TELEPHONE SUPPORT FOR SYMPTOM MANAGEMENT AND SUPPORTIVE CARE IN HAEMATO-ONCOLOGY PATIENTS

A thesis submitted to The University of Manchester for the degree of Doctor of Philosophy in the Faculty of Biology, Medicine and Health

2018

SARAH J. LIPTROTT

SCHOOL OF HEALTH SCIENCES

Division of Nursing, Midwifery and Social Work

CONTENTS

Abstract…… 14
Declaration and copyright…… 16
Acknowledgements…… 17
About the author…… 18
Chapter 1: Introduction…… 19
1.1 Aim of the PhD study…….. 20
1.2 Objectives of the study…… 20
1.2.1 Phase 1 of the PhD study – identifying the evidence base 20
1.2.2 Phase 2 of the PhD study – modelling process..…….. 21
1.3 Structural organisation of the thesis……..…….. 22
Chapter 2: Background…… 24
2.1 Haematological malignancies…….. 24
2.2 Epidemiology……... 26
2.3 The shifting context of cancer treatment…… 27
2.4 The needs of patients with haematological malignancies…… 28
2.5 Supportive care…… 29
2.5.1 Interventions to address patients needs…… 30
2.5.2 Patients preferences for support and remote working……. 30
2.5.3 Telephone as a medium for support provision…… 31
2.5.4 Patients perceptions of support via telephone……. 33
2.6 Providing care in the local context – Italy……. 34
2.7 Summary…… 36
Chapter 3: Methodology…….. 37
3.1 Section one: The MRC framework and development of the research strategy……. 38
3.2 Section two: Identification of the evidence base – reviewing existing literature…… 40
3.2.1 Narrative reviews…… 40
3.2.2 Meta analysis…….. 40
3.2.3 Best evidence synthesis…….. 40
3.2.4 Systematic reviews…….. 41
3.2.5 Meta synthesis……. 43
3.2.6 Mixed methods synthesis……. 43

3.2.7 Realist review…… 44
3.2.8 Quality appraisal of studies within a systematic review…… 44
3.2.8.1 Quality appraisal of quantitative studies…… 44
3.2.8.2 Quality appraisal of qualitative studies…….. 44
3.2.8.3 Quality appraisal of mixed methods studies…….. 45
3.2.9 Rationale for the approach within the PhD study……. 45
3.3 Section three: Philosophical perspectives and methodological approaches…….. 45
3.3.1 Philosophical positions…… 46
3.3.2 Research methodology…….. 47
3.3.3 Research methods……. 47
3.3.3.1 Quantitative approaches……. 47
3.3.3.2 Qualitative approaches……... 48
3.3.3.3 Mixed methods……... 49
3.3.3.4 Rationale for the approach used in the study…….. 49
3.3.4 Theoretical approaches in qualitative research……. 50
3.3.4.1 Theory driven qualitative research……. 50
3.3.4.2 Applied qualitative research……... 51
3.3.4.3 Rationale for the approach for Studies 1 and 2…... 53
3.3.5 Research procedures…….. 54
3.3.5.1 Sampling……. 54
3.3.5.2 Recruitment……. 56
3.3.5.3 Data collection methods…….. 57
3.3.5.4 Qualitative data analysis in studies 1 and 2……. 60
3.3.6 Rigour in qualitative research…….. 62
3.3.7 Research ethics…….. 64
3.4 Section four: Intervention modelling……... 65
Chapter 4: Systematic literature review of studies on acceptability of telephone support as perceived by patients with cancer…….. 67
4.1 Section one: Working methods…… 67
4.1.1 Background…… 67
4.1.2 Rationale for the systematic review……... 68
4.1.3 Aims & objectives of the study…….. 68
4.1.4 Methods…….. 68

4.1.4.1 Inclusion and Exclusion criteria…….. 69
4.1.5 Search Strategy…….. 71
4.1.6 Study selection……... 73
4.1.7 Data extraction……... 73
4.1.8 Quality appraisal of studies within the systematic review…. 73
4.1.9 Data analysis…….. 74
4.1.10 Data synthesis…….. 75
4.1.11 Ensuring rigour in the systematic literature review……. 75
4.2 Section two: Results……. 76
4.2.1 Study Characteristics……. 78
4.2.2 Quality appraisal…… 78
4.2.3 Sample sizes……... 79
4.2.4 Participant characteristics…….. 80
4.2.5 Intervention characteristics…… 80
4.2.6 Acceptability outcome data…… 81
4.2.6.1 Consistent findings across intervention categories.. 82
4.2.6.2 Treatment side-effect/ toxicity monitoring……. 83
4.2.6.3 Psycho-educational interventions……... 84
4.2.6.4 Telephone follow-up interventions……. 85
4.3 Section three: Discussion……. 85
4.3.1 Summary of findings……. 85
4.3.2 Strengths and limitations……... 88
4.3.3 Conclusions…… 89
Chapter 5: Study 1 - Exploration of the needs of haemato-oncology patients and experiences of a telephone intervention for support and symptom management……. 90
5.1 Section One: Working Methods…….. 90
5.1.1 Background to the study……... 90
5.1.2 Aims of the study……. 91
5.1.3 Study design……. 91
5.1.4 Ethical approval…… 91
5.1.5 Sample…….. 92
5.1.5.1 Inclusion and exclusion criteria……. 93
5.1.6 Recruitment procedures…… 94

5.1.7 Data collection…….. 94
5.1.8 Data analysis……. 96
5.1.9 Ensuring rigour within the study…….. 97
5.2 Section Two: Results……... 99
5.2.1 Patients and demographic data……. 99
5.2.2 Themes from the interviews with patients…… 100
5.2.2.1 Theme 1: Personal emotional distress and coping strategies……. 102
5.2.2.1.1 Experiences of personal emotional distress……. 102
5.2.2.1.2 Adaptive coping strategies……... 105
5.2.2.1.3 Maladaptive coping strategies and their contributors…….. 108
5.2.2.2 Theme 2: Unmet needs of patients…….. 110
5.2.2.2.1 Unmet psychological and emotional needs…… 110
5.2.2.2.2 Lack of continuity of care after treatment……. 112
5.2.2.2.3 Unmet information needs……. 114
5.2.2.3 Theme 3: Meeting patients' needs via the telephone intervention……. 117
5.2.2.3.1 An intervention addressing patients needs…… 117
5.2.3.3.2 Acceptability of telephone method for the intervention……. 119
5.2.2.3.3 Refining the intervention……. 120
5.3 Section Three: Discussion…… 123
5.3.1 Summary of findings……. 123
5.3.2 Strengths and limitations……... 129
5.3.3 Reflection on interviews…… 130
5.3.4 Conclusion……. 131
Chapter 6: Study 2 - Investigation of expert nurses perceptions of the needs of haemato-oncology patients and the use of telephone interventions to address needs……. 132

6.1 Section One: Working Methods…….. 132
6.1.1 Background to the study……... 132
6.1.2 Aims of the study ……. 132
6.1.3 Study design…….. 133
6.1.4 Ethical approval…… 133
6.1.5 Sample……... 133
6.1.5.1 Inclusion and exclusion criteria……... 134
6.1.6 Recruitment procedures……. 134
6.1.7 Data collection…… 134
6.1.8 Data analysis…….. 136
6.1.9 Ensuring rigour within the study…… 136
6.2 Section Two: Results…… 138
6.2.1 Study participants (expert nurses) and demographic data…. 138
6.2.2 Themes from the qualitative study with expert nurses…….. 139
6.2.2.1 Theme 1: Variability of needs across the cancer trajectory…… 140
6.2.2.1.1 Factors influencing needs…… 140
6.2.2.1.2 Tailored information needs……. 143
6.2.2.1.3 Continuity of care…… 146
6.2.2.2 Theme 2: Applicability of support via telephone... 148
6.2.2.2.1 Meeting patients and service needs…….. 148
6.2.2.2.2 Limitations to the application of telephone support…… 152
6.2.2.3 Theme 3: Maximising the quality of telephone interventions…… 154
6.2.2.3.1 Shaping the intervention to meet the need…… 154
6.2.2.3.2 Caller characteristics and professional training…… 156
6.2.2.3.3 Organisational support……. 158
6.3 Section Three: Discussion…… 158
6.3.1. Summary of findings…… 159
6.3.2 Strengths and limitations……... 163
6.3.3 Conclusion……. 164

Chapter 7: Reaching Consensus……. 166
7.1 Section One: Working Methods…….. 166
7.1.1 Background to the consensus group meeting…… 166
7.1.2 Aims of the consensus group meeting…….. 167
7.1.3 Consensus Process…… 168
7.1.3.1 Defining the task…… 168
7.1.3.2 Participant selection and invitation…… 169
7.1.3.3 Information provision……. 170
7.1.3.4 Consensus approach…… 171
7.1.3.5 Output……. 171
7.1.4 Ensuring rigour…….. 172
7.2 Section Two: Results…… 173
7.2.1 Consensus group meeting participants and demographic data…… 173
7.2.2 Recommendations from the consensus group meeting……. 173
7.2.2.1 The appropriateness of a telephone intervention to meet patients needs……. 175
7.2.2.2 Formulating a description of the intervention……. 175
7.2.2.3 Methods for intervention evaluation……... 178
7.3 Section Three: Discussion…… 178
7.3.1. Summary of findings…… 178
7.3.2 Strengths and limitations……... 180
7.3.3 Conclusion……. 180
Chapter 8: Discussion…….. 182
8.1 Section one: Identifying the evidence base…….. 182
8.3 Section two: Reaching consensus……. 183
8.3 Section three: Strengths and limitations of the thesis……... 184
8.3.1 Strengths…… 184
8.3.2 Limitations……. 185
8.4 Section four: PhD study in context and recommendations…….. 187
8.4.1 The PhD study and the current literature…… 187
8.4.2 Recommendations for practice……... 190
8.4.3 Recommendations for future research…… 191
8.5 Conclusion……. 192

9 References……194

List of appendices

Chapter 4

Appendix 1 Published article……. 227

Appendix 2 Protocol for Systematic Review of the Literature (Version 9 – 16th Oct 2014)……. 255

Appendix 3 Systematic review search strategy……. 260

Appendix 4 Data extraction form for the systematic review of the literature… 265

Appendix 5 Rationale for exclusion of papers……... 270

Appendix 6 Systematic review - Patient and Study Characteristics (Liptrott *et al.*, 2017)…….. 271

Appendix 7 Systematic Review Overall Study Quality (Liptrott *et al.*, 2017)... 282

Appendix 8 Systematic review - Acceptability / Satisfaction Data Quality (Liptrott *et al.*, 2017)……. 285

Appendix 9 Systematic review - summary of outcomes (Liptrott *et al.*, 2017)……. 288

Chapter 5

Appendix 10 Study 1: Ethical approval from the European Institute of Oncology, November 2014……. 289

Appendix 11 Study 1: Ethical approval from the European Institute of Oncology, June 2015…….. 291

Appendix 12 Study 1: Ethical approval from the University of Manchester Committees on the Ethics of Research on Human Beings, July 2015…… 293

Appendix 13 Study 1: Ethical approval from the European Institute of Oncology, June 2015…….. 295

Appendix 14 Study 1: Ethical approval from the University of Manchester Committees on the Ethics of Research on Human Beings, January 2016…… 297

Appendix 15 Study 1: Patient Information Sheet and Consent Form – Italian… 299

Appendix 16 Study 1: Patient Information Sheet and Consent Form – English…308

Appendix 17 Study 1: Data collection sheet…… 316

Appendix 18a Study 1: Interview Topic Guide……. 318

Appendix 18b Study 1: Adapted Interview Topic Guide – additional areas of interest…….. 318

Appendix 19 Study 1: Distress Protocol…….. 319
Appendix 20 Study 1: Sample of quotes - Thematic chart for Theme 1.0: Personal emotional distress and coping strategies……. 320

Chapter 6

Appendix 21 Study 2: Ethical approval from the University of Manchester Committees on the Ethics of Research on Human Beings, March 2016……. 333
Appendix 22 Study 2: Participant Information Sheet and Consent Form…… 334
Appendix 23 Study 2: Focus Group Topic Guide…… 339
Appendix 24 Study 2: Distress Protocol…….. 340
Appendix 25 Study 2: Quotes - Thematic charts for theme 2.0 Applicability of telephone support…… 341

Chapter 7

Appendix 26 Needs of haemato-oncology patients – a summary of evidence…. 351
Appendix 27 Acceptability of a telephone intervention – a summary of evidence…….. 352
Appendix 28 Nature and content of a telephone intervention – a summary of evidence……. 353
Appendix 29 Questions for the Consensus Meeting…… 354

List of tables

Chapter 3

Table 1	Six criteria to a methodologically sound systematic literature review (adapted from Vickers, 1995, p. 93-94)……	42
Table 2	Purposeful Sampling Strategies (adapted from Patton, 2001, p. 243-244)……	55

Chapter 4

Table 3	Systematic review study inclusion / exclusion criteria…….	70
Table 4	Databases searched for the systematic review……..	72

Chapter 5

Table 5	Study 1: Sampling matrix……..	93
Table 6	Study 1: Patient demographics……..	100
Table 7	Study 1: Conceptual framework outlining the main themes and subthemes from the qualitative study with patients……..	101

Chapter 6

Table 8	Study 2: Participant demographics……	138
Table 9	Study 2: Conceptual framework outlining the main themes and subthemes from the qualitative study with expert nurses……..	139

Chapter 7

Table 10	Consensus group meeting: Participant demographics……...	173
Table 11	Findings from the consensus group meeting TELECARE intervention core components……	174
Table 12	The TELECARE intervention……	179

List of figures

Chapter 1

Figure 1 Study development process…… 22

Chapter 2

Figure 2 Overlap of concepts defining patients' perceptions…… 33

Figure 3 5-year age-standardised net survival rate for survival (%) by geographical area and gender, 2005-2009 - Haematological malignancies (AIRTUM, 2017)…….. 35

Chapter 3

Figure 4 Key elements of the MRC complex intervention development and evaluation process (Craig *et al.,* 2013)……. 39

Figure 5 Applications for Thematic Analysis (Boyatzis, 1998, p. 4-5)……. 52

Figure 6 Key Features of 'Framework' (Ritchie and Spencer, 1994, p. 176)…….. 53

Chapter 4

Figure 7 Systematic review study selection process (Liptrott *et al.*, 2017)…77

Chapter 5

Figure 8 Study 1: Example excerpt from the thematic analysis coding tree – Sub Theme 2.2: Lack of continuity of care after treatment……. 102

Chapter 6

Figure 9 Study 2: Example excerpt from the thematic analysis coding tree – Sub Theme 1.1: Factors influencing needs…….. 140

