were derived to:

1.   Ensure primary carers and CYP are invited to be part of the care and treatment decision-making process while considering the following:

  ➢   Age and capacity of the CYP

  ➢   How much the child wishes to have the parent "involved" or "informed"

  ➢   How much or what support the family needs in order to be involved

2.   Review clinicians' time schedules so they can provide sufficient time and encourage primary carers to ask questions and raise concerns during and within sessions

3.   Highlight the need for emotional support to be provided to primary carers especially at the initial stages of accessing CAMHS or at crucial decision-making time-points

4.   Propose a need for a key person at CAMHS that can provide answers to more general questions or be a liaison between clinicians and families especially during periods when there is a changeover of service providers

5.   Consider the inclusion of the primary carer or key person (i.e. an advocate for the family who is not the primary service provider) at multidisciplinary meetings when care and treatment options are being considered

6.   Review the role of parent support groups and explore the potential for further responsibilities

7.   Highlight the need for SDM support interventions as an adjunct to routine care

8.   Suggest that when SDM interventions are being developed to be used with the CAMHS populations that the following are considered:

> ➢   PPI is at the core of design, development, testing and implementation

> ➢   Equal voices are given to service users and services providers

> ➢   Interventions are accessible, acceptable, suitable and appropriate for the population, easy-to-use, useful and do not incur additional time burden to the service providers and the service users.

Reflections

The research process involved in conducting this thesis presented many challenges that resulted in many learning experiences. The main challenge was the development of the intervention and having to work with the development team who were less interested in the research process and mostly focused on the app interface. Therefore, having to manage the team, in order to strike a balance, resulted in having to maintain weekly meetings and make unscheduled visits to the app company. Additionally, having to review many iterations of the prototype and sometimes make quick judgements required subjective opinions, which made it difficult to dedicate fully to the co-design process. However, guidance and support from my experienced supervisors, the parent partners and the steering committee guaranteed that my personal preferences did not profoundly influence the app development or the research process.

Furthermore, the app development process was unavoidably lengthy. Without careful management and setting aside perfectionist traits, this could have potentially delayed the research project. Nonetheless, it was rewarding to see the "finished" prototype and obtain positive feedback from parents and healthcare providers.

Once the feasibility study began, making changes to the prototype was not encouraged. Therefore, the rigidity of the trial design made it difficult to facilitate mid-trial changes, which could have potentially positively influenced usage. This resulted in participants sometimes providing feedback to improve on the same items within the app. Ideally, completing user-testing of the app (i.e. interviews and FGDs), implementing changes based on the participants' feedback and then conducting the pilot feasibility randomised trial may have significantly influenced usage and interest. However, due to the aims of this thesis and the time and budget constraints, this was not possible or essential at this stage. Nonetheless, being able to collect qualitative data on acceptability and usability alongside the feasibility trial proved useful to inform future studies arising from this thesis.

On reflection, the addition of the community recruitment also potentially promoted ecological validity of the study as recruitment was conducted "in the wild" (Shrout, 1980) and obtained data from participants who used the intervention as a stand-alone tool instead of collaboratively with service providers. Although parent partners highlighted that CYP do not always welcome involvement from their parents, both parents and healthcare providers in the qualitative study expressed the importance of including parents in the SDM process. In hindsight, it may have been important to probe the answers to further understand what can be done to support the process when CYP wish for their parents not to be involved. However, the

concept of an "informed vs involved" parent emerged. It would be interesting to hear the CYP's views on this, because with resistance from the CYP the intervention may not be widely used or accepted by CAMHS.

Looking back at where I started to now, it overwhelms me to realize how much I have developed personally and professionally as a researcher. The modules undertaken to obtain skills in systematic reviews, qualitative research and statistics facilitated an adequate foundation for which I can continue to build on. Dissemination of various aspects of this thesis (i.e. conferences and journal publications) throughout the research process and thesis write-up has also enabled the development of presentation skills and the capacity to receive constructive criticisms.

Conclusion

The overarching aim of this thesis was to understand the role of parents' emotional experiences in CYPMH decisions, explore possible associations, and develop and pilot an intervention that is acceptable and feasible to support parents and promote involvement in care and treatment decisions. First, this thesis explored the phenomenon of emotions and health decision-making in a CYPMH context (Chapter 2,3,6). Emotions were found to either promote active involvement in decision-making or hinder involvement. Then an exploration of parents' experience of SDM in CAMHS (Chapters 5, 6) and identification of available decision support tools was conducted (Chapter 7). Taken together, the findings highlighted 23 available interventions and suggested that many parents report experiencing SDM. However, when accounting for service level factors, parents of children with behavioural problems may experience lower levels of SDM. Additionally, findings were generally in line with the systematic review (Chapter 2) suggesting parents' emotional state

may affect the SDM process. Consequently, the Power Up for Parents intervention was developed (Chapter 8) and tested for feasibility and acceptability with parents and HCPs (Chapter 9). The intervention was found to be acceptable, and with some adjustments and further explorations to improve recruitment and retention, the intervention can be evaluated in future research.

Overall, the thesis contributed to the growing body of knowledge in the area of SDM in CYPMH. An affective appraisal model emerged describing parental affective states as an influencing factor to the SDM process. Although existing SDM models and interventions fail to acknowledge this concept, this thesis revealed that it was feasible and acceptable to develop and pilot an intervention utilising this model as an evidence base. In so doing, the exploration of theory, evidence and interventions highlighted the importance of an affective appraisal approach to SDM to provide a foundation for future research, clinical practice and policy.

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Appendices

Appendix A Search strategy for study 1 – Chapter 3

Search engine	Search strategy	Record number
PsycINFO	**Decision making: exp** Decision Support System or exp Decision Making or exp Group Decision Making or exp Choice Behavior or exp Choice Shift or exp Client participation or exp Parental Involvement or Participation or "shared decision making" or "medical decision making" or "clinical decision making" or "parent participation" or "parent engagement" or decision* or choice* or "decision support" or "decision support technique*" or "decision making behavio?r" or "choice behavio?r" or dilemma* AND **Parent: exp P**arents or exp Adoptive parents or exp Foster parents or exp Homosexual parents or exp Single parents or Stepparents or exp Surrogate parents (humans) or exp Grandparents or exp Fathers or exp Single Fathers or exp Mother or exp Single Mothers or exp Unwed Mothers or exp Caregivers or exp Family or exp Family members or exp Social Support or exp Stepfamily or exp Extended family or exp Biological family or exp Family of origin or guardian* or carer* or caretaker* or "child mind*" AND **Child Mental Health: exp Mental Health**/ or exp Emotional States or exp Community MH/ or exp MH services or exp Community MH services/ or exp Community MH Centres or exp Chronic mental illness or exp Mental disorders or exp MH Programs or exp MH Services or exp Primary MH prevention/ or exp Community Psychiatry or exp Psychiatry or exp Behaviour Disorders or exp Behavior Problems or exp Conduct disorder or exp Anxiety Disorder or exp Affective Disorders or "mental problem*" or "mental difficult*" or "MH challenge*" or "MH difficult*" or "MH problem*" or "mental challenge*" or "mental	2283

	well$being" or "MH well$being" or "mental illness" or "MH illness" or "mood disorder*" AND exp Adopted children or exp Foster Children or exp Only Children or child* or teen* or "young person*" or "young people" or kid* or adolescen* or infan* or toddler* or "young adult*" or student* or girl* or boy* or pupil* OR exp Child guidance clinics or exp Child psychiatry or exp Child Psychology or exp Child Psychotherapy or exp School Based Intervention or exp Student personnel services/ or "child* and adolescen* MH service*" or CYPMH* or "child* health mental institution*" or "child* psych* ward*" or "child* psych* hospital* or "school base* MH program*"	
MEDLINE	**Decision Making**: exp Clinical decision making or exp Decision Making or exp Decision Support Systems, Clinical or exp Decision Support Techniques or exp Choice Behavioir or exp Patient Participation or "parent* involve*" or participat* or "shared decision making" or "medical decision making" or "parent* participat*" or "parent* engagement" or decision* or choice* or "decision support" or "decision making behavio?r" or dilemma* AND **Parent:** exp Single Parent or exp Parents or exp Fathers or exp Mothers or exp Caregivers or exp Families or exp Social Support or "foster parent*" or "adopt* parent*" or "homosexual parent*" or stepparent* or "surrogate parent*" or grandparent* or "single father*" or "single mother*" or stepfamil* or "extended famil*" or "biological famil*" or "family of origin" or guardian* or carer* or caretaker* or "child mind*" AND **Child Mental Health:** exp MH services/ or exp community MH services/ or exp mental competency/ or exp community MH centers/ or exp mental disorders/ or "Chronic mental illness" or exp Mental disorders or exp MH Programs or exp MH Services or "Primary MH prevention" or exp Community Psychiatry or exp	2906