Chapter 7

Figure 10 Research undertaken in Phase 1 of the PhD and synthesis……. 167

List of abbreviations

ALL	Acute Lymphoblastic Leukaemia
AML	Acute Myeloid Leukaemia
CASP	Critical Appraisal Skills Programme
CLL	Chronic Lymphocytic Leukaemia
CML	Chronic Myeloid Leukaemia
CNS	Clinical Nurse Specialist
CONSORT	CONsolidated Standards of Reporting Trials
CT scan	Computerised Tomography
EIO	European Institute of Oncology
EBMTNGRC	European Blood and Marrow Transplantation Society Nurses Group Research Committee
FU	Follow-up
GP	General Practitioner
HL	Hodgkin lymphoma
HNHCP	Haematology Nurses and Healthcare Professionals Group
IEO	Istituto Europeo di Oncologia
LTSE's	Long-term side effects
MDT	Multidisciplinary Team
MM	Multiple Myeloma
MRC	Medical Research Council
NHL	Non-Hodgkin lymphoma
NICE	National Institute for Clinical Excellence
PDT	Photodynamic therapy
PET	Positron Emission Tomography (Scan)
pt	Patient
RE_AIM	Reach Effectiveness Adoption Implementation Maintenance
RAND	Research AND Development
RCT's	Randomised Controlled Trials
SCT	Stem Cell Transplantation
SLL	Small Lymphocytic Lymphoma
TKI's	Tyrosine Kinase Inhibitors
UPN	Unique Patient/ Participant Number

Abstract

Background: The incidence of haematological cancers is increasing, however developments in treatment and survival rates mean that longer-term prognosis is improving. Nonetheless, the impact of cancer and its treatments remains with both short-term and long-term effects for patients and carers, which often results in persisting unmet supportive care needs. In addition, the shift of care delivery from inpatient to ambulatory setting and earlier hospital discharge, emphasises the need for services to support patients ability to self-manage. The healthcare team in an Italian Comprehensive Cancer Centre hospital implemented an ad hoc symptom management and supportive care telephone intervention based patients expressed feelings of abandonment after discharge. The intervention was unsustainable due to personnel resources and lacked a rigorous evaluation of patient acceptability. The aim of the PhD study was to develop a telephone intervention providing support and symptom management that is acceptable to patients undergoing or having undergone treatment for a haematological malignancy, based on the best available evidence.

Methods: The MRC Framework was used as the basis for the development of the intervention. The evidence base to inform development was drawn from 3 sources. Firstly a systematic review of existing literature, and secondly qualitative research with key stakeholders: in-depth interviews with 20 patients with haematological malignancies and focus group(s) with a total of 10 expert haematology nurses. Framework Analysis was used to analyse data from the qualitative research. A synthesis of these findings was presented to a consensus group of key stakeholders within the local hospital setting in the subsequent modelling phase of the intervention development.

Results: The application of telephone-based interventions to address cancer patients needs was evident throughout the literature within a variety of settings. Whilst it is said to be convenient, provide accessible and timely reassurance and continuity of care, it was not necessary or desirable for everyone. Stakeholders in qualitative research confirmed these findings, emphasising the need for individuality in interventions to adequately address the uniqueness of needs at different time points in the cancer trajectory. Factors including effective training for the intervention delivery,

organisational support and integration into current practice were imperative for the sustainability of an intervention. The consensus group meeting agreed the definition and outline of an intervention delivered by the Primary Nurse, to monitor patients for physical, social or psychological needs and provide support through individualised care planning that can be trialled in practice.

Conclusion: Unmet needs persist in patients with haematological malignancies throughout their survival trajectory, and telephone based interventions are one means of addressing these supportive care needs. The use of the MRC Framework as a guide has resulted in the development of a detailed intervention incorporating evidence from key stakeholders in order to arrive at an intervention that is acceptable both for those receiving and those delivering the intervention. Such a model may be the basis for supportive intervention in other clinical areas.

Key terms: Telephone, intervention, cancer, haematology, support, acceptability, MRC Framework

Declaration

No portion of the work referred to in the thesis has been submitted in support of an application for another degree or qualification of this or any other university or other institute of learning.

Copyright

i. The author of this thesis (including any appendices and/or schedules to this thesis) owns certain copyright or related rights in it (the "Copyright") and s/he has given The University of Manchester certain rights to use such Copyright, including for administrative purposes.

ii. Copies of this thesis, either in full or in extracts and whether in hard or electronic copy, may be made **only** in accordance with the Copyright, Designs and Patents Act 1988 (as amended) and regulations issued under it or, where appropriate, in accordance with licensing agreements which the University has from time to time. This page must form part of any such copies made.

iii. The ownership of certain Copyright, patents, designs, trademarks and other intellectual property (the "Intellectual Property")and any reproductions of copyright works in the thesis, for example graphs and tables ("Reproductions"), which may be described in this thesis, may not be owned by the author and may be owned by third parties. Such Intellectual Property and Reproductions cannot and must not be made available for use without the prior written permission of the owner(s) of the relevant Intellectual Property and / or Reproductions.

iv. Further information on the conditions under which disclosure, publication and commercialisation of this thesis, the Copyright and any Intellectual Property and/or Reproductions described in it may take place is available in the University IP Policy (see http://documents.manchester.ac.uk/DocuInfo.aspx?DocId=24420), in any relevant Thesis restriction declarations deposited in the University Library, The University Library's regulations (see http://www.library.manchester.ac.uk/about/regulations/) and in the University's policy on Presentation of Theses

Acknowledgements

I would like to express my sincere gratitude to everyone who contributed to this experience and supported me during the thesis.

To my supervisors Dr Penny Bee and Professor Karina Lovell, for sharing their extensive knowledge, their guidance, their inspiration and constant encouragement.

To the patients, expert nurses and consensus group participants for the time they dedicated, and for sharing their experiences. To my colleagues whose initiatives and desire for high quality patient care have motivated me in this project.

To the Fondazione IEO for funding this project.

To my family and friends, without whom I would not have started the PhD and could not have got through the difficult times.

Finally, thank you to Gae for the positivity, patience, belief and unconditional support over these years.

About the Author

I completed my Bachelor of Nursing (Hons) degree and qualified as a Registered General Nurse (Adult) in 1997. I continued my studies completing an ENB Oncology Nursing Certificate in the same year, and worked in a large Comprehensive Cancer Centre in Manchester for several years within a variety of areas: surgical oncology, medical oncology and as a Chemotherapy Nurse within a Day Case Unit.

In 2001 I left the CCC to move to a large University Hospital in Central England, taking up the role of Haematology Clinical Nurse Specialist. During this time, I undertook the MSc in Clinical Nursing at Staffordshire University and obtained the Independent / Supplementary Prescribing qualification, also running nurse-led clinics for patients with Essential Thrombocythaemia. It was during this role that my interest in audit and research began.

I took a sabbatical year to go to the European Institute of Oncology in Milan to teach nurses in Haematology, Stem Cell Transplantation and Research, developing educational programs, clinical trial pathways and participating in nurse led research. At this time I also became a member of the Research Committee of the European Blood and Marrow Transplant Society Nurses Group.

After 3 years in Italy, I returned to the UK as Team Leader for the Oncology research team at a large University Hospital in Manchester. During this time I undertook the PGCert in Clinical Research at the University of Manchester and was more determined to continue my studies in developing nurse-led research. In 2010, I returned to Italy as a Research Nurse in the Division of Haemato-oncology. The post was unlike the traditional role of 'Clinical Research Nurse' recognised within many other countries as a key component includes the elaboration and participation in nurse-led research, and not only working within the context of clinical trials. This allowed me to become more involved in research as co-investigator, but with the recognition that my skills needed developing and further education through PhD study, was the means to enhance my knowledge and capability. In September 2011, I formally registered at the University of Manchester as a PhD student at the School of Nursing, Midwifery and Social Work.

Chapter 1: Introduction

Data shows that in 2012, 14.1 million new cases of cancer were reported, and 32.6 million people were living with cancer (within 5 years of their diagnosis) (Ferley *et al.*, 2013). Whilst methods for cancer screening, diagnosis and treatments are continually developing, providing better longer term prognosis for patients, the impact of cancer and its treatments remain, with short-term effects and potentially long-term effects for both patients and their carers.

Haematological malignancies are a heterogeneous group of cancers originating in blood forming tissues such as bone marrow or immune system cells and include leukaemia, lymphoma and myeloma (NCI, 2017), accounting for 9% of all cancers. Although prevention programs and screening initiatives are not offered for haematological malignancies, improvements in patient management, treatment development and supportive therapies have contributed to improving survival rates in this patient group. This would imply an increasing need for services to support increasing numbers of patients where on-going needs are identified.

There has also been a notable shift in the management of patients with haematological malignancies from inpatient to outpatient settings and earlier discharge (Mank *et al.*, 2011), often with disease-related or treatment-related symptoms being managed at home. This has been in response to improved outpatient management strategies, changes in treatment regimens and modified ways of working within a setting of finite healthcare resources. Such a shift implies reduced contact with healthcare professionals and the need to prepare and empower patients to self-care and encourage early signalling of potential complications.

The author is employed as a research nurse in a comprehensive cancer centre in Italy, where following patients' reports to medical staff of feeling abandoned after discharge with side-effects of treatment still on-going, an ad hoc telephone based intervention was devised and implemented. The intervention was initiated by medical staff or nurses, and aimed to provide symptom management and support for patients after discharge – primarily where side effects of cancer or treatment existed, or where social support was perceived as lacking. Patients were telephoned by one of two experienced nurses of the

inpatient unit, 2-3 days after therapy or discharge, to see if they had any problems, needs or questions. The nurse responded where possible, referring on to other healthcare professionals where necessary. Subsequent calls were made in order to verify improvements or worsening of situations. There was no further structure to the telephone support provided. Anecdotal feedback from patients suggested that the intervention was useful and increased perceptions of safety at home. There was also the impression that this type of telephone support allowed for early identification of problems and reduced the number of inappropriate telephone calls to medical staff. However the intervention had not been rigorously evaluated and high quality evidence of patient acceptability was limited. During the course of this PhD study, the intervention was stopped due to lack of personnel resources.

The overall aim of the thesis was therefore to elaborate a telephone support intervention which is acceptable to patients, addresses identified needs, and both feasible and sustainable in terms of resource implications and delivery.

1.1 Aim of the PhD study

The aim of the study was to develop a telephone intervention providing support and symptom management that is acceptable to patients undergoing or having undergone treatment for a haematological malignancy, based on the best available evidence. Guidance published by the Medical Research Council (MRC) for the development and evaluation of complex interventions is the basis for the study, following a systematic approach, using best evidence available and appropriate theory in a phased approach to intervention construction (Craig *et al.*, 2013). The process development of the study is shown in Figure 1.

1.2. Objectives of the study

There were two distinct phases to the study each with well-defined objectives.

1.2.1 Phase 1 of the PhD study – identifying the evidence base

Phase 1 of the study was performed in line with the MRC Guidance of identifying existing evidence, and aimed to provide insight into existing evidence in relation to the acceptability of, and satisfaction with telephone based interventions among patients. Working definitions for acceptability and satisfaction provided the underpinnings for

investigation within the PhD study, where acceptability is defined as "*pleasing, agreeable, welcome*", and also as "*tolerable or allowable; not a cause for concern; within prescribed parameters*" (OED online, 2013a), and satisfaction is defined as "*the satisfying of a need or desire as it affects or motivates behaviour"* (OED online, 2013b).

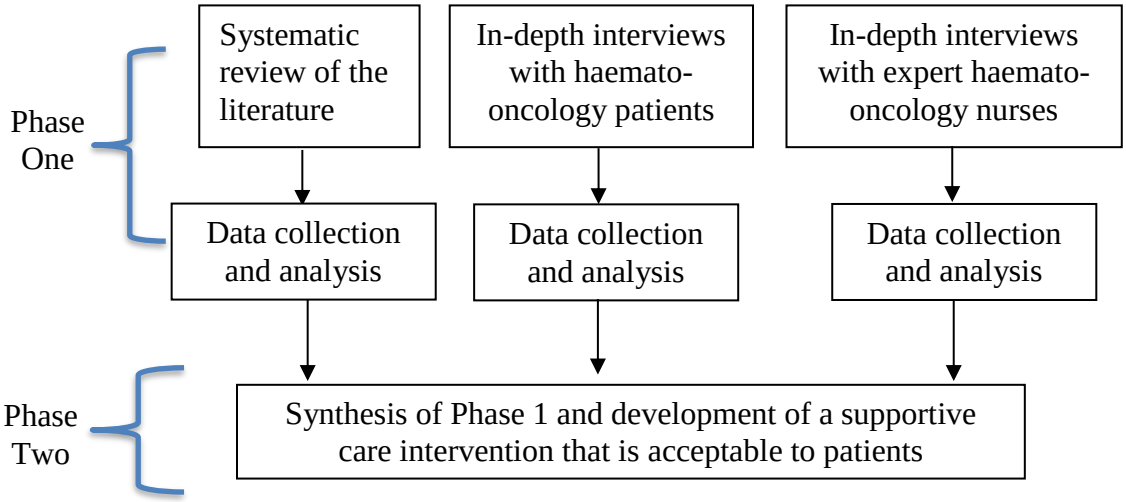
Research contributing to the first phase of the study had the following objectives:

- to synthesise existing evidence of patients' perspectives of the acceptability of telephone interventions for patients with a cancer diagnosis, in order to provide support associated with the disease and cancer treatment by conducting a systematic review of the literature.
- to determine the needs of haemato-oncology patients during treatment and post-treatment phases of the cancer trajectory, and understand the acceptability of telephone support, through qualitative interviews with patients
- to explore stakeholders perceptions of the needs of haemato-oncology patients during treatment and post-treatment phases of the cancer trajectory, experience with telephone-based supportive interventions for this patient group, and identify potential barriers and facilitators for patients and nurses in delivery of a telephone intervention, through focus groups with expert nurses

1.2.2 Phase 2 of the PhD study – modelling process

Phase 2 of the study aimed to develop a telephone based intervention based on the systematic review of the literature, patient interviews and expert nurse focus groups by synthesising the data to develop an acceptable intervention through application of the Medical Research Council (MRC) Framework for the development of complex interventions (Craig *et al.,* 2008), and a consensus process to inform application of the intervention to a local setting.

Figure 1 – Study Process Development



1.3 Structural organisation of the thesis

Chapter two will provide a frame of reference for the study by introducing the background for the research, terminology within this field, and the theoretical background in which the research is to be set.

Chapter three describes research methodology in relation to the study, including the MRC Framework as the basis for this study, and an overview of philosophical positions and related methodological approaches with particular attention to the methods applied within the study.

Chapter four presents the rationale and working methods for the systematic review of existing literature surrounding patient reported acceptability and satisfaction of telephone delivered supportive interventions during or post-treatment for cancer, as well as the analysis and results. A discussion of the findings as well as considerations of strengths and limitations are given along with conclusions from the review.

Chapter five explores the perspectives of patients having received the existing telephone based intervention as well as rationale and working methods for this qualitative research, analysis and results. Findings are discussed along with reflections on strengths and limitations of the research and conclusions.

Chapter six describes the views of expert nurses as stakeholders delivering telephone based interventions and rationale and working methods for the focus groups, data analysis and results. The findings are presented along with a discussion of strengths and limitations of the research and its conclusions.

Chapter seven describes the consensus process undertaken to develop the intervention with the rationale and working methods, analysis and results. Findings are discussed along with reflections on strengths and limitations of this methodology and the conclusions and implications for practice.

The final chapter provides an overall summary of the research findings, and reflection on the strengths and limitations of the thesis. It includes recommendations for practice and future research.

Chapter 2: Background

This chapter presents the background to the thesis and the current literature in relation to telephone-based interventions for supportive care. It provides an outline of haematological malignancies, their epidemiology, patients' needs, and methods to address needs including remote working practices and patient preferences. It will also describe the local context in which the PhD study is framed.

2.1 Haematological malignancies

Haematological malignancies are cancers originating in blood forming tissues such as the bone marrow, lymph nodes or immune system cells (NCI, 2017). This group of cancers are broadly divided into lymphoma (Hodgkin lymphoma and non-Hodgkin lymphoma), leukaemia (acute and chronic) and multiple myeloma (including other plasma cell neoplasms).

Hodgkin lymphoma (HL) involves the lymph nodes and lymphatic system and is most commonly diagnosed between ages 15 and 30, with another peak incidence in > 55 years of age (NCCN, 2017a). Whilst there is a significant chance of cure for these patients (80%, NCCN, 2017a), long-term effects of toxicity from treatment are notable. Treatment depends on the subtype of HL, stage, the presence of unfavourable factors (i.e. mediastinal adenopathy, >3 sites of disease, B-symptoms (fever >38°C), night sweats or weight loss >10% in 6 months), the general condition of the patient and existing comorbidities. Initial treatment will include combination chemotherapy +/- involved field radiotherapy. In case of relapse, further chemotherapy, monoclonal antibody treatment or autologous stem cell transplantation (SCT) is considered.

Non-Hodgkin lymphomas (NHL) are lymphoproliferative disorders originating in B-lymphocytes (90% of NHL's) or T-lymphocytes (10% of NHL's) (NCCN, 2017b, 2017c), and they encompass over 60 different subtypes. Incidence of NHL tends to increase with age, and similar to HL, treatment depends on the subtype of NHL, stage, the presence of unfavourable factors (reported earlier), the general condition of the patient and existing comorbidities. NHL's cover a spectrum of diseases. For indolent slow growing lymphomas, treatment may be unnecessary at diagnosis, instead a 'watchful waiting' approach is taken to monitor for symptoms or disease changes –

these lymphomas have a tendency to relapse over time. At the other end of the spectrum are aggressive lymphomas, which develop rapidly, usually requiring intensive chemotherapy perhaps with monoclonal antibodies and radiotherapy. In case of relapsed NHL, further combined approaches to treatment are considered, including that of autologous or allogeneic SCT.

Acute leukaemia's include both Acute Lymphoblastic Leukaemia (ALL) and Acute Myeloid Leukaemia (AML) and are characterised by an acute rapid onset and development of disease. ALL is the proliferation of immature lymphoid cells in the bone marrow, peripheral blood and other organs, and accounts for approximately 20% of leukaemia's in adults (Jabbour et al, 2005). Treatment is said to be one of the most complex and intensive programs in cancer therapy (NCCN, 2017d) over a period of years, with chemotherapy in phases of induction – to reduce tumour burden, consolidation - to eliminate remaining leukemic cells, and maintenance – to prevent disease relapse. The initial induction treatment often means prolonged periods of hospitalisation.

AML is the proliferation of myeloid blasts in the peripheral blood, bone marrow and / or other tissues, and is the most common form of acute leukaemia with patients a median 67 years of age at diagnosis (NCCN, 2017e). Similar to ALL, treatment is divided into phases of induction and consolidation therapy, but overall with a much shorter duration. Treatment decisions are based on age, previous myelodysplasia of the bone marrow or exposure to chemotherapy and general condition of the patient.

In both types of leukemia's, allogeneic SCT may also be a treatment option for patients depending on the presence of cytogenetic risk factors. For patients who are unfit to receive such intensive treatment, supportive care is provided in order to provide symptom control.

Chronic leukaemia includes both Chronic Lymphocytic Leukaemia / Small Lymphocytic Lymphoma (CLL/SLL) and Chronic Myeloid Leukaemia (CML), both tending to have a more indolent nature. CLL/SLL is the most common type of leukaemia in adults, its incidence increasing with age (median 72 years old at diagnosis) and is characterised by an increasing number of leukemic cells in the peripheral blood, bone marrow and lymphoid tissues (NCCN, 2017f). Treatment depends on co-morbidities of the patient, stage and the presence of cytogenetic abnormalities and

mutations. Treatment may be unnecessary at initial diagnosis, and a 'watchful waiting' approach is taken. When treatment is necessary, this may include immune-modulating agents, monoclonal antibodies, combination chemotherapy regimens and more recently small molecule inhibitors as targeted therapies.

CML has a median age of 67 years at diagnosis, and accounts for 15% of adult leukaemia's, being characterised by the presence of Philadelphia chromosome – a translocation between chromosomes 9 and 22, which has a key role in CML pathogenesis (Faderl *et al.*, 1999; NCCN, 2017g). It is usually diagnosed during the chronic phase of the disease, however if untreated this can progress to an accelerated or blast phase, behaving similarly to an acute leukaemia. Treatment is primarily based on the use of oral Tyrosine Kinase Inhibitors (TKI's), however allogeneic transplant may be considered in patients presenting with accelerated or blast phase disease.

Multiple myeloma (MM) is a plasma cell neoplasm leading to bone destruction and marrow failure, and is most commonly diagnosed between 65 and 74 years of age (NCCN, 2017h). At present this is not a curable disease rather a disease characterised by periods of treatment and remission. Several new agents are now in use including immunomodulatory drugs, proteasome inhibitors, monoclonal antibodies and histone deacetylase inhibitors, however where possible, autologous SCT remains a key component in first line treatment for patients with MM.

2.2 Epidemiology

Haematological cancers account for 9% of all cancers, although the use of multiple laboratory, imaging and clinical parameters to define and characterise such malignancies has been said to be a barrier to data collection (Smith *et al.*, 2011), and as such, the incidence may actually be higher than reported.

Although often grouped under the umbrella term 'haematological malignancies' this heterogeneous group of diverse cancers have different clinical outcomes, activity and treatments impacting on the course of the disease. As such, reporting of incidence and survival is usually disease focused. Data relating to 2012 cancer incidence in Italy where the PhD study is based, report non-Hodgkin lymphomas to account for 3.5% of all cancers, Hodgkin lymphomas 0.4%, leukaemia 2.4% and myeloma 1.5% (Ferlay *et al.*, 2013). The 5-year survival rate for non-Hodgkin lymphomas is 65%, 85% for Hodgkin lymphomas, 51% for myeloma and 65% and 30% for chronic and acute

leukaemia's respectively (AIRTUM, 2017). With these incidence and survival rates, healthcare services for patients are required to address the care needs of increasing numbers of patients over a lengthy course.

2.3 The shifting context of cancer treatment

As highlighted, there is a wide and ever increasing range of treatments used for the management of haematological malignancies, and a general shift in the setting of treatment delivery for these patients has been observed. The majority of treatments are delivered in an outpatient setting not requiring overnight hospitalisation, as infusions, injections or oral medications to be taken at home. There has also been a movement of treatments traditionally administered in the inpatient setting to outpatient care (Ganzel and Rowe, 2012), including more intensive treatments such as high dose chemotherapy, autologous SCT and some types of allogeneic SCT (Sive *et al.*, 2012). In addition, where patients are hospitalised for treatment, there is a tendency to discharge patients early, reducing duration of stay (van Tiel *et al.*, 2005), the risk of hospital acquired infections, impaired functioning (George *et al.*, 2013), and providing a sense of normalisation (Reid *et al.*, 2016).

This shift in the context of treatment delivery has not been undertaken without consideration. Treatments are not without side effects, some having significant toxicities that require prompt and appropriate management so as not to progress to life threatening or disabling outcomes. Patients are susceptible to side effects of treatment, be they either on-going at discharge and presumed manageable at home, or problems that develop following discharge. These include gastro-intestinal disturbances such as nausea and vomiting (Gonella and Di Giulio, 2015), mucositis, opportunistic infections due to the use of prophylactic antibiotics, increased risk of infection from neutropenia and immunosuppression (Rimkus, 2009), general malaise (Breen *et al*, 2009), peripheral neuropathy (Polovich *et al.*, 2005), cardiac toxicity (Loerzel and Dow, 2003), pulmonary complications (Crawford, 1999), acute renal failure (Parikh *et al.*, 2004) and liver toxicity (Rimkus, 2009). Specific treatments such as allogeneic SCT may have additional potential complications such as Graft versus Host Disease where the donor cells attack the recipients' body causing potentially fatal damage to a variety of organs.

The evolution of side effects following discharge and their correct management are important for patients. The recognised link between physical well-being and that of emotional health and quality of life (Naughton and Weaver, 2014) would suggest that inadequate management of physical symptoms may have much wider consequences for patients. Individual patient assessment, disease and treatment type, potential toxicities and the patients ability for self-care, are factors in evaluating the feasibility and decisions regarding outpatient treatment. Patient education regarding side effects of treatment and self-care, methods of early detection and providing support for patients continuing complex therapies in the community are also necessary to ensure patient safety. Support services do however, need to reflect the context of increasing patient numbers, and finite resources available within the healthcare system.

2.4 The needs of patients with haematological malignancies

Given the burden of this group of diseases and complexity of treatments, this creates substantial demands on patients and significant others.

Research acknowledges that this group of patients experience significant psychological and emotional challenges (Bryant *et al.,* 2016). Greater levels of anxiety, depression and distress have been noted compared with the general population (Jones *et al.,* 2015a; Linden *et al.,* 2012; Swash *et al.,* 2017) as well as fear of recurrence and persisting uncertainty in survivors (Black and White, 2005; Grundy and Ghazi, 2009). This is an important factor as psychosocial well-being has also been correlated with greater intensity of physical symptoms, poor quality of life, and greater functional impairment (Sharp *et al.,* 2015; Skarstein *et al.,* 2000) in cancer patients. Whilst it is recognised that elevated levels of distress do not automatically imply a wish for support (Merckaert *et al.,* 2010), one systematic review reported on the unmet psychosocial needs of haematological cancer patients over their cancer trajectory highlighting their practical needs, fear of recurrence and psychological needs during the treatment period, with unmet needs in terms of fear of recurrence after treatment (Swash *et al.,* 2014). This would suggest that for many patients there are areas for improvement.

The need for information is also a predominant feature for this group of patients. Themes identified from the literature include information in relation to the disease, treatment and coping with side effects, prognosis and follow-up, rehabilitation and long-

term side effects, coping, social functioning and health surveillance as well as body image, sexuality and fertility issues (Gansler *et al.*, 2010; Rood *et al.*, 2014; Swash *et al.*, 2014), with the tendency to change over time and according to individual requirements.

For patients undergoing stem cell transplantation, the experience is seen to be both intensive and unique (Cooke *et al.*, 2009) imposing significant physical and psychological demands (Stephens, 2004), over and above those of oncology patients in general (Andrykowski, 1994). The need for support in this sub-group of patients with haematological malignancies is evident however it is highlighted within the literature that unmet needs still prevail (Barata *et al.*, 2016; Hall *et al.*, 2015).

Even following treatment, uncertainty remains for many patients. The intensity of care during treatment and close contact with the specialist clinical team is replaced by prolonged periods with infrequent communication and is seen as a time of 'letting go' of the patient (Högberg, 2013). This may also involve returning patients to the care of the local hospital or GP, leaving patients with unmet needs as there is no clear responsibility for on-going care (Parry *et al.*, 2010).

2.5 Supportive care

In providing comprehensive and holistic care for patients it is necessary to encompass

> "*not only diagnosis, staging, and treatment of cancer, but also impeccable assessment and management of …physical, psychological, spiritual, social, and informational needs – collectively known as the supportive care issues*" (Hui, 2013, p. 373).

This advocates supportive care as a key component throughout the cancer trajectory.

What constitutes supportive care and how it should be delivered in order to be effective and acceptable to patients, is not clearly defined. Recommendations provided in the NICE Guidance (2004), include good face-to-face communication, information giving, and psychological, social and spiritual service provision. However this is a generic document, leaving room for interpretation of the support measures to be provided according to the patients needs at any time.

Unmet supportive care needs are determined to be the desire for support in the management of physical, social and psychological effects of illness (Swash *et al.*, 2014) and are said to be closely linked to psychological well-being (Armes *et al.*, 2009). It is therefore paramount that individuals needs are identified and addressed in order to promote patient well-being.

2.5.1 Interventions to address patients needs

There is a wealth of literature referring to unmet patients needs, and acknowledgment that someone should meet these needs. This may be informally by family or caregivers, but commonly this is formally as an intervention by healthcare professionals. An intervention is defined as "*intervening, 'stepping in', or interfering in any affair, so as to affect its course or issue*" (OED Online, 2013c), which may be seen as addressing a deficit e.g. lack of knowledge, understanding, ability to manage certain situations.

There is an increasing number and variety of supportive care interventions delivered by healthcare professionals for patients such as work-related support for gastro-intestinal cancer patients (Zaman *et al.*, 2017), psychosocial interventions for colorectal cancer patients (Mosher *et al.*, 2017), symptom detection and control interventions during radiotherapy (Sundberg *et al.*, 2017), and lifestyle interventions for breast and prostate cancer patients (Balneaves *et al.*, 2014; Bourke *et al.*, 2014) to name but a few. Similarly, interventions specifically targeting patients with haematological malignancies are also increasingly evident with examples such as exercise-based interventions (Furzer *et al.*, 2016), massage in leukaemia patients (Miladinia *et al*., 2017), mindfulness based programs to improve quality of life (Grossman *et al*., 2015) and life coaching following stem cell transplant (Kenyon *et al*., 2015), reported in the literature.