	Psychiatry or exp Behaviour Disorders or exp Behavior Problems or exp Conduct disorder or exp Anxiety Disorder or exp Affective Disorders or "mental problem*" or "mental difficult*" or "MH challenge*" or "MH difficult*" or "MH problem*" or "mental challenge*" or "mental well$being" or "MH well$being" or "mental illness" or "MH illness" or "mood disorder*" AND exp child, preschool/ or child*.mp. or exp child, orphaned/ or exp child/ exp Adolescent exp Infant or "adopted children" or "foster child*" or "only child*" or teen* or "young person*" or "young people" or kid* or adolescen* or infan* or toddler* or "young adult*" or student* or girl* or boy* or pupil* OR exp Child guidance clinics or exp Child psychiatry or exp Child Psychology or "child Psychotherapy" or "School Base* MH program" or "Student personnel services"/ or exp School Health Services or "child* and adolescen* MH service*" or CYPMH* or "child* psych* ward*" or "child* psych* hospital*	
Cochrane Library	**Decision Making**: Decision making or clinical decision making or decision support systems or decision support techniques or choice behaviour or patient participation or "parent invol*" or "participat*" or "shared decision making" or "medical decision making" or "parent* participat*" or "parent engag*" or "decision" or "choic*" or "decision support*" or "decision making behave*r" or dilemma AND **Parent**: Parents or "single parent*" or mother* or father* or caregivers or family of "social support" or "foster parent" or "adopt* parent*" or stepparent or grandparent or "single father*" or "single mother*" or stepfamily* or "extended famil*" or "biological famil*" or guardian* or carer* or caretaker* or "child mind*" AND **Child Mental Health:** MH Services or Community MH Services or Community MH Centers or Mental Disorders or Psychiatry or Behaviour Disorders or Conduct Disorders or Anxiety Disorders or Mood	985

	Disorders or "primary MH prevention" or "mental *problem*" or MH*"	
	AND Child or Adolescent or Infant or Adopted Child or Foster Child "young person" or "young people" or young adult" or Students or girl* or boy*	
	OR Child Guidance clinics or child psychiatry or child psychology or school health services or "school based MH program*" or "student personnel service" or "child and adolescent MH" or CYPMH* or "child psychiatry*"	
Web of Science	**Decision Making**: "decision making" OR "group decision making" or "parental involvement" or involvement or "medical decision making" or "parent choice" or "parent opinion" or "shared decision making" or "decision making" or "clinical decision making" or "decision support systems" or "decision support technique*" or "choice behavio*r*" or "patient participation" or "parent involv*" or "parent engag*" or decision* or choice* AND **Parent**: parent* or "surrogate parent*" or "adopt* parent*" or "homosexual parent*" or "foster parent*" or "single parent*" or "unwed mother*" or "single mother*" or mother* or "single father*" or father* or mother* or stepparent* or grandparent* or stepfamil* or "extended famil*" or "biological famil*" or caregiver* or guardian* or carer* or caretaker* or "child mind*" AND **Child Mental Health**: "MH service*" or "community MH service*" or "community MH cent$r*" or "mental disorders" or psychiatr* or "behavio*r*" or "conduct disorder*" or "anxiety disorder*" or "mood disorder*" or "primary MH prevention" or "MH problem*" or "MH difficult*" or MH challenge*" AND "child* or adolecen* or "adopted child*" or infan* or "foster child*" or "young person*" or "young people" or "young adult" or student* or girl* or boy* or kid* or teen* OR "child guidance clinic*" or "child psychiatry" or "child psychology" "school health service*" or "school based MH program"	2686

	or "student personnel service*" or "child* and adolescen* MH service*" or CAMHS*)	
Embase	**Decision making**: exp clinical decision making or exp clinical decision support or exp decision making or exp decision support system or exp family decision making or exp medical decision making or exp patient decision making or exp shared decision making or decision* or "parent* involve*" or involve* or "parent choice*" or "parent opinion" or "decision support technique*" or exp choice behaviour or exp patient participation or "parent* engag*" or exp decision or choice* AND **Parent**: exp adoptive parent or exp divorced parent or exp parent or exp separated parent or exp single parent or exp single parent family or exp foster care or exp mother or exp father or exp grandparent or exp great-grandparent or "single mother*" or "single father*" or "step parent*" or or exp extended family or exp family or exp nuclear family or exp caregiver or exp care giver support or exp legal guardian or guardian* or carer* or caretaker* or "child mind*" AND **Child Mental Health:** exp MH or exp community MH or exp MH service or exp mental disease or psychiatric nursing or exp psychiatry or exp mental disease or exp depression or exp mood disorder or "community MH service*" or "community MH cent*" or exp conduct disorder or exp behaviour disorder or exp anxiety disorder or "primary MH prevention" or "MH problem*" or "MH difficult*" or MH challenge*" AND exp only child/ or exp adopted child/ or exp orphaned child/ or exp adult child/ or exp single parent child/ or child* or adolecen* or infan* or "foster child*" or "young person*" or exp young adult or teen* or exp student* or exp girl* or exp boy* or kid* OR exp child psychiatry or "child guidance clinic*" or exp child psychology or "child* pscholog*" or exp school health service*" or "school based MH program" or "student personnel service*" or "child* and adolescen* MH service*" or CAMHS*	2998

CINAHL	**Decision making:** (MM "Decision Making+") OR "decision making" OR (MM "Decision Making, Patient+") OR (MM "Decision Making, Clinical") OR (MM "Decision Making, Family") OR (MM "Decision-Making Support (Iowa NIC)") OR (MM "Decision Making (Iowa NOC)") or "shared decision making" (MM "Parental Attitudes+") "Parental Behavior") AND **Parent:** (MM "Biological Parents") OR (MM "Single Parent") OR OR (MM "Adoptive Parents") OR (MM OR "parent" (MM "Single Parent") OR (MM "Family+") OR (MM "Foster Parents") or (MM "Mothers+") OR (MM "Foster Parents") OR "mother" Or (MM "Extended Family+") OR (MM "Nuclear Family+") OR (MM "Dependent Families+") AND **Child MH:** (MM "Community MH Services+") OR (MM "MH Personnel+") OR (MH "Hospitals, Psychiatric") OR (MM "Research, MH") OR (MM "MH Services+") OR (MM "MH Treatment (Saba CCC)") OR (MM "MH Promotion (Saba CCC)") OR (MM "MH Screening (Saba CCC)") OR "child MH" or (MM "Psychology+") (MM "Psychiatric Service") OR (MM "Psychiatrists") (MH "Community MH Services") OR (MH "Hospitals, Psychiatric") OR "MH problems" (MM "Emotions+") OR (MH "MH (Omaha)") OR (MM "Stress, Psychological+") OR (MM "Affective Disorders+") AND (MM "Adult Children") OR (MM "Child, Preschool") OR (MM "Child, Hospitalized") OR (MM "Child, Medically Fragile") (MM "Child, Adopted") (MM "Adolescence") OR (MM "Adolescent, Hospitalized") OR (MM "Adolescent Behavior") boy* or girl* or child* or teen* or kid* or "young adult*" or "young people*" or "young person*" OR (MM "Child Psychology") OR "child psychology" (MM "Child Psychiatry") ""child guidance clinic*"" (MM "School Health Services") OR (MM "Schools, Allied Health") "school based MH program*" or "child and adolescent MH services"	964

Appendix B Current View Tool – Chapter 5

Current View

CYP Name ....

DOB: ....

NHS ID: ....

Practitioner's Name ....

Practitioner's ID ....

Service Allocated Case Id ....

Please indicate your reason for completing this form:

First Contact	☐
Changed Situation	☐
Changed Understanding	☐

Date: ☐☐ / ☐☐ / 20☐☐   Time: ☐☐ h ☐☐ m

	Provisional Problem Description Rating need not imply a diagnosis	None	Mild	Moderate	Severe	Not known
1	Anxious away from caregivers (Separation anxiety)	☐	☐	☐	☐	☐
2	Anxious in social situations (Social anxiety/phobia)	☐	☐	☐	☐	☐
3	Anxious generally (Generalized anxiety)	☐	☐	☐	☐	☐
4	Compelled to do or think things (OCD)	☐	☐	☐	☐	☐
5	Panics (Panic disorder)	☐	☐	☐	☐	☐
6	Avoids going out (Agoraphobia)	☐	☐	☐	☐	☐
7	Avoids specific things (Specific phobia)	☐	☐	☐	☐	☐
8	Repetitive problematic behaviours (Habit problems)	☐	☐	☐	☐	☐
9	Depression/low mood (Depression)	☐	☐	☐	☐	☐
10	Self-Harm (Self injury or self-harm)	☐	☐	☐	☐	☐
11	Extremes of mood (Bipolar disorder)	☐	☐	☐	☐	☐
12	Delusional beliefs and hallucinations (Psychosis)	☐	☐	☐	☐	☐
13	Drug and alcohol difficulties (Substance abuse)	☐	☐	☐	☐	☐
14	Difficulties sitting still or concentrating (ADHD/Hyperactivity)	☐	☐	☐	☐	☐
15	Behavioural difficulties (CD or ODD)	☐	☐	☐	☐	☐
16	Poses risk to others	☐	☐	☐	☐	☐
17	Carer management of CYP behaviour (e.g., management of child)	☐	☐	☐	☐	☐
18	Doesn't get to toilet in time (Elimination problems)	☐	☐	☐	☐	☐
19	Disturbed by traumatic event (PTSD)	☐	☐	☐	☐	☐
20	Eating issues (Anorexia/Bulimia)	☐	☐	☐	☐	☐
21	Family relationship difficulties	☐	☐	☐	☐	☐
22	Problems in attachment to parent/carer (Attachment problems)	☐	☐	☐	☐	☐
23	Peer relationship difficulties	☐	☐	☐	☐	☐
24	Persistent difficulties managing relationships with others (includes emerging personality disorder)	☐	☐	☐	☐	☐
25	Does not speak (Selective mutism)	☐	☐	☐	☐	☐
26	Gender discomfort issues (Gender identity disorder)	☐	☐	☐	☐	☐
27	Unexplained physical symptoms	☐	☐	☐	☐	☐
28	Unexplained developmental difficulties	☐	☐	☐	☐	☐
29	Self-care issues (includes medical care management, obesity)	☐	☐	☐	☐	☐
30	Adjustment to health issues	☐	☐	☐	☐	☐