Such innovative interventions are however, delivered within a climate of finite healthcare resources and as such interventions need to be both cost-effective and patient-focused in order to be feasible and acceptable to both patients and stakeholders.

2.5.2 Patients preferences for support and remote working

Healthcare aims to provide patient-centred care – where patient choice is seen as a core element (Kitson *et al.*, 2013). Services that are developed for patients should ensure that

patients will engage in the interventions, and here recognition of receptivity is fundamental, being defined as:

> "*the range of factors (individual, social, geographical) that affects an individuals desire or availability to receive or engage with supportive care services designed to meet his or her needs"* (McGrath, 2013, p. 30).

Traditionally, support has been provided face-to-face, however for some patients the time, availability of transport resources, and having other commitments, are barriers to attending programs including face-to-face psychotherapy (Mohr *et al.,* 2006) and lifestyle interventions (van der Bij *et al.,* 2002). To address issues of accessibility and preference, methods of support provision are moving in line with the availability of newer technology and a remote working approach. In a study of health behaviour intervention delivery modalities for cancer survivors, computer based interventions were most appealing to one-third of respondents – particularly in those familiar with other technology platforms, whilst more traditional clinic and telephone-based interventions were seen as preferable for less than one-fifth of patients (Martin *et al.,* 2016). In a study of cancer patients looking at home symptom monitoring (Kleiboer *et al.,* 2010), patients preferences when receiving information were face-to-face, via telephone with a nurse they knew or in written form. The study also identified differences between gender and age, with younger patients preferring modern methods of internet, email or text messaging. Face-to-face support was the strongly preferred method of intervention delivery (versus telephone follow-up) for a group of breast cancer patients (Kimman *et al.,* 2010a).

Evidence would suggest that the best method of providing support for patients remains conflicting, indicating that no single strategy is perfect for all patients and all interventions.

2.5.3 Telephone as a medium for support provision

Despite mixed findings about preference of telephone as a means of providing support, it is an expanding field with up to one quarter of care consultations are conducted by telephone (Vaona *et al.,* 2017). Finite health resources feature in service provision, and economic evaluation of telemedicine has suggested increased cost-effectiveness (Davalos *et al.,* 2009), prevention of re-hospitalization (Krumholz *et al.,* 2002) and time-saving (Pare *et al.,* 2007). Providing consultations by telephone is also suggested

to help in addressing quality and accessibility to services within an environment of rising patient numbers and raised patient expectations (Car and Sheik, 2003).

In 2016, an estimated 62.9% of the population had access to a mobile phone (Statista, 2017), making it a convenient method of contacting patients. Telephone monitoring and support has been used in diverse areas for many years (Mistiaen and Poot, 2006), including chronic conditions such as asthma and diabetes. A recent meta-analysis of nurse-led telephone interventions suggests interventions can reduce cancer symptoms, emotional distress, improve self-care, and health-related quality of life (Suh and Lee, 2017).

Psychosocial care by telephone is said to overcome barriers such as geographical location, physical limitations or preference for a non face-to-face approach (McGrath, 2015), and there is evidence that this approach has been widely adopted. There is an increasing amount of literature describing telephone interventions for cancer patients addressing issues such as pain, depression and quality of life (Agboola *et al.*, 2015), psychological and psycho-social interventions (Jones *et al.*, 2015a; Okuyama *et al.*, 2015; Wenzel *et al.*, 2015), symptom management post chemotherapy (Davoodi *et al.*, 2016; Hintistan *et al.*, 2017; Traeger *et al.*, 2015), supportive care post-surgery (Malmstrom *et al.*, 2016) and healthy lifestyle programs for cancer survivors (Eakin *et al.*, 2015; Gordon *et al.*, 2015).

Although the literature focusing solely on patients with haematological malignancies remains limited, there is evidence of the use of telephone interventions including cognitive behavioural therapy in patients post stem cell transplant to address post-traumatic stress disorder and distress symptoms (DuHamel *et al.*, 2010), ambulatory assistance post chemotherapy for lymphoma patients (Compaci *et al.*, 2015), and psychosocial support (McGrath, 2015), as well as evidence of proposed research in symptom management and support (Breen *et al.*, 2015; Bryant *et al.*, 2015).

Support and monitoring via telephone provides a means to overcome barriers such as distance and resource availability. There is however no ‘one size fits all’ approach to support provision, and service developments must be in-line with patient’s expectations and needs.

2.5.4 Patients perceptions of support via telephone

In developing services for patients, feedback is crucial and satisfaction with care and services is central in evaluating quality (Martin *et al.*, 2007). Service evaluations often use a variety of conceptually different terms to investigate patients perceptions. Satisfaction is defined as "*the satisfying of a need or desire as it affects or motivates behaviour"* (OED online 2013b), whereas needs and desires are individual, so is the subjectivity of any evaluation of satisfaction. Satisfaction is often seen with evaluation of acceptability – defined as "*pleasing, agreeable, welcome*", and also as "*tolerable or allowable; not a cause for concern; within prescribed parameters*" (OED online 2013a). Other terms used include feasibility – "*capability of being done; practicability*" (OED online 2013d), or preference – "*to favour (one person or thing) in preference or to another; to like better*" (OED online 2013e). It is recognised that whilst being individual concepts, they are interrelated (Figure 2).

Figure 2 – Overlap of concepts in defining patients' perceptions

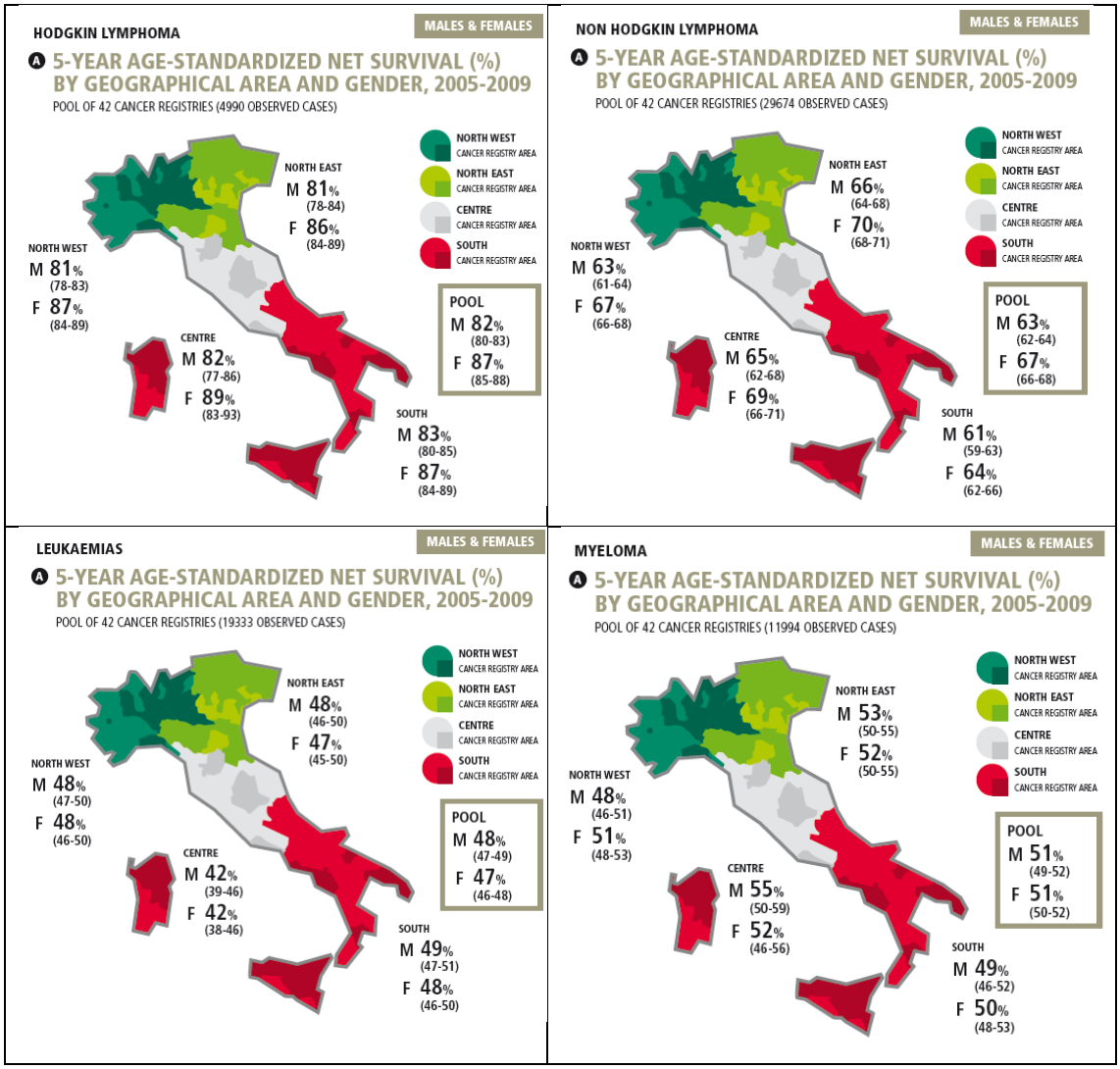
This inter-changeability of terms to evaluate patients perceptions of telephone interventions is reflected in a variety of studies. In one literature review of telephone follow-up in cancer patients, a small number of studies that met the inclusion criteria described telephone follow-up as acceptable (Cusack and Taylor, 2010). A more recent systematic review and thematic analysis of telehealth (incorporating telephone along with internet and hand-held mobile technology) investigated patients experiences (including acceptability and satisfaction) describing such methods as being convenient, promoting independence, personalised care and remote assurance – however for some it was seen only as an additional burden (Cox *et al.*, 2017). Other studies of telephone consultation for haematology patients have also reported satisfaction (Smeenk *et al.*,

1998), it being the preferred method of providing support (McGrath, 2000). While perceptions of telephone based supportive interventions appear to be regarded positively, investigation should ensure consideration of all possible applied terminology to capture the true extent of patients experiences.

2.6 Providing care in the local context - Italy

The Italian healthcare system is a regionally based national health service. The Ministry of Health allocates funds to Regions within which, the Local Health Authorities (geographically and population-defined institutions) are responsible for the organisation and delivery of public health and healthcare services at a local level (Ferré *et al.,* 14). As reported at the beginning of the chapter, there are significant survival rates for patients diagnosed with haematological malignancies (AIRTUM, 2017), and subsequently the need to provide support for increasing numbers of patients. Cancer survival in terms of geographical area highlights differences between the North and South of Italy. Lower survival rates are observed in Southern Italy for all cancers, a phenomenon which is hypothesised to be in relation to inequality in access to treatment, quality of diagnostic and care services, enduring quality and continuity of multidisciplinary team (MDT) care for patients receiving part of their treatment far from their place of residence and a limited approach to MDT models of care (AIRTUM, 2017). Although the incidence rate for haematological malignancies is lower in southern regions of Italy, the 5-year age-standardised net survival rate is lower than the national average for some haematological malignancies (Figure 3).

Figure 3 - 5-year age-standardised net survival rate for survival (%) by geographical area and gender, 2005-2009 - Haematological malignancies (AIRTUM, 2017)



Specialist healthcare services may be accessed via the patients General Practitioner for a national health service appointment, or by patient self referral to a specialist doctor through a private appointment. In both cases, further secondary care services may be publicly or privately financed, and the patient may choose which hospital – a public or an accredited private hospital. The core members of the specialist team caring for haemato-oncology patients are not uniform. The Clinical Nurse Specialist is a core component of the haemato-oncology multidisciplinary team (NICE, 2017) in many countries, providing continuity of care throughout the patients pathway, however this role does not currently exist within the Italian healthcare context. Patient contact with experienced nurses specialising haemato-oncological patient care takes place only during the Day Hospital appointment for treatment delivery or during hospital

admission. Similarly, follow-up with the specialist medical team according to national health service funding will guarantee the patient is seen by a member of the team, however some patients prefer continuity of care, opting for private appointments with a named clinician.

Reports suggest that 800,000 Italians per year move from their Region of residence to search for cancer treatment in another area, especially from the South to the North, and in particular Milan (Martinella, 2016). With Italy covering an area of 301,000km^2, including the two main islands of Sicily and Sardinia, the greatest distance from the north-west to the south-east is over 1,000km meaning travel of significant distances for patients and carers. Depending on the treatment, this may include relocation for a few days, or sometimes months away from home where treatment is protracted or necessitates frequent hospital visits.

It is acknowledged that patients relocating for care encounter additional costs associated with travel and accommodation (McGrath, 2001), and at the same time, may be experiencing reduced income due to time off, or leaving work (Cheung *et al.*, 2009; McGrath *et al.*, 2012). Supporting patients with high quality and continuous care in this context therefore necessitates flexibility in methods of providing support when dealing with such significant geographical distances and developing services that are accessible and do not cause additional burden in what is already a difficult time.

2.7 Summary

In summary, there are increasing numbers of patients undergoing sometimes complex treatments for haematological malignancies. Survival rates are improving however the physical, psychological and social sequelae of cancer and its treatments demands that support is available for patients to deal with such issues. The needs of this particular group of patients are evidenced within the literature as well as some examples of interventions to address needs, reflecting novel ways of working within the limitations of finite healthcare resources. The local context is particular in the challenge of care provision not only for local patients, but also for those residing long distances from the treatment centre. The task is therefore to develop a service that addresses individual needs, is acceptable for patients, and is feasible within such a reality.

Chapter 3: Methodology

The aim of the study was to develop a telephone intervention providing support and symptom management that is acceptable to patients undergoing or having undergone treatment for a haematological malignancy, based on the best available evidence. The Medical Research Council (MRC) guidance relating to the development of designing complex interventions was the basis for the development of this study. The purpose of this chapter is to provide further detail of the methodology adopted for the study. As described in Chapter 1 there were 2 phases of the study.

Phase 1 comprised of 3 interrelated studies:

- to synthesise existing evidence of patients' perspectives of the acceptability of telephone interventions providing support associated with the disease and cancer treatment, by conducting a systematic review of the literature,
- to determine the needs of haemato-oncology patients during treatment and post-treatment phases of the cancer trajectory, and understand the acceptability of telephone support, through qualitative interviews with patients (Study 1),
- to explore stakeholders perceptions of the needs of haemato-oncology patients during treatment and post-treatment phases of the cancer trajectory, their experiences with telephone-based supportive interventions for this patient group, and identify potential barriers and facilitators for patients and nurses in delivery of a telephone intervention, through focus groups with expert nurses (Study 2).

Phase 2 of the study aimed to synthesise the data from the systematic review, interviews with patients and the focus group(s) with expert nurses to develop an acceptable intervention and utilised a consensus process to inform application of the intervention to a local setting.

There are four sections to this chapter.

Section one describes the MRC framework as a basis for the research methodology.

Section two describes the various methodological approaches to a review of existing evidence on the subject, and the rationale for the chosen methodology of the systematic

review performed. The distinct challenges of evaluating both quantitative and qualitative research findings are also discussed.

Section three provides an overview of philosophical standpoints within research and related methodological approaches. The rationale for using a qualitative approach for the studies will be discussed, including methodological issues such as sampling, data collection and analysis methods.

Section four gives consideration to methodological approaches in intervention modelling. The rationale for using consensus group approach will be discussed, including issues in relation to consensus methods.

3.1 Section one: The MRC framework and development of the research strategy

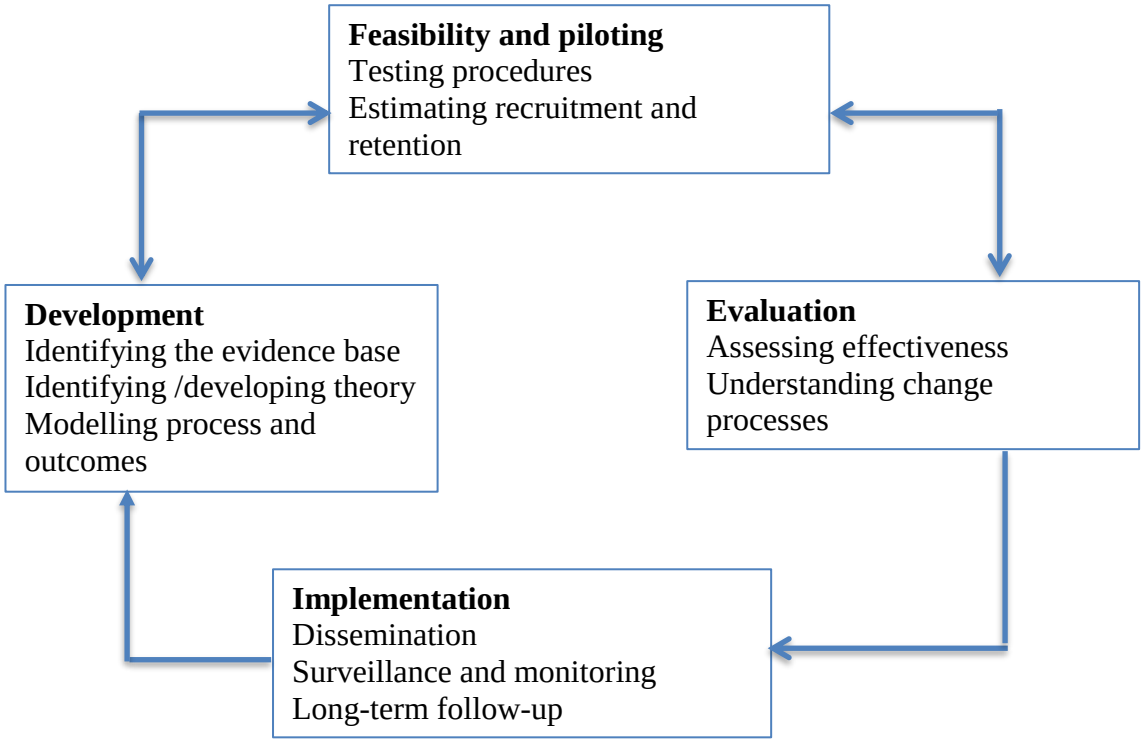
As the objective of this PhD is to develop a telephone-based support intervention for symptom management and supportive care that is acceptable and feasible for patients undergoing or having undergone treatment for a haematological malignancy, development of such an intervention is multifaceted. The MRC provides guidance for the systematic approach to development and evaluation of complex interventions, described as containing several interacting elements acting both independently and interdependently, which may include the behaviours and skills required of those delivering the intervention, the number of groups or organisational levels targeted, the number and variability of outcomes and the level of adaptation allowed within the intervention (Craig *et al.,* 2013).

The key elements of the process are shown in figure 4, where movement between elements guides development. The development process begins with identification and review of existing evidence, investigating similar interventions and approaches to evaluation that will provide a basis for knowledge in the area. Incorporating a broad range of study designs including primary and secondary evidence enriches this part of the development process. Such evidence may be sourced from the literature and reports of existing interventions, but also from key stakeholders delivering and receiving such interventions in order to understand the context, extent of problems and focus on the identification of for whom and when, interventions may be of benefit.

The next step is identifying and developing theory, which is said to facilitate the focus on planning, implementation and sustainability of an intervention (Datta and Petticrew, 2013). Use of a theoretical basis aims to conceptualise problems in order to understand and explain issues, and aids in the identification of which processes an intervention may target in order to improve healthcare. Finally, in the development phase, modelling is suggested to clarify the means by which an intervention can achieve its aims (Campbell *et al.*, 2007a), influencing processes identified as responsive to change within the intended group.

Feasibility and piloting of the intervention are the next elements in the development of the process. Finally evaluation by means of randomized controlled trials (RCT's) is performed, said to provide the 'gold standard' of efficacy evidence (Soumerai *et al.*, 2015), providing the most valid means of demonstrating effectiveness (Moore *et al.*, 2014). Evaluation of effectiveness will therefore lead to further refinement of the intervention and testing or onto implementation.

Figure 4 - Key elements of the MRC complex intervention development and evaluation process (Craig *et al.*, 2013)



3.2 Section two: Identification of the evidence base – reviewing existing literature

There is increasing evidence available from healthcare research, which needs to be critically appraised and interpreted in order to be of use to healthcare professionals. In order to identify existing evidence relevant to a topic of interest, a review of the literature is often performed. There are various approaches to literature review and synthesis, including narrative reviews, meta analyses, best evidence synthesis, systematic reviews and meta syntheses (Grant and Booth, 2009; Slavin, 1995).

3.2.1 Narrative reviews

Narrative reviews are a more informal approach summarizing different primary studies and subsequently drawing conclusions to give an integrated interpretation (Kirkevold, 1997; Mays *et al.,* 2005). Results tend to be qualitative rather than quantitative, and the methodology of the search performed is sometimes either undeclared or does not follow particular principles. Whilst such an approach allows for a wider review potentially encompassing both qualitative and quantitative data, narrative reviews may fail to provide clarity in understanding the authors decisions surrounding the validity of studies chosen for inclusion in the review, limiting the possibility for readers to make their own judgements about the findings presented (Collins and Fauser, 2005).

3.2.2 Meta analysis

Meta analysis involves the analytical testing of large numbers of quantitative studies in order to evaluate the effect of a variable (Bryman, 2008). The aim is for a synthesis of research, which is objective rather than subjective (Slavin, 1995), and it has been applied in a variety of fields including psychology and healthcare research. Rather than the potential for bias in selection of studies for inclusion – a criticism of a narrative review – a meta analysis requires inclusion of all studies, including those such as conference proceedings and unpublished or rejected material. This may be a time consuming process and difficult to perform where resources are limited and where data on the topic is not solely quantitative in nature.

3.2.3 Best evidence synthesis

Also known as a ‘systematic search and review’, a best evidence synthesis draws together the aspects of a critical review with an extensive search process (Grant and Booth, 2009). This type of review allows incorporation of various research designs,

potentially providing a more comprehensive understanding of research and findings within the field of interest. However it is suggested that whilst the search may be rigorous, the successive critical review may be prone to bias where the lack of clear inclusion and exclusion criteria for the review makes it unclear if there has been a subjective selection of research for inclusion in the review (Grant and Booth, 2009).

3.2.4 Systematic reviews

Systematic reviews have become significantly popular over time, allowing collation and processing of the literature in order to reduce bias and increase reliability in findings, with an aim to assist in decision-making and forming conclusions from research (Antman *et al.,* 1992; Oxman and Guyatt, 1993). Features of a systematic review include clear objectives, structured searching, pre-defined eligibility criteria for study inclusion and declared methodology (Green *et al.,* 2011), allowing for transparency and reproducibility of the review. Studies are critically appraised, depending on design, methodology and analysis performed (Higgins *et al.,* 2011). However not all areas of literature are conducive to a systematic review approach, and limitations include contexts where research questions are unable to clearly define variables to be measured, too much focus on the process and not the analysis of findings, and – particularly in qualitative studies – how study quality is judged (Bryman, 2008).

It is suggested that systematic reviews of the literature should be '*subject to the same standards of scientific rigour as primary research*' (Vickers, 1995, p. 93) '*in other words, the process of extracting information from published scientific data should itself be scientific*'.

Vickers (1995) continues to describe 6 main elements to a methodologically sound, systematic literature review (Table 1). Each is important in ensuring that the reasons for any conclusions drawn by the author are made explicit (transparency) and that the review could be repeated by the reader with similar results (replicability).

Table 1 - Six criteria to a methodologically sound systematic literature review (adapted from Vickers, 1995, p. 93-94)

Criteria	Rationale
1. A clearly focused question	This is standard criterion for any form of research
2. A thorough search for relevant studies	Reviewers need to ensure that all relevant studies have been included in the review. A suitable search strategy (using, for example, the MEDLINE database and checking the citation lists of relevant articles) should be conducted and full details of this search strategy provided to the reader
3. Explicit criteria for including studies in the review	Reviewers should specify the intervention, the disease and any methodological criteria (for example, randomisation) used to determine which studies will be reviewed
4. Explicit criteria for judging the validity of the studies	Not all studies are valid: many contain methodological flaws. Reviewers should assess each study using a methodological checklist. One suitable scoring for clinical trials is reproduced in table 1. To use the checklist, every paper is ranked as good, fair or poor for each criterion; 'good' indicates that the criterion was met adequately, 'fair' indicates that, though the criterion was not fully met, the results of the trial were unlikely to have been affected; 'poor' indicates that the criterion was not met, and that this may well have affected the results of the trial.
5. A suitable method of data synthesis	The data for all studies should be combined. In some cases, this can be done mathematically, as if all studies were part of one large trial. In other cases, a simple 'vote count' comparing the numbers of positive and negative studies may be more suitable.
6. Logical data interpretation	Conclusions drawn by the author should follow logically from the data presented. The strength of the recommendations should depend on the strength of the evidence. Caution should be taken in interpreting 'no evidence of effect' as 'evidence of no effect'. This is a particular problem in complementary medicine, where good studies are few and far between. For example there is no methodologically sound research showing that acupuncture is of benefit in MS. This does not prove however that acupuncture is not of benefit.

Without a thorough bibliographic search, it is possible that a review will be based on an unrepresentative sample of the literature. This is a particular problem because it is commonly thought that researchers are likely to keep to hand papers and references, which support their point of view. Lack of explicit inclusion criteria for studies can also lead to an unrepresentative literature set, as reviewers may, consciously or unconsciously, find grounds for excluding studies which do not accord with their own beliefs. Explicit criteria are also required for judging the scientific rigour of each study: it is all too easy for reviewers to find flaws in studies with unexpected results or to skate

over flaws in studies, which support their convictions. Finally, without a formal method of data synthesis and its logical interpretation, it is possible for the reviewer to come to a logical conclusion, which is not fully supported by the evidence presented. Systematic reviews are costly, time consuming and require expert skills.

3.2.5 Meta synthesis

Many approaches to literature reviews deal with quantitative data, however recognition of the need for synthesis of qualitative data has been a much later development, where the aim of a 'qualitative meta-synthesis' is to develop theory or models to explain findings in a group of similar qualitative studies (Stern and Harris, 1985). Walsh *et al.*, (2005, p. 205) suggest that the collation of such studies enabling "…*nuances, taken for granted assumptions, and textured milieu.. to be exposed, described and explained…*" gives way to new understanding. This may be seen as particularly important where qualitative studies - often with small sample sizes and limited representativeness – could benefit from synthesis in order to give more credibility to findings. Nonetheless, conflict is evident where qualitative data, renowned for it's depth and individuality, is summarised as part of a synthesis – a move said to "*destroy the integrity of the individual projects and thin out the desired thickness of particulars*" (Sandelowski *et al.*, 1997, p. 366).

3.2.6 Mixed methods synthesis

The incidence of mixed methods research is increasing, also within health sciences research (Curry and Nunez-Smith, 2015), where studies may include both qualitative and quantitative elements of research, and as such, literature reviews must be able to deal with such data. A mixed methods synthesis involves both qualitative and quantitative (statistical) analyses, where the standard approach to a systematic review is honoured with however two similar, separate yet simultaneous pathways for the review process for each type of study (Harden and Thomas, 2005). Whilst study quality evaluation and data extraction are separate, a subsequent synthesis of findings provides further information with regards the effectiveness of an intervention from numerical data and a greater understanding of the perceptions of an intervention from qualitative insight. One limitation to this approach however is the dependency of the reviewer on a detailed description of intervention components so as to allow sub-group analysis of findings (Harden and Thomas, 2005), which is often not provided in a comprehensive

manner.

3.2.7 Realist review

Realist reviews focusing on 'how' complex interventions function in particular contexts (Pawson *et al.*, 2005), and have become an accepted strategy in the synthesis of healthcare research. The approach builds on that of a systematic review in acknowledging the necessity to explicate what the complex intervention actually is and which, if any, of its components are responsible for the effects that are observed, with the aim of constructing an explanation (Taylor *et al.*, 2012). This methodology is fitting in dealing with complex interventions, which are multi-faceted, where a component of intervention deconstruction can facilitate understanding, and is an approach recommended by the MRC (Moore *et al.*, 2015).

3.2.8 Quality appraisal of studies within a systematic review

Studies included with a review should be appraised for their quality in order to ascertain the strength by which any recommendations given are truly supported by the findings (Grade Working Group, 2004). A variety of tools are available for quality appraisal according to study and data type.

3.2.8.1 Quality appraisal of quantitative studies

Appraisal in a quantitative review looks at the methodology of the research undertaken in terms of its validity and aims to assess for bias. For RCT's, this is more clearly defined as selection-bias – including randomisation issues, performance-bias – equality of treatment apart from the intervention in question, attrition-bias – whether all subjects are accounted for, detection-bias – looking at outcomes and their interpretation (Evans, 1999), and reporting bias (Higgins *et al.*, 2011).

3.2.8.2 Quality appraisal of qualitative studies

A qualitative research approach aims to understand or explain phenomena, looking at meanings for people (Greenhalgh and Taylor, 1997), and whilst it is argued by some that critical appraisal of qualitative research stifles creativity (Dixon-Woods, 2004), it is generally acknowledged that qualitative research is to be evaluated as is any research, however the approach will differ. Hannes (2011) describes 4 core criteria in the assessment of quality in qualitative research:

- credibility – whether the findings are true to the opinions of participants
- transferability – whether results can be applied to other settings
- dependability – whether the research is coherent, traceable and recorded
- confirmability – whether the findings are genuine, coming from the data

There are a range of instruments designed to facilitate quality appraisal both generic and some more specific, allowing a more detailed appraisal of a particular qualitative research methodology.