	SELECTED COMPLEXITY FACTORS	Yes	No	Not known
1	Looked after child	☐	☐	☐
2	Young carer status	☐	☐	☐
3	Learning disability	☐	☐	☐
4	Serious physical health issues (including chronic fatigue)	☐	☐	☐
5	Pervasive Developmental Disorders (Autism/Asperger's)	☐	☐	☐
6	Neurological issues (e.g. Tics or Tourette's)	☐	☐	☐
7	Current protection plan	☐	☐	☐
8	Deemed "child in need" of social service input	☐	☐	☐
9	Refugee or asylum seeker	☐	☐	☐
10	Experience of war, torture or trafficking	☐	☐	☐
11	Experience of abuse or neglect	☐	☐	☐
12	Parental health issues	☐	☐	☐
13	Contact with Youth Justice System	☐	☐	☐
14	Living in financial difficulty	☐	☐	☐

CONTEXTUAL PROBLEMS	None	Mild	Moderate	Severe	Not known
HOME	☐	☐	☐	☐	☐
SCHOOL, WORK or TRAINING	☐	☐	☐	☐	☐
COMMUNITY	☐	☐	☐	☐	☐
SERVICE ENGAGEMENT	☐	☐	☐	☐	☐

EDUCATION/EMPLOYMENT/TRAINING					
ATTENDANCE DIFFICULTIES	☐	☐	☐	☐	☐
ATTAINMENT DIFFICULTIES	☐	☐	☐	☐	☐

Appendix C. Permission to analyse children and young people MH services

administrative data – Chapter 5

Shaun Liverpool

From:	CORC
Sent:	27 April 2018 11:33
To:	Shaun Liverpool
Subject:	RE: Request for CYP IAPT dataset - Shaun

Follow Up Flag:	Follow up
Flag Status:	Flagged

Hi Shaun,

I am pleased to say your research request dataset is now ready for you to access. You will be able to access the data from a secure login from one of two computers in the large office space at Jordan House.

You will be able to access the data from a secure login. This login does not allow you to move any files from the computer, or access the internet, meaning the data cannot leave the premises. If you need to take home any output from your analysis we ask that you e-mail the CORC team (at this address) with the location of the files you need. Please ensure that any output only contains aggregate-level data pertaining to 3 or more service users. The team will then password-protect the files and (as long as they do not contain any individual-level data) we can e-mail the analysis to you.

Please do contact me when you plan to come and work on the dataset so I can reserve a computer for you. I will give you the details you will need to login to the secure computer when you arrive.

The data will be in a folder labelled with your name, and is in a Comma-separated values file (.csv) format. The dataset you have access to is a research dataset that has already partly been processed by the CORC team for analysis, including dealing with duplicate records and creating clinical threshold variables. It contains the data submitted by CYP IAPT partnerships over the course of the CYP IAPT Data Collation and Analysis project, between the end of 2011 and Q2 2015 (October 2015) (see this report for more info on the project, and note that the dataset you have access to contains an addition quarter's worth of data). The dataset was originally in the 'CYP IAPT dataset specification (v4.1)', but after processing a large number of variables are now in the format detailed in the document 'Wide Data – V4 2017-01-16 – Variable Definitions and Descriptors'. I have included all of these documents in the folder with the data (note that they all contain the full info about the dataset, not just the variables included in your request!).

There are a few other key things to note about the dataset that I have included below:

- The data is in "wide" format, meaning that each row relates to a unique period of contact, i.e. a spell of care of an individual within a service. Some people may have been seen more than once, but if their periods of contact did not overlap, they would appear on separate rows in the dataset.
- The dataset specification included two versions of the SDQ form – the assessment version, and the follow-up version. These have been merged to generate a first and last overall subscale score per valid period of contact, but the individual items from the first and last assessment version, and first and last follow up version are included as well, and are indicated as "SDQ_ASS_" and "SDQ_FUP_" in the dataset
- As the dataset was processed in R, any blank entries are populated with the default missing-values code used by R (which is "NA") so when you load the data into your chosen programme, you will likely see a lot of entries of "NA" – this means they were left blank.
-

I hope that is all clear – however, if you have any further questions please do let me know.

Many thanks,

Meera

Appendix D.1. Stage 1 Consent form for Clinicians – Chapter 6

LONDON'S GLOBAL UNIVERSITY

Site Name: Participant Number:

Consent Forms for Clinicians

Stage 1: Interviews and Focus Groups for Power Up for Parents: A Pilot Study

Thank you for your interest in taking part in this research study. Please complete this form after you have read the Information Sheet and listened to the purpose and risks of this research. If you have any questions arising from the Information Sheet or explanations already given to you, please ask the researcher before you decide whether to join this study. 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 un-initialled boxes mean 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 Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction.	
2.	I consent to participate in the study. I understand that my personal information will be stored securely at all times and will be used only for the purposes explained to me. I understand that according to data protection legislation, informed consent will be the lawful basis for processing.	
3.	I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified.	
4.	I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
5.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
6.	I understand the direct/indirect benefits of participating.	
7.	I understand that the data will not be made available to any commercial organizations but is solely the responsibility of the researcher(s) undertaking this study.	
8.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	

9.	I agree that my anonymized research data may be used by others for future research and no one will be able to identify me when this data is shared.		
10.	I consent to my interview/focus group participation being audio recorded and understand that the recordings will be securely destroyed immediately following transcription.		
11.	I consent to being contacted by the research team in relation to my participation in this study.		
12.	I am aware of whom I should contact if I wish to lodge a complaint.		

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
taking consent

_____   _____   _____
Name of Chief Investigator   Date   Signature

Appendix D.2. Stage 1 Consent form for Parents – Chapter 6

LONDON'S GLOBAL UNIVERSITY

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Site Name: Participant Number:

Consent Forms for Parents/Caregivers

Stage 1: Interviews and Focus Groups for Power Up for Parents: A Pilot Study

Thank you for your interest in taking part in this research study. Please complete this form after you have read the Information Sheet and listened to the purpose and risks of this research. If you have any questions arising from the Information Sheet or explanations already given to you, please ask the researcher before you decide whether to join this study. 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 un-initialled boxes mean 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 Box
1.	I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction.	
2.	I consent to participate in the study. I understand that my personal information will be stored securely at all times and will be used *only* for the purposes explained to me. I understand that according to data protection legislation, informed consent will be the lawful basis for processing.	
3.	I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified.	
4.	I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.	
5.	I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.	
6.	I understand the direct/indirect benefits of participating.	
7.	I understand that the data will not be made available to any commercial organizations but is solely the responsibility of the researcher(s) undertaking this study.	
8.	I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.	

9.	I agree that my anonymized research data may be used by others for future research and no one will be able to identify me when this data is shared.	
10.	I consent to my interview /focus group being audio recorded and understand that the recordings will be securely destroyed immediately following transcription.	
11.	I consent to being contacted by the research team in relation to my participation in this study.	
12.	I am aware of whom I should contact if I wish to lodge a complaint.	

_____   _____   _____
Name of Participant   Date   Signature

_____   _____   _____
Name of Person   Date   Signature
taking consent

_____   _____   _____
Name of Chief Investigator   Date   Signature

Appendix E. Participant Information Sheet – Chapter 6

LONDON'S GLOBAL UNIVERSITY

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Participant Information Sheet

Stage 1: Interviews and Focus Groups for Power Up for Parents: A Pilot Study

YOU WILL BE GIVEN A COPY OF THIS INFORMATION SHEET

We would like to invite you to take part in this research, which is being offered as part contribution to a PhD in Child and Adolescent Mental Health. Before you decide, we would like you to understand why the research is being done and what it involves. A researcher will go through this information sheet with you and answer any questions you may have. This should take about 10-15 minutes. Talk to others, if you wish, and ask us if there is anything that is not clear.

What is the purpose of the study?
A smartphone app has been developed to support young people to make shared decisions throughout their care and treatment with Child and Adolescent Mental Health Services (CAMHS). This study is expected to build on this app, named Power Up for Parents, and aim to allow parents/caregivers to communicate effectively with professionals and their child, therefore, taking a more active role in treatment/therapy. It provides parents/caregivers with tools to use within and between CAMHS sessions, independently from clinicians. It can however, be used in partnership with children and clinicians (optional). This app will include space to record things that matter to you, things you want to talk about, questions to ask and things to remember; for example, appointments at CAMHS

We want all parents to be involved in designing Power Up for Parents, so they may find it a valuable part of their practise in the future. To do this we want to hear parent's decisional support needs and opinions on the first version of Power Up that has been developed. We will use the opinions and feedback from these interviews to develop and make changes to the app before it is piloted in services.

What will happen if I take part?
If you decide to take part, we would like to hear your decision support needs and opinions on the first version of the Power Up app which we will share with you. This can be done in one of two ways.

1) You could take part in an interview. This can take place either at a face-to-face meeting at a research site most convenient to you, or a researcher can conduct this interview on the phone. This interview will be conducted at a time and place convenient to you.
2) You could take part in a focus group. Here you will discuss your experiences and views with other parents/caregivers. The focus group will last up to two hours. Focus groups will be dependent on other people wanting to take part as well. If you agree to take part in a focus group, we will find out yours and others' availability to find the most convenient time and place for everybody. Everybody that attends the focus group will be asked to keep everything strictly confidential to protect everyone's views and opinions.