3.2.8.3 Quality appraisal of mixed methods studies

Consensus of an approach to critically appraising mixed methods studies remains lacking (Heyvaert *et al.,* 2013), and several reasons are hypothesised for this current shortfall. Fixed criteria to determine quality may be irrelevant for researchers with a different perception of quality, as well as being restrictive to this developing methodology, and politically influenced (Fàbregues and Molina-Azorin, 2017). The Cochrane Handbook for Systematic Reviews (Noyes *et al.,* 2011) however, suggests a multi-level synthesis in order to appraise the quality of mixed methods studies – where synthesis of qualitative and quantitative evidence is performed separately but later combined.

3.2.9 Rationale for the approach within the PhD study

Phase 1 of the study aimed to provide insight into existing evidence in relation to the acceptability of, and satisfaction with telephone based interventions among patients with a cancer diagnosis, during or post-treatment. For the purpose of this study, a systematic review of the literature was selected as the preferred methodology in order to provide a comprehensive and methodical approach to investigate the current evidence available in this field. Chapter 4 describes the systematic review in detail.

3.3 Section three: Philosophical perspectives and methodological approaches

The determination of the methods used within the PhD was guided by the aims of the research, as well as methodological and theoretical perspectives in terms of a paradigm underpinning the research. These perspectives are qualified by recognition of ontological, epistemological and axiological assumptions. Whereas ontology refers to "*a branch of philosophy concerned with articulating the nature and structure of the*

world" (Wand and Weber, 1993, p. 220), epistemology refers to the study of knowledge and how we accept the legitimacy of a research finding (Kelly, 2011), and axiology – the study of value or goodness (Hart, 1971).

3.3.1 Philosophical positions

Ontology and its interest in the structure and nature of social entities lends itself to important considerations in terms of the influence of social beings on social phenomena, and as such whether reality is subjective or objective. There are 2 key philosophical perspectives on how reality is perceived. Objectivism views the interpreter or researcher as a passive recipient of knowledge, being separate and independent from the object (Hekman, 1983), whilst constructivism (or constructionism) suggests that the meaning of such events is created by the observer or group (Ostlund *et al.*, 2011) implying the influence of the individual on interpretation.

Epistemology is concerned with the nature of knowledge, and a key consideration in epistemology is whether the study of the social world can be subject to the same principles and procedures as that of the natural sciences (Bryman, 2008). Positivism is an epistemological stance that confirms the relevance of using such approaches in social enquiry, suggesting a unique objective reality exists that is independent from the researcher's perspective or conviction (Hudson and Ozzane, 1988), and therefore consistent between subjects (Newman, 1998). In this way, knowledge can be produced that is objective and deductive, explaining how and why things happen, and therefore the nature of research is most commonly quantitative. In contrast, interpretivism argues that multiple realities exist and depend on other factors to give meaning (Lincoln and Guba, 1985) and as such, knowledge is inductive, subjective, and aims to understand the how and why of events. Qualitative or mixed methods research is usually employed in research investigating insight.

Despite recognition of underlying philosophical perspectives and a researcher's attempts to be truthful to the paradigm, the nature of the research questions itself may pose a challenge to the research design and data collection methods chosen in order to answer the research question. It is suggested that a pragmatic methodological awareness has gained interest (Robson, 2002), where pragmatism focuses rather on the research problem, applying various approaches to understanding the problem (Creswell, 2003),

rather than being led by a particular paradigm in the conduct of a scientific enquiry. It provides a philosophical framework for mixed-methods research (Tashakkori and Teddlie, 2003), where researchers may use both qualitative and quantitative approaches to gain both depth of understanding and validation (Johnson *et al.*, 2007).

3.3.2 Research methodology

The philosophical approach to research will significantly influence the research methodology in terms of the means by which knowledge is acquired. The character of the association between theory and research will also determine the approach to research. Deductive theory postulates that conclusions about a phenomenon or behaviour are based on theoretical or logical reasoning (Bhattacherjee, 2012), and as such, the approach to research is based on existing knowledge and theory and moves to hypothesis testing. In contrast, inductive theory aims to derive conclusions from observations or findings of research in order to develop theory. Despite appearing as separate entities, both approaches may be utilized in an iterative process, moving through theory testing or development, modifying, and re-testing, in order to refine the outcome.

3.3.3 Research methods

With a clear understanding of the research question and the theoretical and methodological perspectives, the strategy for performing research is developed. Research is broadly separated into 2 categories - quantitative and qualitative.

3.3.3.1 Quantitative approaches

Quantitative research focuses on quantification when collecting and analysing data (Bryman, 2008), and is the prevalent approach in a positivist epistemological stance. There is a deductive approach to research, being theory led and often with the formulation of a hypothesis, which is then subject to testing in order to prove or disprove the theory. In this approach, the researcher is viewed as a separate entity to the research being undertaken. The aim of quantitative research from a positivist perspective is that of validity where it is assumed that the selected methodological approach should be gauged on its capability of disclosing accurate empirical phenomena (Schutt, 2011), by means of measurement validity – whether the 'number' reflects the actual value given, generalizability – the extent to which the results are applicable to

other groups and causal validity – the accuracy of the assumption that B is the cause of A (Schutt, 2009). Research designs tend to be experimental, quasi-experimental, descriptive or observational, where the former two designs involve use of an intervention, and the latter designs measure variables of interest without intervening. Common quantitative approaches to data collection by measurement include the use of instruments including tests, surveys, and questionnaires, with large sample sizes in order to permit generalizability to a wider population (Carr, 1994), however whilst such approaches may provide objective reproducible results, there is little ability to investigate in any detail, and variables being measured may not always reflect those which are relevant.

3.3.3.2 Qualitative approaches

In contrast, qualitative research aims to describe aspects of a phenomenon thereby explaining the subject of study (Cormack, 1991), and is the dominant approach in an interpretivist epistemological stance. The approach to research here is inductive, where generalizable inferences are drawn out of observations (Bryman, 2008), and a subsequent step is the production of theory. Here the researcher is acknowledged as an integral part of the research being undertaken, and it is suggested that the benefit of such an interactive relationship means gaining valuable and meaningful data (Duffy, 1986). The purpose of qualitative research is "*to provide a rich, contextualized understanding of human experience through the intensive study of particular cases*" (Polit and Beck, 2010, p. 1452). Research methods linked with qualitative research tend to be ethnography / participant observation, qualitative interviewing, focus groups, language based approaches and qualitative analysis of texts and documents (Bryman, 2008). Sample sizes in qualitative research tend to be smaller as the aim is to identify participants with relevant characteristics that are pertinent to the research subject, in order to deepen understanding about a social process or relationship (Neuman, 2014), rather than produce results that are generalizable to a wider group. Whilst a qualitative approach does not produce objective results, the subjective experience and flexibility in the research process provides the opportunity to explore in further detail, potentially new or emerging themes that are relevant to participants.

3.3.3.3 Mixed methods

Both quantitative and qualitative research paradigms have their own strengths and weaknesses, and in some cases the use of both methodologies may be useful in answering a research question. Increasingly, mixed methods research is recognised as a valid approach to research, in which knowledge and theory is dealt with by taking into account multiple viewpoints and perspectives, including those of qualitative and quantitative research (Burke Johnson *et al.,* 2007), in order to gain the best of both worlds. It is the leading approach in a pragmatic epistemology, where researchers concentrate rather on what works to answer the research question rather than the methods used. It is suggested that using such a combined approach to research provides "*the most persuasive evidence…through a triangulation of measurement processes*" (Webb *et al.,* 1966, p. 3), permitting validation of results from differing methodologies, more in-depth analysis of data and opportunity for further investigation where ambiguity between methods arises (Rossman and Wilson, 1985). The approach may be used within a single study involving combination of data collection methods, over a program of research where connections are made through data analysis and this informs data collection in another study, or by embedding a source of supporting data within a larger study in order to provide more detail (Creswell, 2008).

3.3.3.4 Rationale for the approach used in the study

In order to develop a model for telephone based support and symptom management for haemato-oncology patients, the MRC framework provides a step by step approach to the development of complex interventions with a preclinical or theoretical phase, modelling, exploratory or pilot trial, definitive randomised controlled trial and finally implementation (Craig *et al.,* 2013). The systematic review demonstrated paucity of high quality evidence in relation to patients' perceptions of acceptability of telephone based supportive interventions. This was further confounded by contrasting findings according to the research methodology undertaken. In order to gain further insight of key stakeholders (patients and expert haemato-oncology nurses), a qualitative approach to research was selected so as to enhance subjective understanding of the experience, building on the evidence base so as to inform intervention development.

3.3.4 Theoretical approaches in qualitative research

The term qualitative research encompasses a range of methodologies and approaches to the collection and analysis of data, and can be grouped into theory driven, or applied research.

3.3.4.1 Theory driven qualitative research

Theory driven approaches incorporate the use of theory in the development, design and performance of research and its subsequent interpretation (Coryn *et al.,* 2011), with hypotheses that the researcher has determined *a priori* and a process that is more structured (Namey *et al.,* 2008). These approaches to qualitative research are focused on testing, generating or building knowledge within a particular field (Ritchie and Ormson, 2014) and those commonly used include phenomenology, discourse analysis, and grounded theory.

The term phenomenology was used initially in reference to a sub-discipline of philosophy (Smith and Woodruff Smith, 1995), describing a theory in which a descriptive process (rather than one aiming to provide explanations) is used to study the phenomena of interest. German philosopher Edmund Husserl (1859-1938) who established the school of phenomenology, defined the science as "*study of the essence of conscious experience, and especially of intentional experience*" (Smith and Woodruff Smith, 1995, p. 9). It aims to obtain the richness of an experience according to the person who has lived it, and is described as "*the unprejudiced, descriptive study of whatever appears to consciousness, precisely in the manner in which it so appears*" (Moran, 2002, p.1). One key aspect of phenomenological inquiry is the necessity for the researcher to disregard suppositions and personal inferences in order to understand more clearly the perceptions, emotions and the behaviour of the subject (Bhattacherjee, 2012), also known as 'phenomenological reduction', 'bracketing' or 'epoché'. Common methods of data collection include participant observation, focus groups and interviews. Whilst providing in-depth detail of the experience and meaning for the participant, a phenomenological approach does not openly investigate issues surrounding the experience such as precipitating factors or consequences. The quality of the data depends heavily on the ability of the participant to articulate their experience which, depending on the time-frame, may become a challenge to recall all relevant information.

Discourse analysis is based on the work of philosophers such as Michel Foucault (1926-1984) who perceived discourse as the way that we understand an object by the linguistic categories and characteristics we apply to it (Bryman, 2008). It is said to be a study of language in use (Gee, 2014), by descriptive or critical means. A descriptive approach involves the analysis of language, looking at content, and themes arising, but also at its structure and how it can be used to give more meaning to the language. A critical approach builds on this in order to explain and provide meanings that are useful to the world. Data for analysis stems from written or spoken words ranging from focus group transcripts to government policies or speeches. Some authors criticize this approach as being too distanced from clinical practice and that description and explanation do not provide means to transform practice (O'Connor and Payne, 2006).

Grounded theory developed by Glasser and Strauss in the 1960's, is defined as:

> "*theory that was derived from data, systematically gathered and analysed through the research process…data collection, analysis and eventual theory stand in close relationship to one another*" (Strauss and Corbin, 1998, p. 12).

Key features in this approach to qualitative research include theoretical sampling – where emerging themes guide the selection of research participants, coding – breaking down data in order to attach a name, theoretical saturation – no new data is emerging and categories are well developed, and constant comparison – where the development of theory in concomitance with the collection of data moving back and forth between them (Bryman, 2008). Common methods of data collection include participant observation and interviews. Challenges to use of grounded theory include the feasibility of dealing with large amounts of data, which may be difficult to manage and require researchers skilled in such methods. Whilst the coding process is not standardised and can be seen as flexible, this may actually infer bias, also where acknowledgement of the researcher's role data construction and interpretation is not recognized (Bryant and Charmaz, 2007).

3.3.4.2 Applied qualitative research

Applied qualitative research or a data driven approach involves the researcher reading and re-reading data in order to identify any themes that guide the analysis before it is undertaken (Namey *et al.*, 2008). Rather than focusing on the construction of, testing or link to theory, it is concerned with the acquisition of knowledge in order to understand

or resolve an issue (Ritchie and Ormson, 2014). Examples include evaluation research, action research and social impact assessment research.

One approach to data analysis within applied qualitative research is that of Thematic Analysis, which is not linked to a particular philosophical or methodological approach. It is described as "*a method for identifying, analysing and reporting patterns (themes) within data"* (Braun and Clarke, 2006, p. 79), with authors suggesting it provides a basis for obtaining core skills which can be applied to a variety of other qualitative analytical methods. Potential applications for Thematic Analysis are shown in Figure 5.

Figure 5 - Applications for Thematic Analysis (Boyatzis, 1998, p. 4-5)

1. A way of *seeing*
2. A way of *making sense* out of seemingly unrelated material
3. A way of *analysing* qualitative information
4. A way of *systematically observing* a person, an interaction, a group, a situation, an organization or a culture
5. A way of *converting* qualitative information into quantitative data

It involves the determination of key or recurring arguments across the data being analysed, such that a theme (or themes) are described, capturing meaning which is relevant to the research question itself (Braun and Clarke, 2006). There are 6 distinct phases: familiarisation with the data, initial code generation, search for themes, theme review, refining and defining themes and producing the report (Braun and Clarke, 2006), which allows for a well-defined approach to data analysis, and enables the researcher to incorporate the meaning of the context within the analysis (Loffe and Yardley, 2004).

The Framework Method is another approach to the analysis of data in applied qualitative research, and whilst developed for use with large-scale policy research (Ritchie and Lewis, 2003), it has been applied widely in healthcare research, most commonly in thematic analysis of semi-structured interviews. It is not affiliated with any particular philosophical or methodological approach, and is not bound by the need to create new theory, making it an approach that is adaptable but also transparent in it's clear structured approach to the analysis of data. The key features of the Framework method are summarised in Figure 6.

Figure 6 - Key Features of 'Framework' (Ritchie and Spencer, 1994, p. 176)

Grounded or generative: it is heavily based in, and driven by, the original accounts and observations of the people it is about *Dynamic*: it is open to change, addition and amendment throughout the analytic process *Systematic*: it allows methodological treatment of all similar units of analysis *Comprehensive*: it allows a full, and not a partial or selective, review of the material collected *Enables easy retrieval:* it allows access to, and retrieval of, the original textual material *Allows between- and within-case analysis:* it enables comparisons between, and associations within, cases to be made *Accessible to others:* the analytical process, and the interpretations derived from it can be viewed and judged by people other than the primary analyst.

The output of the analysis is the construction of a matrix system of rows (cases / individuals) and columns (codes) in which data is summarised to facilitate reduction, comparison and contrast (Ritchie and Lewis, 2003) both within the group and of the individual.

As for all qualitative data analysis, it is a time consuming process. Appropriate training needs to be undertaken by researchers new to this methodology in order to accurately interpret data and its meaning, as well as recognition of the role of the researcher and the need for reflexivity so as to identify the impact of the researcher and his own subjective experience on the various steps within the research process (Gough, 2003).

3.3.4.3 Rationale for the approach for Studies 1 and 2

The purpose of the PhD study is to answer specific questions in relation to the needs of haemato-oncology patients during and after treatment and the acceptability of a telephone based intervention for support and symptom management in haemato-oncology patients. Phase 1 (identification of the evidence base) was directed towards investigation of both patients and expert nurses perceptions of such interventions. The research undertaken was not aimed to generate new theory as in a grounded theory approach, and although a key area of investigation was participant experience in both of the research studies, the issues of interest have been investigated to some level and therefore a detailed account of the experience as in a phenomenological approach is also inappropriate. The Framework Analysis was fitting for Studies 1 and 2, as it permits

participant experience to be investigated whilst allowed pre-defined areas of interest to be explored, which had been identified from the literature review (Parkinson *et al.*, 2016).

3.3.5 Research procedures

Research procedures cover the practical aspects of data collection and analysis to be employed in order to answer the research question, taking into account earlier philosophical and theoretical considerations (Bryman, 2008). This includes sampling, recruitment, data collection methods and the analysis of data.

3.3.5.1 Sampling

A sample is defined as "*the set of data sources that are drawn from a larger population of potential data sources*" (Given, 2008, p. 797). Appropriate selection of the sample as the source of data has important implications for the utility of research findings in terms of the depth of understanding and completeness of findings in relation to the phenomenon of interest. There are two distinct approaches to sampling – probability sampling and non-probability sampling.

Probability sampling is considered as the 'gold standard' for obtaining a sample that is representative of a wider population with mathematically predictable errors (Neuman, 2014), however as previously discussed, the aim of qualitative research is rather to gain insight into a particular phenomenon of interest rather than generalize results. Non-probability sampling aims to select a sample with specific criteria of interest for the study rather than being representative of a given population and is the approach used within qualitative research. Types of non-probability sampling include convenience sampling, snowball sampling and purposeful sampling.

Convenience sampling is also known as accidental or opportunity sampling. It involves obtaining a sample from part of the population that is available or convenient such as those attending a particular hospital or clinic. Although it is suggested as a useful approach for exploratory studies, it has been criticized as producing significantly non-representative samples (Neuman, 2014).

Snowball or referral sampling commences with the identification of a key individual with the characteristics required for participation in the research and asking the individual to suggest other potential participants with comparable characteristics (Trotter, 2012). Whilst this approach may facilitate access to subjects that may otherwise be difficult to access, the influence of the initial 'key individual' may incur bias in participant selection and representativeness cannot be guaranteed (Dudovskiy, 2016).

A purposeful sampling strategy aims to identify participants that reflect the argument of interest – either due to their characteristics or experiences, by selecting "*information-rich-cases from which one can learn a great deal about issues of central importance to the research*" (Patton, 1990, p. 169). There are two key aims to purposeful sampling – ensuring all areas of interest are covered and also allowing for some diversity within the group so as to enable enquiry into the impact of the experience / characteristic (Ritchie *et al.*, 2003). There are a variety of purposeful sampling strategies, a summary of which are shown Table 2. Purposeful sampling is also known as judgement sampling (Burgess, 1984), as the researcher judges which criteria are important in order to determine the sample of interest. Judgements made must be transparent and justifiable so as to reduce potential bias.

Table 2 – Purposeful Sampling Strategies (adapted from Patton, 2001, p. 243-244)

Sampling Strategy	Purpose
Maximum variation	Based on the conceptual model, sample across expected differences among persons with otherwise common characteristics
Homogenous	Find persons expected to be similar regarding the phenomenon of interest
Stratified Purposeful Sampling	Illustrate characteristics of subgroups of interest; facilitate comparisons

Whilst for quantitative studies sample sizes may be determined by use of a power analysis to produce a statistically significant result (Cohen, 1988), in qualitative research the aim is to ensure the sample is manageable but enough to ensure "*an new and richly textured understanding of experience*" (Sandelowski, 1995, p.183). In a thematic analysis – of which Framework method is one such approach – 'small' projects

are suggested to engage a recommended 6-10 participant interviews (Braun and Clarke, 2013), so as to be able to demonstrate themes whilst not being overburdened with data. Another approach is that of theoretical saturation (Glaser, 1965), undertaking analysis of data to the point where no new themes are revealed, however arrival at the point of saturation is reported to be variable (Guest *et al.,* 2006; Wright *et al.,* 2007).

Sampling procedures for studies 1 and 2

The aim of study 1 was to answer specific questions in relation to the needs and perceptions of a specific cohort of patients in relation to the acceptability of a telephone based intervention for support and symptom management. With this in mind, a purposeful sampling approach was adopted and the sampling frame was patients treated at the European Institute of Oncology (EIO) who had received the telephone intervention. The working methods for this study are detailed in section 5.1.5.
The aim of study 2 was to investigate expert haematology nurses perceptions of telephone interventions within the haematology setting. Similarly, as experts were sought, a maximum variation purposeful sampling technique was employed in order to capture variety across contexts, geographical experiences and nursing roles. The working methods of this study are detailed in section 6.1.5.

3.3.5.2 Recruitment

Recruitment is the process of identification and invitation of individuals to participate in a research study (Eide, 2008). It is acknowledged that researchers are challenged with the balance between ensuring patient care and obtaining an adequate number of participants in a research project (Steinke, 2004), however the rights of any individual are of primary importance. Respect for and adherence to legal and regulatory guidance as well as ethical principles are paramount in research practice. This includes clear delineation and approval by the appropriate bodies of the proposed recruitment process and documentation.

Recruitment procedures for studies 1 and 2

Study 1 involved recruitment of patients with haematological malignancies to participate in the qualitative study involving interviews. Prior to any research procedures being undertaken, the study protocol – detailing the recruitment process, Patient Information Sheet and Consent Forms along with other supporting

documentation was submitted for ethical approval to both the EIO and the University of Manchester Research Ethics Committees. Further detail on the working methods are found in section 5.1.6.

Study 2 involved recruitment of expert haematology nurses invited to participate in one of two planned focus groups. Prior to any research procedures being undertaken, the study – detailing the recruitment process, along with Participant Information Sheet and Consent Forms and other supporting documentation was submitted for ethical approval to the University of Manchester Research Ethics Committees. Further detail on the working methods are found in section 6.1.6.

3.3.5.3 Data collection methods

Qualitative data can be grouped into verbal and non-verbal sources. Non-verbal data includes sources such as photographs, maps or pictures, whereas verbal data is the analysis of words, and includes surveys, interviews, focus groups and field notes (Schreiber, 2008). Similarly, there are two broad categories of data collection – naturally occurring and generated data. Methods which collect naturally occurring data such as participant observation, facilitate understanding of the experience within a natural setting as it happens (Ritchie, 2003), whilst generated data such as interviews, are a 'post-event' product where the individual expresses perceptions or experiences, being data that would not exist if not for the researchers involvement (Silverman, 2001).

Interviews are described as a data gathering technique which aims to "*obtain descriptions of the life-world of the interviewee with respect to interpreting the meaning of the described phenomena*" (Kvale, 1996, p. 5-6), and they are the most frequently used approach to qualitative data collection. It is argued that a series of 3 interviews through which a trusting researcher-participant relationship is developed and areas are explored in greater detail are necessary to elicit data that is of adequate depth (Seidman, 1991). Whilst useful for documenting change over time in longitudinal research (Saldaña, 2003), where the nature of the investigation is to investigate differing experiences from a number of participants, resource constrictions may mean repeated interviews are neither feasible nor provide adequate insight into the breadth of varied experiences. Facilitating the interviewee to provide an in-depth description of the issue of interest, especially in a single interview session, requires particular skills.

Maintaining rapport and gaining the confidence of the participant, aids in promoting openness in order to share experiences (Glaser, 1978), as well as probing by the interviewer to encourage further exploration of issues as they arise. Whilst interviews provide accounts that are reconstructions of experiences occurring in the past, accuracy of recall is not guaranteed, however this is not the aim of the interview – rather it is to give the interviewee a chance to reflect on the meaning of the experience (Polkinghorne, 2005).

Most qualitative interviews are either unstructured, where the interviewer may have just a single question allowing a free response (Bryman, 2008), or semi-structured, where the interview uses a schedule to provide guidance ensuring similar topic areas are covered (Hoepfl, 1997). It is important for the researcher to be mindful of the potential for bias in the interview process and need for objectivity. Interview schedules or topic guides should be clearly stated and justifiable, similarly in facilitating the interview and asking questions, the researcher should be aware of the potential influence of 'interviewers suggestions' (Polkinghorne, 2005) on interviewee recall and responses. A further discussion of methods to ensure rigour is discussed in section 3.3.6.

Although interviewing has traditionally been done face-to-face, telephone interviews are becoming more commonplace in qualitative interviewing (Drabble *et al.,* 2016). Its benefits include convenience in terms of time and travel expenses for both parties, and anonymity – facilitating open and honest discussion, however it may limit the possibility of the researcher to build a good rapport with the interviewee and to pick up on non-verbal cues (Hughes, 2008). The interviewer needs to be skilled in probing in order to elicit detail in telephone based interviews and although it is recognised that there are differences between approaches (Irvine *et al.,* 2012), the impact is unclear and in some cases, a pragmatic approach is needed in order to provide choice to participants and ensure data collection is achievable.

Focus groups have similar features to interviews however, data collection is performed with several people at one time in order to gain collective views and meanings in relation to a particular topic (Gill *et al.,* 2008). They are the methodology of choice where investigating group norms, or in the clarification of data collected by other methods (Bloor *et al.,* 2001), but should be avoided where participants are unwilling to

talk openly with others about a topic (Morgan, 1998). The key here is the use of group dynamics and interaction of the participants in order to facilitate a more in-depth investigation (Freeman, 2006), challenging and discussing thoughts and perspectives between participants. Selection of the participants is usually purposeful in order to ensure those with similar characteristics of interest participate in the group. A moderator (usually the researcher) performs the focus group, and is fundamental to gaining rich and valid data from the participants (Stewart *et al.*, 2007). The role of the moderator within the focus group is important and requires good listening skills, responsiveness to nonverbal as well as verbal cues (Redmond and Curtis, 2009), directing attention to the topic (Krueger, 2006) and encouraging interaction (Plummer-D'Amato, 2008), however the moderator should be mindful to avoid influencing discussions by leading the group rather than facilitating. Section 3.3.6. discusses methods to ensure rigour.

A topic guide or interview schedule can be used as a means to enhance the collection of data, ensuring that all aspects of the area of interest are covered in the data collection process. It is argued that qualitative interviews should be performed using questions that are open-ended, beginning with easy to answer questions before moving on to more difficult or sensitive topics (Britten, 1999). Similarly, in developing schedules for focus group the move from general to focused questions is also recommended but also question order in relation to the importance of the issue (Stewart and Shamdasani, 1990). Although this may be an ideal situation, an important factor in qualitative study is allowing the participant(s) to reveal what experiences are important to them. A pragmatic flexible approach is necessary where questions in a schedule are dealt with out of the researcher's defined 'order'.

Interviews are usually digitally or tape recorded and transcribed where possible, in order to permit more detailed and repeated reflection on the interviewees' responses, and allow access data for analysis by other researchers (Heritage, 1984).

Data collection procedures for studies 1 and 2

Two separate methods of data collection were used. In-depth interviews were used for Study 1 to investigate patients' needs and perceptions of a telephone support intervention, whilst Study 2 used focus groups to investigate expert nurses perceptions/ opinions of haemato-oncology patients needs and their perceptions of telephone support

interventions. Further detail of the working methods of these studies are reported in sections 5.1.7, and 6.1.7 respectively.

3.3.5.4 Qualitative data analysis in studies 1 and 2

Framework analysis was used to analyse the data elicited from both the in-depth interviews and the focus groups (see section 3.3.4.2), following the key stages of familiarization; coding; developing and applying a working analytical framework; charting, and interpretation (Gale *et al.*, 2013).

Familiarisation

After the verbatim transcription of qualitative data recording, familiarisation with the recording and the written data is the first analytical stage. It is argued that this is a moment to gain a feeling for the data as a whole (Ritchie and Spencer, 1994), and note taking is encouraged to highlight ideas and themes that are initially evident. It is at this point that any notes made during the data collection process (e.g. of non-verbal cues) may be useful in aiding reflection.

Coding

After familiarization, the researcher moves systematically through the interview/ data, applying a label or code to each line or phrase. Codes can be words or phrases, and can make reference to emotions, behaviours, values or even methodological issues such as interviewee difficulty in expression (Saldaña, 2009). The aim of coding is to classify data in order to facilitate comparison through and across the data (Gale *et al.*, 2013). It should be acknowledged that coding is however a judgement on the part of the researcher performing the analysis (Sipe and Ghiso, 2004), and as such may be influenced by the subjectiveness and orientation of the researcher and the purpose of the study. Often initial coding is performed by more than one researcher independently with the aim to ensure rigour in the research process.

Developing a working analytical framework

In this stage, codes that have been developed are grouped into categories and themes, which then make up the analytical framework (Gale *et al.*, 2013). Although in the initial stages, categories may be influenced by issues that were identified *a priori*, these are usually adapted and refined according to new and emerging codes from subsequently

analysed data. It necessitates logical and intuitive thinking, and decision-making about the importance & relevance of phenomena and cross connections (Ritchie and Spencer, 1994). In order to aid application of the analytical framework, codes, categories and themes are assigned a number (an index number).

Applying the analytical framework

This stage – also known as indexing, involves the application of the analytical framework to the data. It can be performed in different ways – by recording numbers in the margins of transcripts and linking back to the index (Ritchie and Spencer, 1994), or by use of Computer Assisted Qualitative Data Analysis Software (CAQDAS) (Gale *et al.,* 2013). Again this stage requires the researcher to decide the significance of the phrase or passage and indexing accordingly. During the process of indexing, further evidence of interconnection and patterns may arise which may inform later analytical stages.