Both the interviews and focus groups will be audio recorded so that we can transcribe the conversations. The audio recordings of your conversations made during this research will be transcribed and used only for analysis.

No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

Why have I been invited to take part?
We are looking for parents/caregivers of young people who are currently attending Child and Adolescent Mental Health Services (CAMHS). The CAMHS your child attend is part of the project. We will talk to other parents/guardians and healthcare professionals too.

Do I have to take part?
It is up to you to decide whether you are willing to join the study. From the date of receiving this information sheet you will have until the end of the recruitment period to decide if you wish to take part. Also, as a participant, you can discontinue participation in this study at any time if you think this research is a burden to you.

What will happen to me if I take part?
We will describe the study in detail and go through this information sheet. You will be given detailed verbal information by a researcher about the nature, purpose and risks of your involvement in the study in a clear and unambiguous way before consenting. Additionally, this information sheet outlining the purpose and details of the study will be available to you at all times. All participants will sign an informed consent form before they participate in the study. If you agree to take part, the researcher will then ask you to sign a consent form, which will be secured. You are free to withdraw at any time, without giving a reason. This would not affect you or your child's health care or legal rights.

If, after you have taken part, you decide that you want us to remove your responses, you can contact us and ask us to delete them.

What are the possible disadvantages of taking part?
There are no known risks to taking part in these interviews or focus groups. If any risks become known during the research, you will be informed straight away. Since the main purpose is to obtain parent's feedback to develop a decision tool, questions may require you to explore sensitive topics. However, if you experience discomfort you will be treated with compassion and signposted to further help if needed.

What are the possible benefits of taking part?
Whilst there is no guaranteed benefit in taking part in this study, one advantage is that you will get to help shape a tool that caregivers, clinicians, and service users may use in the future. Most people find taking part in research rewarding, as they contribute to the development of knowledge that may benefit themselves and others.

Will I be compensated for taking part?
Travel reimbursement will be offered to all participants once you attend the interview or focus group. All participants will receive the full amount of their travel costs once receipts are provided. For participants who are unable to provide a receipt, you will receive £10 as a standard minimum amount.

Will my taking part in the study be kept confidential?
We will assign you a unique code, and this will appear on any data we collect from you. Consent forms will be

kept in their own locked filing cabinet at the Evidence Based Practice Unit of University College London (UCL) and Anna Freud National Centre for Children and Families (AFNCCF) and accessible by the student researcher and supervisors only. Interviews transcribed by the student researcher, will be identified only by the unique code we assign to you. The audio file will be deleted once it has been transcribed. Only the student researcher and supervisors will have access to full transcribed data. Quotations from interviews and focus groups will be analysed, however any information that may identify a participant will be removed.

All information we collect from participants in the interviews and focus groups is strictly confidential, though we may have to break confidentiality in the highly unlikely event that you tell us something that puts you or others at risk. In this unlikely event, we will inform you that there is a need for us to discuss the issue with others, for example someone working in the service your child attends.

What will happen to the results of the study?
The anonymised results will be published in project reports, scientific journals, presented at conferences, disseminated on the AFNCCF and UCL website and form part of the final PHD write up. The results will be shared once the last person completes the research and the data has been analysed. You will not be identified in any report or publication. Data collected during the course of this study might be used for additional or subsequent research but no identifiable data will be used.

How will my personal data be stored?
Personal data will be stored securely at all times in password protected files or in locked filing cabinets at the Evidence Based Practice Unit (part of the Anna Freud Centre and University College London), away from other study materials and accessible only by the student researcher and immediate supervisors. It will be stored for up to 3 months after the study has ended, and then destroyed securely. The research data generated from the study (e.g. responses to questions) will be stored for up to 10 years in accordance with the UCL long term storage plan which meets clinical trial regulations.

Data Protection Privacy Notice

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 at data-protection@ucl.ac.uk. UCL's Data Protection Officer can also be contacted at data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes of informing research into the area of shared decision making.

The legal basis that would be used to process your *personal data* will be your consent as agreed on the informed consent sheets.

***Your personal data will be processed so long as it is required for the research project*. If we are able to anonymise or pseudonymise the personal data, you provide we will undertake this and will endeavour to minimise 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/individuals-rights/

What happens if something goes wrong?

If you wish to complain or have any concerns about any aspect of the way you have been approached or treated by members of staff due to your participation in the research, National Health Service or Psychology and Language Sciences (PALS) division of University College London (UCL) complaints mechanisms are available to you. Please ask the researchers if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available.

If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with Mr Shaun Liverpool, please make the claim in writing to Dr Julian Edrooke-Childs who is the Chief Investigator for the research and is based at Evidence Based Practice Unit (EBPU) of Anna Freud National Centre for Children and Families and University College London - Old Street Site, Jordan House, 47 Brunswick Place, N1 6EB. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

Who is organising, sponsoring and funding the research?

This research is being carried out by researchers at University College London. The study is sponsored by the University College London and funded by European Union's Horizon 2020 research and innovation programme under the Marie Curie grant agreement.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been ethically reviewed by the London Surrey Research Ethics Committee and given a favourable response by the Health Research Authority.

What happens after this research is completed?

Participants will have the option to continue to use the app after the trial has ended. Researchers will further develop the app based on feedback from the trial to use as part of a larger Randomized Control Trial. Once the evidence for the efficacy of the app has been obtained, a plan to ensure as many parents as possible have access to the app will be put in place.

Contact details:

If you have any questions about research in general, this research in particular, your rights as a participant, or would like to report any problem or complaint arising from this research, please contact any of the following:

Dr Julian Edbrooke-Childs, Senior Research Fellow.
Tel.: 020 7794 2275. Email: Julian.Edbrooke-Childs@annafreud.org

Appendix F. Data Protection and Data Governance Sheet – Chapter 6

LONDON'S GLOBAL UNIVERSITY

University College London (UCL) is the sponsor for this study and is 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 will keep identifiable information about you for 3 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 can delete all information if this is your desire or keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

For the purpose of this research we will request your contact details ONLY from your CAMHS site, which they will only supply to us, after your permission. Researchers will use your name, and contact details 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. Individuals from UCL and regulatory organisations may look at the data we collect to check the accuracy of the research study. The student researcher and immediate supervisors are the only people who will have access to your contact information and it would be used only to contact you to schedule interview dates or audit the data collection process.

Your information will only be used by researchers to conduct research in accordance with the UK Policy Framework for Health and Social Care Research. This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you for other reasons or to make decisions about future services available to you, such as insurance.

You can find out more about how we use your information by contacting UCL's Data Protection Officer at **data-protection@ucl.ac.uk.**

Appendix G. Telephone Interview Script – Chapter 6

LONDON'S GLOBAL UNIVERSITY

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Script for Phone Interviews

Starting the phone interviews

Hello, my name is _____, I am a PhD student at the University College London and the Anna Freud National Centre for Children and Families. I'm part of a team of researchers at the Evidence Based Practice Unit who will be conducting the Power Up for Parents feasibility study. We would have communicated prior to this phone call and you expressed interest in being part of this this study.

Are you in a comfortable place to talk?

Can you confirm your name and that you wish to proceed with being interviewed?

You were given an information sheet and consent forms before today, which we will go through together and if you have any questions feel free ask. In this interview, I'd like to find out about your experiences of shared decision making and obtain your input on the Power up for Parents intervention.

I'd like to emphasise there really aren't any right or wrong answers, and what you say will be kept confidential and goes directly to the research team. When we write up the information for reports, the results are presented anonymously.
Everything that you and I talk about today is private or confidential unless I'm worried that any harm or danger is going to come to you or to anyone else, in which case then I would need to speak to my supervisor and the safeguarding officer at the Anna Freud Centre, but I would tell you if I was worried in this way first.

You are welcome to stop the interview at any time.
I'd like to record the interview, because it's just not possible to take notes to capture all the information. Is this okay?
To ensure anonymity, it's best if you don't introduce yourself by name while the recording is running. I'm going to turn on my audio recorder now.

Ending the phone interviews
Do you have anything further to add to any of the points we discussed today?

Thank you for taking the time to talk with me today. If you have any questions or concerns, please feel free to contact me or a member of the research team. Our contact details can be found on the information sheet.

Goodbye.

Appendix H.1. Demographic Sheet for Parents/Carers – Chapter 6

LONDON'S GLOBAL UNIVERSITY

UCL

POWER UP

Participant number:

Date:

Parent/Caregiver (Stage 1-Demographics)

About you

1. What is your relationship to the child (e.g. mother)?

2. How old are you?

3. What is your gender?

- Male
- Female
- Prefer not to disclose
- Other (please specify, if you would like to)

4. What is your ethnicity?

- White or White British
- Black or Black British
- Asian or Asian British
- Mixed
- Other (please specify, if you would like to)

5. Is English your first language?

☐ Yes

☐ No

☐ Prefer not to say

About your child

6. How old is your child?

[   ]

7. What is their gender?

☐ Male
☐ Female
☐ Prefer not to disclose
☐ Other (please specify, if you would like to)

[   ]

8. What is his/her diagnosis?

[   ]

Appendix H.2. Demographic sheet for clinicians – Chapter 6

LONDON'S GLOBAL UNIVERSITY

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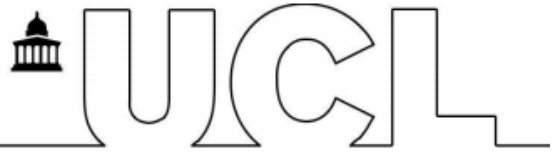
POWER UP™ Clinician (Stage 1)

Participant number:

About you

1. What is your role/occupation or capacity of working with children (e.g. psychologist)?

2. How long have you been in this role?

About the children

3. How old are the children you work with?

4. What are their diagnoses?

5. Is it inpatient/outpatient care?

Appendix I.1. National Health Services Research Authority Approval.

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Julian Edbrooke-Childs
Lecturer
University College London & Anna Freud National Centre for
Children and Families
Jordan House
47 Brunswick Place
London
N1 6EB

Email: hra.approval@nhs.net
Research-permissions@wales.nhs.uk

13 July 2018

Dear Dr Edbrooke-Childs

HRA and Health and Care
Research Wales (HCRW)
Approval Letter

Study title:	**Power Up for Parents: A pilot study, promoting parental involvement in shared decision making through technology**
IRAS project ID:	**236277**
Protocol number:	**1**
REC reference:	**18/LO/0978**
Sponsor	**University College London**

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.

Following the arranging of capacity and capability, participating NHS organisations should **formally confirm** their capacity and capability to undertake the study. How this will be confirmed is detailed in the "*summary of assessment*" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

IRAS project ID	236277

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:

Name:	Shaun Liverpool
Tel:	02031089888
Email:	shaun.liverpool@annafreud.org

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 **236277**. Please quote this on all correspondence.

Appendix I.2. University Ethics Approval

UCL RESEARCH ETHICS COMMITTEE
OFFICE FOR THE VICE PROVOST RESEARCH

23rd April 2018

Dr Julian Edbrooke-Childs
Research Department of Clinical, Educational and Health Psychology
UCL

Dear Dr Edbrooke-Childs

Notification of Ethics Approval
Project ID/Title: 12009/003: Power up for Parents: A pilot study, promoting parental involvement in shared decision making SDM through technology

I am pleased to confirm in my capacity as Joint Chair of the UCL Research Ethics Committee (REC) that the data collection element of your study has been approved by the UCL REC until **30th June 2019**.

Ethical approval is 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
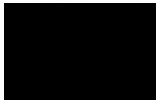
Dr Lynn Ang
Joint Chair, UCL Research Ethics Committee

Cc: Shaun Liverpool & Miranda Wolpert

Appendix J. Additional quotes from parents and health care professionals – Chapter 6

Categories, Themes and Subthemes	Parents	HCPs
Attitudes, beliefs and experiences		
Definition Key decision-makers	I think shared decision is obviously medical practitioners and experts, they will obviously look at a case, review it and then they will have their opinion of what should happen. But likewise, as a family member or a person involved, you've got an idea of what you feel would be best for you. And so, joint decision making to me is people listening, talking to one another, discussing the situation and then coming to an agreement as to what should happen going forward. (parent 206)	shared decision making makes me think about trying to combine the best decision, in terms of clinical outcomes, as well as the young person's wishes and the parents. So, we try to bring together the three dimensions and to come up with an idea or a solution. (Clinician 481) sharing the information that we as clinicians know, to the young people and their parents. Trying to help them make an informed decision. I guess it's working with

I think if I'm always making all the decisions, then I'm taking any power away from her, at 14, to make decisions herself. Then with what we've been through with her MH issues, she has to be, you know… I have to be sure that she's comfortable with what I'm doing. I don't want to isolate her and think that she's not able to make any decisions herself. (Parent 373)

two-way thing between me and my child, and, if I think that the decision she's making would not be the right decision, then explaining to her and saying why I think we need to look at it from a bigger angle (Parent 373)

them, giving advice where appropriate but then also listening to their views as well, both young person and the parent's views. (Clinician 193)

For example, after we have completed an assessment we might ask family what it is that they are wanting from, support from the service. We might then take that information and discuss that within our multidisciplinary meeting, come up with our own recommendations. (Clinician 482)

Her dad would be part of it as well. So, it would be the three of us (Parent 207)

Because I believe he's at an age now where he needs to start taking responsibility and it's his body, so I've got to make sure that he feels happy enough to make it. (Parent 067)

I think it's important because although J is growing into a young adult, she still needs guidance and support (Parent 065)

I think, obviously, Maggie's point of view is extremely important. From the child's point of view it's very, very important, but I

	wish CAMHS would listen to the parents because we are the carers 24/7. And I know sometimes we do have insight. (Parent 217)	
Positive experiences of SDM	Yeah it was a positive experience. We did not necessarily get the results I wanted but I felt like I was heard and taken into consideration. They didn't kind of just think of all that was important to them, they kinda saw what was important to me. Although some of it I had to stretch myself but I still felt that they took on my particular approach as much as they could. (Parent 1)	It just went really smoothly. I think it was down to the fact that we were all singing from the same hymn sheet and that the outcome was the desired one, that she was seen very quickly by our specialist eating disorders team. (Clinician 421)
Negative experiences	It's only ever really been in the private system that it's felt as if it's not adversarial. (Parent 3)	Often parents and young people have an idea of their expectations that they'll get more support than they had. It's really kind of difficult at that point to have a

	I'm struggling to think of it ever been said, "This is how we see it, what do you think would be a good way forward?" It's always been, "Well, yeah, that's great, but we haven't got the money to do it unless you pay for it yourself," kind of thing (UCL Parent 3)	collaborative decision because it's just, the resources aren't there really. (Clinician 193) I think parents like the idea of being involved and improves communication between them but sometimes it can be quite difficult especially if they have expectations that we can't meet or not appropriate. For example if the parents want medication and we don't feel it was immediately appropriate at that time and they should access talk therapy first then there is a bit of discomfort I guess. (Clinician 211) I think the other thing is, you know, because of the demographics, a lot of our parents are quite difficult to

		engage. They're not very proactive. We have to proactively engage them into coming to see us quite hard and I think that they're not going to go away, necessarily, and contact another service. (Clinician 212)
Emotions		
Positive emotions	So positive things are, it's quite nice not being involved in a way because having a child with anxiety and with other co-morbidities is really time consuming and very emotional. And to have people that you feel understand your child and can make good offers to them that you trust, is a great relief. (UCL Parent 3)	

Negative emotions	I felt quite isolated really. And sometimes not supported by the MH team, especially in crisis situations. (NHS Parent 217)	
	I thought the world had stopped. This came like a bolt out of the blue, and for the first two days I didn't know what had hit me. I was absolutely shell shocked. (NHS Parent 373)	
Mixed emotions	It always makes me feel quite anxious. Because I know that it makes my daughter then quite anxious and upset. She doesn't like talking about her problems. But it also makes me feel like I'm relieving something. (NHS Parent 207)	
Impact of emotions	I think where I was very much in doubt, you know, I was myself always and I had one	so if I can see if someone's quite upset or worried, I know that it's probably quite unlikely they're

professional who gave me too much information, too fast and I couldn't deal with it. I had a lot of professionals who gave me a smaller unit of information in a way that I could deal with it. I could take it in, understand, put it into application. The other professionals, she just gave me bunch and bunch of facts and places I can turn to. And in the end, my head was like a beehive and I didn't retain anything, anything at all. I'm sorry. (NHS Parent 372)

So the anger makes me feel more pushy I would say. It takes a while to process things when I feel like this so I have to talk to other people to hear what they think. The emotions cause me to have a delayed kinda reaction. So I

going to be taking in a lot of the information that I may give to them. So, I try and keep it as succinct as possible in those situations. And what I try to do is say, "We will talk about this again." To reassure them that this isn't the only time they're going to hear this information. (Clinician 498)

Anxious, worried, sometimes angry, depending on how long it's taken them to get into the service, I guess. Towards the end of an appointment, I guess, if I've been able to give them a few options and we've had a bit of shared decision making, then it does turn a bit more hopeful and promising. (Clinician 498)

	agree to something and then go away and then be like, no way I am actually not ok with this. So whatever they said, now I don't think it is actually the right thing for us. (UCL Parent 1)	if they've got heightened… Difficulties with heightened anxiety, it's difficult to make decisions anyway for themselves, never mind their child. So, yes, people, I guess, find it difficult to hear, to listen when they're extremely anxious, so again decision-making is difficult when you're not able to take on information to start with. (Clinician 181)
		I can imagine that shared decision making on this scale, when people are feeling quite frustrated and angry, they just, they think that they know better for their young person. They want to just get things done, I suppose, instead of thinking about what other things might be available or what other

		professional's opinions are (Clinician 192)
		But we do have a number of families where they see the problem purely within the young person and they don't actually want to interact very much with the solution. And they get frustrated when you're trying to involve them in the decision making process. I think they're the people we struggle with quite a lot because they will almost shut down, have their own perspective and they stop listening to, maybe, other possibilities and then they become insistent on a perspective. (Clinician 212)

		Yes I think sometimes some of the parents are can be understandably very emotionally involved and could impact on the decision making so for example desperation. This means they will push for medication or insist another intervention but when you speak to the YP they don't to engage so it's the parents kinda stepping up. (Clinician 211)
Support systems		
Families own support network	Just my wife. (NHS Parent 067) I mean, I have good friends that listen to me (NHS Parent 217)	
External agencies	I did obviously the Timeout for ADHD course and things. I got a little bit of support through that.	Well, I know that through our service, we do provide parents with an information leaflet for

| | Well, we've had a family support worker in the past, but she worked more with Aaron than us. (NHS Parent 067) | gaining access through internet and other services that are out there for self-referrals. (Clinician 189)

There are some educational groups that … that parents could go to (Clinician 190)

social services within social care that look at more social needs and look at some of the emotional needs within the family, We signpost to other kinds of charities and other services that can offer those kinds of support structures for parents, as well. (Clinician 181) |
|---|---|---|
| Online services | | |

Well, we've had a family support

worker in the past, but she

worked more with Aaron than

us. (NHS Parent 067)

gaining access through internet

| Internal | So, I may ring them. I have spoken to them a couple of times. (NHS Parent 207) | We will offer sessions to go through options with them. And that's about the limit of our resource, really. What I find, though, is, I mean, we give out a lot of leaflets and literature and really, it's rarely looked at. It's very rarely that someone will, you know, when they come back and we want to discuss it, often they haven't even looked at it. That's quite a common experience. But then you find that you have to go through it again in the session. (Clinician 212)

So, one of the major interventions we have is our family therapy because we have quite a lot of families that really just either repeat negative behaviours or are quite hostile to each other. (Clinician 212) |

		we'll have a multi-agency offer through Mindsight CAMHS and within that, not only is there outpatient provision, what myself and colleagues offer within CAMHS, but also we have online counselling that's available. (Clinician 242)
		It's a part of my everyday working life to have to respond to parents who come back to you for support and advice and for clarity. I'm actually looking at an email from a parent who has done just that, even though I'm technically no longer involved in the care of her young person, she comes back to me for clarity, for advice and support. (Clinician 421)

Appendix K. Conceptual framework of an affective appraisal approach to shared decision making - Chapter 6

Parents' emotional state

"I think if you're at that end of the scale where you are relieved and you're grateful and you know, willing to accept any help there is out there, the more willing they are to participate but if they've been left to the point where they are feeling frustrated and a little bit out of control and not knowing what's going on, I think that sort of clouds anything positive that then comes up" (Clinician, xxx)

Age and capacity of the child

"I think it's important because although J is growing into a young adult, she still needs guidance and support" (Parent, 065)

CYP

Attitudes, beliefs & experiences of SDM

"shared decision-making means some joined up thinking between clinicians, parents and young people if they're of an age where they can contribute" (Parent, xxx)

Parent

(Dis)advantages

"Difficulties with heightened anxiety, it's difficult to make decisions anyway for themselves, never mind their child." (Clinician, 181)

HCP

Support systems

"Local charity that we have in our area that supports children and their families with ADHD. So a lot of my emotional support and information gathering has come from them. I've done my own research online as well, but most of my support has come from the local charity." (Parent, xxx)

Appendix L. Public Engagement Funding Letter

Train and Engage result

Caffrey, Tadhg <t.caffrey@ucl.ac.uk>
Wed 11/07/2018 11:36
To: Liverpool, Shaun <shaun.liverpool.14@ucl.ac.uk>

Dear Shaun,

Thank you for your recent Train and Engage. I'm happy to tell you that the panel has decided to fund your project in full. Congratulations!

The panel felt that the project was well-articulated, and that it was a clear example of two-way engagement. The panel were impressed by the manner in which the groups will be brought together and the multi-stage engagement. The panel wondered about ethics, and what steps you have taken to ensure that the project is compliant with UCL ethics and data protection, so please do keep this in mind. Overall though, they were very impressed and are excited to see the project develop.

In terms of next steps, if you can let us know ASAP if you need to change the information of the finance contact that you indicated on your form that would be helpful. At the end of this week we will ask our finance lead to begin the process of transferring the funds with your named finance contact. Our aim is to make the money available to you by the beginning of this August, 2018.

Following this, we will be back in touch next week in relation to kicking off your project and how we hope to support you to make the project as successful as possible.

Well done again and we very much look forward to working with you,

Tadhg

Tadhg Caffrey
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Twitter: @UCL_Culture

This year, the UCL Public Engagement Unit celebrates its 10th anniversary. Find out more about how we're marking the occasion and let us know what you think.

Power Up for Parents: A mobile application to support parents and primary carers making child mental health decisions

1

This work has been produced in part fulfilment of a PhD research project and sponsored by the University College London.

This research project is supported by TEAM, an Innovative Training network, funded by European Union's Horizon 2020 research and innovation programme under the Marie Skłodowska-Curie grant agreement No. 722561.

This app was developed as a collaboration between researchers at the Anna Freud National Centre for Children and Families, University College London and Create Health.

For support or assistance needed while using this app please contact:

Shaun Liverpool

Shaun.liverpool@annafreud.org

+44 2031089888

POWER UP FOR PARENTS

The Power Up for Parents app is designed to help facilitate the shared decision-making process. This app can support you and your family when making complex decisions about your child's or young person's (YP) mental health care and treatment.

As the primary carer, this app can help you decide what is most important to you and your family and encourage you to be more involved in care and treatment decisions.

Let's begin by getting you signed in:

1. First, enter an email address (This address will be used to send details if for some reason you forget your password and need to retrieve your account)

Email

testing@testing.com

2. Then create a password (Ensure that it is memorable for you but difficult for others to decipher)

Password

••••••••

Now that you have signed in. Let's explore the main features of Power Up for Parents.

You can use the menu to customize your page.

Personalisation

Name   test

Theme   Dark

Save

Settings

New Password   New Password

Confirm Password   Confirm Password

Notifications   ☐ Enable notifications

Save

You can select any of the features for more guidance.

To return to this homepage at any time, you can click on the

POWER UP logo.

To exit the app select the icon.

DECISIONS

Let us think through a decision that you may be faced with.

Consider that your child's health care professional suggested that you should start thinking of using medication for your child's challenging behaviour.

Click on the [+ Add new] button.

Complete the details of the decision and select [Next].

For example, Should my child take medication for challenging behaviours?

New Decision

| Name | Should my child take medication for challenging behaviour? |

You may want to add some detail, so you remember why you are making this decision. You can enter this using the keypad or audio.

| Description | My child's Dr suggested that there are medicines for challenging behaviour. My child's teacher has reported challenging behaviours at school within the last month. |

Indicate how important this decision is for you and your family (slide the bar).

| How important is this decision? | ————————————————————— |

Think carefully about who else should be involved in this decision process? Using the [+], you can input the name and a photo (optional) of any others you choose to involve.

Add a new person ✕

| Name | Dr |
| Picture | Choose file   Browse |

You may consider your child's clinician for their expertise in mental health.

Depending on the age and capacity of your child you may want to include him or her as they are experts in their own lives.

It is recommended that you add a due date so you can receive reminders to complete or defer your decision as the date approaches.

Once you click [Next] you are ready to compare the options.

In the chosen example, what are the options?

Click [Add new solution] then [Solution #1] to enter the first option then [Submit]

You may want to check to ensure these are all the options available to you and your family. Your child's health care professional may be able to confirm this.

Over the next few days you may want to go into each of these solutions and add the benefits and risks of each. You can do your own research. Ask health care professionals or seek out other parents for advice.

Then, you can select which of the options you prefer, and also take the opportunity to ask the other persons you involved for their preferences or recommendations.

Making a decision can be quite challenging. So it good to monitor your emotions throughout the process. You may want to give some detail about how you feel.

Each time you get new information you may need to revisit and enter new information or update old ones.

Once you are ready to may a decision select [icon] from the [Add new] page. Your options are ranked in order, starting with the option with the highest number of pros to the top of the list.

However, this does not mean #1 may be the best option for you and your family at this time. For example, you may want to review which ones also had more preferences or the least number of cons.

Now you can select which option you are most comfortable with. To ensure you are happy with your decision, the app will check if you understand the decision you are making and how you feel about it.

- ☐ Do you know the benefits and risks of each option?
- ☐ Do you have enough support and information to make a decision?
- ☐ Do you feel ready to make a decision?
- ☐ Have you considered everyone's preferences?

GOALS

You may want to link a goal to your decision or set a goal for yourself, your child or your family to accomplish.

This goal can be linked to the decision on medications as this is one step you think may help you get closer to this goal. However, you can have general goals that are not necessarily linked to a decision.

You may want to use this feature to monitor any progress towards the overall goal. For example, you can set a goal to use the stress bucket feature 5x per day or once per week; whatever works for you.

SUPPORT

Sometimes difficult moments may come up. Imagine there's a bucket you carry with you which slowly fills up when you experience different types of stress. Now imagine you have a bucket and all these stresses fall into this bucket in the form of water.

You may want to add your stressors using the 🔴 ; and think of what helps you reduce stress here using the 🟢 icon.

Remember to rate your stressors to help you monitor your stress levels.
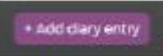
RESOURCES

There are some useful contact details in this section to access further support and guidance if needed.

Feel free to add any resources of your own that you may find helpful. You can also upload images and documents that help you understand your child's mental health problems better.

JOURNEY

This is where you come to have a look back at your journey throughout the decision-making process. You may want to share this with a trusted friend or someone who supports you during difficult times.

You can also use the [+ Add diary entry] to add more details of your feelings and any challenges you face surrounding your child's condition. Remember you are not alone on this journey and there may be some resources your child's health care professional can suggest.
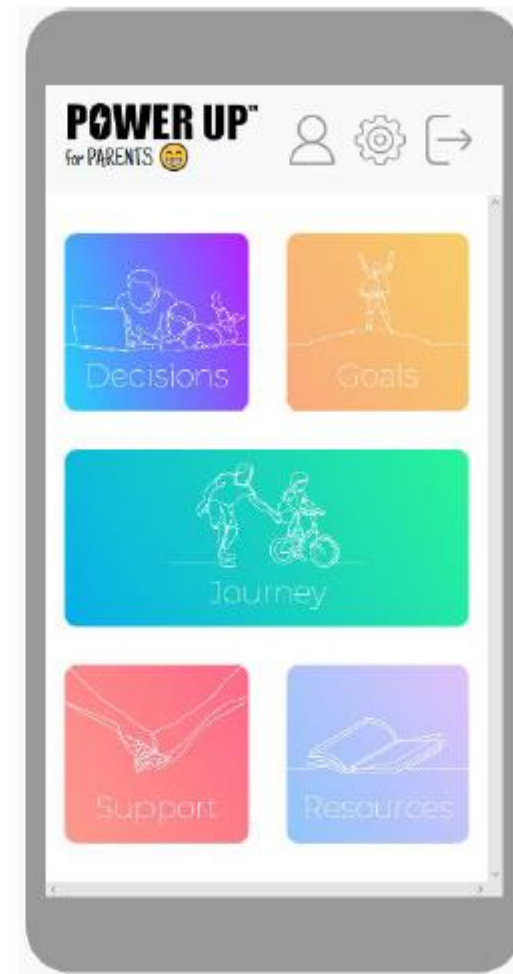
Appendix N.1. Stage 1 Topic Guide for Health Care Professionals

UCL

Power Up for Parents: Topic guide for parent interviews and focus groups

Introduction + Aims
- Power Up project – Phase 1 + 2 – timelines
- Description & purpose of the app
  - Support Parent to be involved in SDM in CAMHS
  - Space for you to record what's going on for them, and their experience of supporting their children through therapy in their own words (input into the app cannot be digitally shared)
  - Video, audio, text, photo
  - Step by step plans, diary entries, questions, decision tool
  - Keep record of sessions and flag things to talk about in session
  - My library
  - Used in sessions and between sessions
- Aims of today
  - Some feedback from you on the design and usability of a current app
  - Identifying areas where decisions are made throughout CAMHS journey (i.e. when this tool may be useful)
  - Some feedback on how the app could aid in decision making and discuss support needed to make decisions.
  - Identify feelings involved during the decision-making process.
  - How these emotions affect parents' interest in being involved in SDM.
  - Some thoughts on how best to integrate the app into therapy.
  - Where do parents turn for decision support?

Shared Decision Making
Give a brief explanation of what shared decision making is. Give an example of what this would mean in CAMHS.
- Do you think this happens in the CAMHS you work in?
- When making decisions about the support young people get in CAMHS, who do you think should be involved?
- Can you give an example of where you have used shared decision making?
  - How did you/ the young person find this experience?
  - What was good/ bad about this experience?

Decision Making
- What sort of decisions you are asked to make about/with your child and when?
  - Medication?
  - Interventions?
  - Goals?

  - Should we go to therapy?
- Where do parents access support to make these decisions?
- How do you go about making these decisions?
- Why is it important for parents to be part of the process?

Emotions
- How do you think parents feel about/when making these decisions?
  - Anxious?
  - Fearful?
  - Stressed?
- Do these emotions affect interest in decision making activities?
  - To be more involved?
  - To be less involved?
- Does it affect how they make decisions?
  - Who can they turn to for help?
  - How quickly they process information?

Tools (Using a decision example + emotion)
Open up the Power Up app and have a look. Read some of the descriptions of the tools as you open them and start having a play.
- Talk me through your thoughts as you are looking at the app
  - What do you like/ not like about what Power Up does and how it looks?

- How do you think using Power Up might help empower parents in discussions about their child's health and care?
- Can you give me some examples of times you might want to introduce Power Up to a parent you are working with?
- Can you give me some examples of situations where you would not want to introduce Power Up to a parent you are working with?
  -

Use of Power Up
- How might you need to adapt your clinical work to support young people's use of Power Up?
- Who/ what would you need to help you to adapt your clinical work to support young people's use of Power Up?
- Does anything worry you about young people in CAMHS using Power Up?
- How could Power Up be made better/ more useful for the young people you work with?

Appendix N.2. Stage 1 Topic Guide for Parents/Carers

UCL

Power Up for Parents: Topic guide for parent interviews and focus groups

Introduction + Aims
- Power Up project – Phase 1 + 2 – timelines
- Description & purpose of the app
  - Support Parent to be involved in SDM in CAMHS
  - Space for you to record what's going on for them, and their experience of supporting their children through therapy in their own words (input into the app cannot be digitally shared)
  - Video, audio, text, photo
  - Step by step plans, diary entries, questions, decision tool
  - Keep record of sessions and flag things to talk about in session
  - My library
  - Used in sessions and between sessions
- Aims of today
  - Some feedback from you on the design and usability of a current app
  - Identifying areas where decisions are made throughout CAMHS journey (i.e. when this tool may be useful)
  - Some feedback on how the app could aid in decision making and discuss support needed to make decisions.
  - Identify feelings involved during the decision-making process.
  - How these emotions affect your interest in being involved in SDM.
  - Some thoughts on how best to integrate the app into your child's therapy.
  - Where do you turn to for decision support?

Shared Decision Making
- What does 'Shared Decision Making' mean to you?
- When decisions about your child is being made in CAMHS, who do you think should be involved?
- Can you give me an example of a time when shared decision making has happened in your CAMHS sessions?
  - How did you find this experience?
  - What was good/ bad about this experience?

Decision Making
- What sort of decisions you are asked to make about/with your child and when?
  - Medication?
  - Interventions?
  - Goals?
  - Should we go to therapy?
- Where do you access support to make these decisions?
- How do you go about making these decisions?
- Why is being part of the process important to you?

Emotions
- How do you feel about/when making these decisions?
  - Anxious?
  - Fearful?
  - Stressed?
- Do these emotions affect interest in decision making activities?
  - To be more involved?

- To be less involved?
- Does it affect how you make decisions?
  - Who you turn to for help?
  - How quickly you process information?

Tools (Using a decision example + emotion)
- Open up the Power Up app and have a look. Read some of the descriptions of the tools as you open them and start having a play. Add some entries as if you were a user of this app.
- Talk me through your thoughts as you are looking at [Insert Tool name]
  - What do you like/ not like about what Power Up does and how it looks?
  - Is it clear what the tool is for?
  - Is the tool easy to use?
- What would you add or improve?
- Any additional support is needed via the app?
  - Emotional support?
  - Prompts?

Use of Power Up
- How could Power Up have an impact on you and your experience of CAMHS?
- Which tools on the app do you think you would use the most/ least?
- How might Power Up be useful/ not useful to you?
- Can you give me an example of a time you might want to use Power Up? (can be chosen from previous examples)
- If someone had given you 'Power up' when you started attending [Insert name of service], would you have found it useful? Why?
- Who/ what would you need to help you to use Power Up?
- Does anything worry you about using Power Up?
- How could Power Up be made better/ more useful for you?
  - Would using the app add or take away any -ve or +ve feelings you describe earlier?
- Can you give me an example of a time when shared decision making has not happened in your child's CAMHS sessions?
  - How did you find this experience?
  - What was good/ bad about this experience?
- What is your preferred medium for using this intervention?
  - Laptop, phone etc etc.

Appendix M. Stage 2 Questionnaire Package for Parents/Carers

LONDON'S GLOBAL UNIVERSITY

≜UCL

POWER UP

Participant number:

Date:

Parent/Caregiver Pre-Test Questionnaire

Thank you for agreeing to participate in this research. Please try to answer as many questions as possible in this questionnaire.

Please feel free to circle, highlight, or write comments next to any questions which you find difficult to understand.

Remember to review the Participant Information Sheets and Consent Forms before taking part in this study.

You can complete the list of questionnaires in this booklet and return to the research team or copy and paste the link provided below to complete an online version.

https://research.sc/participant/login/dynamic/59BCF0DC-1FAC-4498-B576-2C69520F6130

About you

1. What is your relationship to the child (e.g. mother)?

2. How old are you?

3. What is your gender?

- [ ] Male
- [ ] Female
- [ ] Prefer not to disclose
- [ ] Other (please specify, if you would like to)

4. What is your ethnicity?

- [ ] White or White British
- [ ] Black or Black British
- [ ] Asian or Asian British
- [ ] Mixed
- [ ] Other (please specify, if you would like to)

5. Is English your first language?

- [ ] Yes
- [ ] No
- [ ] Prefer not to say

VALIDATED QUESTIONNAIRE [STAGE 2: PROPOSED MEASURES]
IRAS PROJECT ID: 236277
VERSION 1.0 (04/05/2018)

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About your child

6. How old is your child?

7. What is their gender?

- [ ] Male
- [ ] Female
- [ ] Prefer not to disclose
- [ ] Other (please specify, if you would like to)

8. What is their ethnicity?

- [ ] White or White British
- [ ] Black or Black British
- [ ] Asian or Asian British
- [ ] Mixed
- [ ] Other (please specify, if you would like to)

9. Is your child receiving support for their wellbeing?

- [ ] Yes
- [ ] No
- [ ] Prefer not to say

10. Have you or your child used any other digital mental health tools? E.g. apps or websites

- [ ] Yes
- [ ] No
- [ ] Prefer not to say

11. Are you or your child involved in any other mental health projects?

- [ ] Yes
- [ ] No
- [ ] Don't know
- [ ] If yes, please give details

SELF-EVALUATION QUESTIONNAIREs TAI Form Y-1

A number of statements which people have used to describe themselves are given below. Read each statement and then select the appropriate response to indicate how you **feel right now**, that is, at this moment. There are no right or wrong answers. Do not spend too much time on anyone statement but give the answer which seems to describe your **present feelings** best.

	Not at all	Somewhat	Moderately so	Very much so
1. I feel calm	1	2	3	4
2. I feel secure	1	2	3	4
3. I am tense	1	2	3	4
4. I feel strained	1	2	3	4
5. I feel at ease	1	2	3	4
6. I feel upset	1	2	3	4
7. I am presently worrying over possible misfortunes	1	2	3	4
8. I feel satisfied	1	2	3	4
9. I feel frightened	1	2	3	4
10. I feel comfortable	1	2	3	4
11. I feel self-confident	1	2	3	4
12. I feel nervous	1	2	3	4
13. I am jittery	1	2	3	4
14. I feel indecisive	1	2	3	4
15. I am relaxed	1	2	3	4

16. I feel content   . 1   2   3   4

17. I am worried   .. 1   2   3   4

18. I feel confused   . 1   2   3   4

19. I feel steady   .. 1   2   3   4

20. I feel pleasant   .. 1   2   3   4

STAI Form Y-2

A number of statements which people have used to describe themselves are given below. Read each statement and then circle the appropriate number to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on anyone statement but give the answer which seems to describe how you generally feel.

	Almost never	Sometimes	Often	Almost Always
21. I feel pleasant.	. 1	2	3	4
22. I feel nervous and restless	. 1	2	3	4
23. I feel satisfied with myself	. 1	2	3	4
24. I wish I could be as happy as others seem to be	. 1	2	3	4
25. I feel like a failure	. 1	2	3	4
26. I feel rested	. 1	2	3	4
27. I am "calm, cool, and collected"	. 1	2	3	4
28. I feel that difficulties are piling up so that I cannot overcome them	. 1	2	3	4
29. I worry too much over something that really doesn't matter	. 1	2	3	4
30. I am happy	. 1	2	3	4
31. I have disturbing thoughts	. 1	2	3	4
32. I lack self-confidence	. 1	2	3	4
33. I feel secure	. 1	2	3	4
34. I make decisions easily	. 1	2	3	4
35. I feel inadequate	. 1	2	3	4
36. I am content	.. 1	2	3	4
37. Some unimportant thought runs through my mind and bothers me	.. 1	2	3	4
38. I take disappointments so keenly that I can't put them out of my mind	.. 1	2	3	4

39. I am a steady person   .. 1 2 3 4

40. I get in a state of tension or turmoil as I think over my recent concerns and interests   . 1 2 3 4

The Control Preferences Scale for Paediatrics (CSP-P)

The role you play in the treatment option for your child is important.

Please choose **one** of the following statements that best describes how you like decisions to be made:

☐ I prefer to leave all decisions about my child's mental health care and treatment to my child's practitioner.

☐ I prefer that my child's practitioner makes the final decision about my child's mental health care and treatment, but after seriously considering my views and opinions.

☐ I prefer that my child's practitioner and I share responsibility for the decisions made about my child's mental health care and treatment.

☐ I prefer to make the final decisions about my child's mental health care and treatment after seriously considering the practitioners views and opinions.

☐ I prefer to make the final decision about my child's mental health care and treatment.

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Shared Decision Making Questionnaire - PARENT (PSDM-Q-PARENT)

In responding to the statements below, please think about a situation where you spoke with your child's mental health practitioner in making a care decision about your child's care. One example could be a discussion about treatment intervention options.

Nine statements related to the decision-making process are listed below. For each statement please indicate how much you agree or disagree.

1. My child's mental health practitioner made it clear that a mental health care decision needs to be made.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

2. My child's mental health practitioner wanted to know how I want to be involved in making the mental health care or treatment decision.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

3. My child's practitioner told me that there are different options for caring for my child.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

4. My child's practitioner explained the advantages and disadvantages of the different options for my child.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

5. My child's practitioner helped me understand all the information.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

6. My child's practitioner asked me which option I preferred.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

7. My child's practitioner and I went over the different options.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

8. My child's practitioner and I selected a care or treatment option together.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

9. My child's practitioner and I reached an agreement on how to proceed.

completely disagree	strongly disagree	somewhat disagree	somewhat agree	strongly agree	completely agree
☐	☐	☐	☐	☐	☐

Is there anything else that you would like to share about making decisions with your child's mental health practitioner about your child's care?

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[                                                           ]
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Traditional Decisional Conflict Scale (DCS)

Think about a mental health care decision to be made for your child.

While considering the option you prefer, please answer the following questions:

	Strongly Agree	Agree	Neither Agree Nor Disagree	Disagree	Strongly Disagree
1. I know which options are available to me.					
2. I know the benefits of each option.					
3. I know the risks and side effects of each option.					
4. I am clear about which benefits matter most to me.					
5. I am clear about which risks and side effects matter most to me.					
6. I am clear about which is more important to me (the benefits or the risks and side effects).					
7. I have enough support from others to make a choice.					
8. I am choosing without pressure from others.					
9. I have enough advice to make a choice.					
10. I am clear about the best choice for me.					
11. I feel sure about what to choose.					
12. This decision is easy for me to make.					
13. I feel I have made an informed choice.					
14. My decision shows what is important to me.					
15. I expect to stick with my decision.					
16. I am satisfied with my decision.					

EXPERIENCE OF SERVICE QUESTIONNAIRE

Please think about the appointments you, your child and/or your family have had at this service or clinic.

For each item, please tick the box that best describes what **you** think or feel about the service.

	Certainly True	Partly True	Not True	Don't Know
I feel that the people who have seen my child listened to me	❏	❏	❏	
It was easy to talk to the people who have seen my child	❏	❏	❏	
I was treated well by the people who have seen my child	❏	❏	❏	
My views and worries were taken seriously	❏	❏	❏	
I feel the people here know how to help with the problem I came for	❏	❏	❏	
I have been given enough explanation about the help available here	❏	❏	❏	
I feel that the people who have seen my child are working together to help with the problem(s)	❏	❏	❏	
The facilities here are comfortable (e.g. waiting area)	❏	❏	❏	
The appointments are usually at a convenient time (e.g. don't interfere with work, school)	❏	❏	❏	
It is quite easy to get to the place where the appointments are	❏	❏	❏	
If a friend needed similar help, I would recommend that he or she come here	❏	❏	❏	
Overall, the help I have received here is good	❏	❏	❏	

PLEASE TURN OVER...

What was really good about your care?

_____
_____
_____
_____
_____

Was there anything you didn't like or anything that needs improving?

_____
_____
_____
_____
_____
_____

Is there anything else you want to tell us about the service you received?

_____
_____
_____
_____
_____

Thank you for completing these questionnaires.

You can now proceed to use the intervention Power Up for Parents by clicking on the link or copy and paste the link below into a new tab.

https://pufp.createdev.co.uk/sign-up?code=1

The research team would like you to use Power Up for Parents as much as possible in the coming weeks and we will contact you at a later date to complete some similar questions and a few additional ones to hear about your experience of using this app.

You can contact us if you require any further assistance to get started with using this app.

Mr Shaun Liverpool
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Appendix O. Stage 2 Health care professional observed control preference scale

LONDON'S GLOBAL UNIVERSITY

Site Name: Participant Number:

The Control Preferences Scale for Paediatrics (CSP-P)

The role the parent/caregiver play in the care/treatment options for the child is important.

Please choose **one** of the following statements that best describe how the parent/caregiver is involved in mental health care and treatment decisions for their child:

1. The parent/caregiver leaves all mental health care and treatment decisions about the child to the practitioner.

2. The parent/caregiver leaves the final decision about the child mental health care and treatment to the practitioner, but only after the practitioner considered the parent/caregiver's views and opinions.

3. The parent/caregiver shares responsibility for the mental health care and treatment decisions of the child with the practitioner.

4. The parent/caregiver makes the final decision about the child's mental health care and treatment after seriously considering the practitioners' views and opinions.

5. The parent/caregiver makes the final mental health care and treatment decisions about the child.

Appendix P. Stage 2 Post Study Usability Questionnaire

Post-Study Usability Questionnaire Items

1. Overall, I am satisfied with how easy it is to use this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

2. It was simple to use this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

3. I could effectively complete the tasks and scenarios using this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

4. I was able to complete the tasks and scenarios quickly using this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

5. I was able to efficiently complete the tasks and scenarios using this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

6. I felt comfortable using this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

7. It was easy to learn to use this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

8. I believe I could become productive quickly using this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

9. The app gave error messages that clearly told me how to fix problems

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

10. Whenever I made a mistake using the app, I could recover easily and quickly

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

11. The information (such as on-line help, on-screen messages, and other documentation) provided with this app was clear

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

12. It was easy to find the information I needed

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

13. The information provided for the app was easy to understand

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

14. The information was effective in helping me complete the tasks and scenarios

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

15. The organization of information on the app screens was clear

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

16. The interface of this app was pleasant

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○

17. I liked using the interface of this app

Strongly Disagree 1	2	3	4	Strongly Agree 5
○	○	○	○	○