Charting data

In this stage, a spreadsheet is used to produce a matrix and data is transferred or charted directly into the matrix. This facilitates visualisation of the codes, categories and themes emerging from the transcript and requires the researcher to consider both reducing data by means of synthesis, whilst still maintaining the original meaning and gist of the interviewee's responses (Gale *et al.,* 2013). The approach to charting layout may be based on a thematic analysis – looking at a theme across interviewees, or case analysis – looking at the interviewee across all themes (Ritchie and Spencer, 1994). Linking summaries back to the quotes from the original transcript will ensure a clear audit trail (Ward *et al.,* 2013), and facilitate secondary review by other co-researchers.

Interpreting the data

While the previous stages of analysis will have produced categories and emerging patterns, it is the interpretation of data that will lead to the definition of concepts, mapping of a phenomena, description of typologies, connections, explanations or strategies (Ritchie and Spencer, 1994), depending on the nature of the research question asked. It is immersion in data and previous stages that instil familiarity with the data, that allow the researcher to use intuition and imagination in this stage (Ritchie and Spencer, 1994), in order to provide a more holistic view of the data and identify what

may not be so apparently obviously. Interpretation also requires the researcher to move back and forth between the charted data and transcripts to ensure that the interpretation is true to the interviewee's original words, enhancing transparency and rigour (Ezzy, 2002).

Language considerations

When investigating an individuals experiences, the use of language to relay perceptions involves not only single words, but also euphemisms, cultural expressions and nuances to aid story-telling. The results of translating from a source language to another language in healthcare research is not without problems as the integrity of data may be compromised if not systematically reviewed (Temple, 2002), or even lead to misrepresentation of meaning (Temple *et al*, 2006). The rationale for translation should be clear and detailed as well as who performs the translation and at which point the translation occurs allowing the reader to evaluate the impact of the translation on the analysis and subsequent interpretation of data.

So as to preserve the validity of data translation, the use of a bi-lingual, bi-cultural team with knowledge of the phenomenon of interest should be engaged (Al-Amer *et al.*, 2015), as well as a single translator to avoid discrepancies (Twinn, 1997). Rather than a word for word approach to translation, semantic and context equivalence is favoured in an attempt to gain meaning (Larkin *et al.*, 2007), rather than individual words which may not convey the real meaning.

Sections 5.1.8 and 6.1.8 provide the working methods studies 1 and 2 respectively.

3.3.6 Rigour in qualitative research

Research needs to be credible to be of any use, and the term rigour is meant as the quality of the research process (Saumure and Given, 2008). The concept of 'trustworthiness' has been coined by Lincoln and Guba (1985), and is used interchangeably with rigour to describe the way in which integrity and competence are demonstrated (Aroni *et al.*, 1999).

The importance of rigour in qualitative research is well recognised, and although there is no consensus opinion, several strategies exist to assist in evaluation. Dixon-Woods *et al.*, (2004) focus on the evaluation of research methodology as a means to evaluate

quality, whilst Lincoln *et al.,* (2011) focus on the interpretation of the results. More comprehensive approaches include a pragmatic framework based on transparency and systemacity (Meyrick *et al.,* 2006), 6 specified criteria for evaluation (i) clarification and justification, (ii) procedural rigour, (iii) sample representativeness, (iv) interpretative rigour, (v) reflexive and evaluative rigour and (vi) transferability/ generalizability (Kitto *et al.,* 2008) and more recently a mnemonic aid FACTS (Fittingness, Auditability, Credibility, Trustworthiness and Saturation) to facilitate rapid qualitative appraisal (El Hussein *et al.,* 2015).

A common theme throughout the strategies is that of transparency or disclosure of all relevant research processes (Yardley, 2000). The nature of qualitative data means that it is often unstructured and as such, evaluating the reliability of the analysis performed is not possible by means of linear mathematical procedures as for quantitative data, giving rise to the question 'how reliable are these results?'. Documentation of a clear, logical and traceable procedure is the responsibility of the researcher (Schwandt, 2001), which will facilitate evaluation of the research process, and decisions made along the way. This may include independent review of the data and the analysis process including coding, categorising, theme and framework development. Reliability refers to the reproducibility of the results, and although within qualitative research it is accepted that individuals may have differing opinions of the same experience, the important feature here is to be able to follow the process of research in order to theoretically repeat the research, even if the findings are not exactly the same.

Validity refers to the credibility of the findings generated by research (Bryman, 2008) and in qualitative research both internal and external validity are of significant importance. Internal validity or credibility deals with whether the explanation provided by the researcher is in line with the respondent's description of the experience (Janesick, 2000).
Procedures such as checking with participants themselves in order to confirm the researcher's interpretation (McKeganey and Bloor, 1981), triangulation, thick description or peer review are often used by qualitative researchers in attempts to demonstrate validity (Creswell and Miller, 2000). External validity (or transferability) however, refers to the generalizability of research and the extent to which findings from a particular sample can be applied to a wider population (Cook and Campbell, 1979).

The aim of qualitative research is to understand subjective meaning for a defined population, which by its nature means that generalisation of results to a wider population may not be feasible. This does not however negate the need for clear documentation of the participant sample framework and sampling methods, which with exhaustive within-case and across-case analysis, can reinforce analytical generalizability (Ayres *et al.*, 2003).

Another consistent thought is the need for the researcher to reflect and acknowledge their role as an active participant in the research process. Reflexivity is a form of self-judgement where the researcher evaluates both the self and the research, and is a key component in ensuring an audit trail of the process (Tobin and Begley, 2004). As qualitative research often involves direct researcher-participant interactions, researchers must be mindful of their own role in the creation of knowledge and ascertain the potential influence of personal experiences and biases on research (Berger, 2015), which may be both positive and negative.

Strategies to ensure rigour within studies 1 and 2

In order to ensure rigour, the quality framework model proposed by Meyrick (2006) was followed as a means to provide a clear systematic evaluation of quality throughout the different stages of the research process.

For both Study 1 with patients and Study 2 with expert nurses, the aims and objectives of the studies were clearly outlined, rationale for selection of the research methods in line with the research question, sampling frame and selection process, and the process of data collection and analysis. Further details of the working methods employed to ensure rigour within the studies are provided in sections 5.1.9 and 6.1.9 respectively.

3.3.7 Research ethics

The consideration of ethics in research is applicable to all types of research, not only that of trials with medicinal products. Standards for the conduct of research aim to protect participants from harm by following professional and research guidelines (Holloway and Wheeler, 2015). Beauchamp and Childress advocate 4 principles which are central to moral reasoning in healthcare; autonomy – the right for an individual to make his or her own choice, beneficence – the principle of acting with the best interest of the other in mind, non-maleficence – the principle that "above all, do no harm," and

justice – a concept that emphasizes fairness and equality among individuals (Beauchamp and Childress, 2012). In addition, it is argued that "*research.. which is not of sufficient quality to contribute something useful to existing knowledge, is unethical*" (Department of Health, 2005, p. 13). As previously discussed quality in research stems right through the process, from the design, data collection procedures analysis and reporting, and is not just a consideration for the informed consent process and data storage and protecting anonymity.

Ethical considerations for studies 1 and 2

The studies followed the standards laid down by research ethics across two countries. Ethical approval for Study 1 involving patients was obtained from the both the local ethics committee of the European Institute of Oncology (Milan, Italy), and from the University of Manchester Research Ethics Committee. A detailed account of the ethical approval process for this study is provided in section 5.1.4.

Ethical approval for Study 2 involving expert nurse participants was obtained from the University of Manchester Research Ethics Committee. The details of the ethical approval process for this study are provided in section 6.1.4.

3.4 Section four: Intervention modelling

Ambiguity exists with regards to the ideal approach for the modelling phase of complex intervention development (Lovell *et al.*, 2008). In addition, the construction of an intervention is challenging, especially where evidence is incomplete or conflicting. In such situations of uncertainty, consensus group methods such as the Delphi method, nominal group technique or RAND appropriateness methods can be utilised to seek the opinions of experts in the field and facilitate decision-making (Raine *et al.*, 2004; Fitch *et al.*, 2001).

The Delphi method administers questions or issues by mail or email to a group of experts in order to elicit opinions which are collated and then re-evaluated by the same experts, asking for them to rank the list of items according to their level of agreement or disagreement (Tammela, 2013). This method allows large numbers of participants to be involved, and is relatively inexpensive however multiple rounds of questioning can be time consuming. The nominal group technique differs by asking experts to meet as a group to discuss items that are independently rated prior to the meeting and then

discussed within the group setting (led by a facilitator), in order to clarify ideas (Jones and Hunter, 1995). This is often used for item generation alone, involving a smaller number of participants and may subject to improper influence of those more dominant (Humphrey-Murto *et al.*, 2017).

Another method is that of the consensus development conference, whereby conference participants meet to hear evidence regarding the topic of interest, consider key questions and seek to reach a consensus (Black *et al.*, 1999). The consensus conference permits a synthesis of the evidence available, and a consensus process and validation involving key stakeholders involved in the intervention, promoting ownership and involvement (Halcomb *et al.*, 2008).

Rationale for the approach within the PhD study

The aim of the PhD study was to develop a telephone intervention providing support and symptom management that is acceptable to patients undergoing or having undergone treatment for a haematological malignancy, based on the best available evidence. Phase 1 of the study provided an insight into the existing evidence, both published and qualitative evidence from key stakeholders (patients and expert nurses). Findings revealed both complementary and contradictory evidence, and as such the use of consensus group methods to address areas of ambiguity is an appropriate methodology in intervention modelling. In this particular case, where the intervention is to be delivered within a local setting, the consensus development conference was a fitting approach where key stakeholders involved in the delivery of the intervention would be involved in the process, providing the opportunity to incorporate reflections on local context issues. The working methods for this phase of the PhD study are provided in section 7.1.3.

Chapter 4: Systematic literature review of studies on acceptability of telephone support as perceived by patients with cancer

This chapter describes the working methods and findings from Phase 1 of the research; a systematic review of the literature. It aimed to identify relevant literature pertaining to acceptability of telephone support as perceived by patients with cancer, and appraise and summarise findings. The systematic review has been published in the European Journal of Cancer Care (Appendix 1). There are three sections to this chapter.

Section one contains the working methods including the rationale for the review, methods and search strategy and analysis methods.

Section two provides the analysis and the results from the systematic review.

Section three discusses the findings, considers the strengths and limitations, and provides conclusions drawn from the review.

4.1 Section one: Working methods

4.1.1 Background

An initial investigation of the literature describing perceived acceptability of telephone support for patients with haematological malignancies, revealed very few studies varying from the perceptions of patients regarding its use as a potential means of follow-up (FU) (McGrath, 2000), to post-intervention evaluation of a telephone FU service (Tonkin, 2007), and a study of telephone FU post radiotherapy which included some patients with haematological malignancies (Munro *et al.*, 1994). Given the paucity of evidence available relating to this topic and the use of mixed methods to elicit patients' perceptions, the author undertook a broader investigation to identify both qualitative and quantitative studies describing perceptions of cancer patients in relation to telephone based supportive interventions. Several studies were identified including systematic reviews focusing on intervention efficacy (Scott *et al.,* 2013, Rueda *et al.,* 2011). These studies were pertinent to the authors study objectives as they provided insight into the variety of interventions, and perceptions, satisfaction with and opinions of telephone based supportive interventions.

4.1.2 Rationale for the systematic review

Performing a robust systematic review provides a transparent and reproducible analysis and synthesis of current findings.

It was expected that the results from the systematic review would highlight perceptions of acceptability and satisfaction with telephone-based supportive interventions, identifying gaps and appraising the quality of evidence provided, whilst contributing insight into areas of application and factors influencing perceptions.

4.1.3 Aims & objectives of the study

The aim of this review was to systematically evaluate the existing literature surrounding patient reported acceptability and satisfaction of telephone delivered supportive interventions during or post-therapy for cancer.

The objectives for the study were to:

- identify and quantify the type of studies available in this area,
- assess the methodological quality of the existing evidence
- synthesise evidence of patients perceptions of acceptability and satisfaction with telephone interventions.

For the purpose of this review, cancer treatment was defined as surgery, chemotherapy, radiotherapy, immunotherapy or biological therapies, hormonal therapies, radio-immunotherapy, stem cell transplant, bone marrow transplant, photodynamic therapy (PDT) or radiofrequency ablation.

4.1.4 Methods

The purpose of this phase of research was to investigate the current literature available examining whether a telephone-based intervention is an acceptable method of providing support during- or post-treatment as perceived by patients with a cancer diagnosis. The MRC guidance for development of a complex intervention suggests that initially a high quality systematic review of the literature should be performed (Craig *et al.*, 2008), however whilst a systematic review provides a summary of all primary research in response to a research question (Clarke, 2011), providing clear objectives, structure and a stated methodology, the nature of the research question itself 'Is telephone intervention an acceptable method of providing support during- or post-treatment as perceived by patients with a cancer diagnosis?', brings into question the definability of

the variable of interest. An initial investigation of the literature identified a variety of terminologies for the variable 'acceptability', and a range of methodologies including qualitative, quantitative and mixed method studies employed to evaluate them. In an appropriate review of the current evidence base, it was therefore necessary to ensure that all types of data referring to the variable of interest were captured. With this aim, a structured approach to the review was performed with the definition of a systematic review protocol (Appendix 2) describing the objectives, approach to the search and pre-defined eligibility criteria for study inclusion. A broad range of search terms informed by existing knowledge and literature within the field, were utilised to ensure all relevant literature was attained. As both types of research were evident in an initial investigation of the literature, both quantitative and qualitative studies were included in the review.

4.1.4.1 Inclusion and Exclusion criteria

The use of inclusion and exclusion criteria for a systematic review allows for the clarification of boundaries (Centre for Reviews and Dissemination, 2008), and the selection of appropriate studies that are of interest in answering the question posed. Criteria for the review are provided below and summarised in Table 3.

Table 3 – Systematic review study inclusion / exclusion criteria

Inclusion Criteria		Exclusion criteria
Participant related	> 75% of patients (male or female) aged > 18 years of age Diagnosed with cancer (any type)	Support instigated by the patient i.e. patients calling a helpline.
Treatment related	Patients having undergone chemotherapy, immunotherapy or biological therapies, stem cell transplant, bone marrow transplant, radiotherapy, radio-immunotherapy, surgery, hormonal therapies, photodynamic therapy or radiofrequency ablation. Telephone interventions delivered during or post- cancer treatment only	Interventions unrelated to cancer treatment (i.e. smoking cessation). Automated voice response systems (without personal interaction)
Intervention related	Provision of support for physical or psychosocial issues related to cancer or its treatment. Support is defined as physical, social, psychological, emotional, information support or monitoring. Delivered by a qualified healthcare professional ≥ 1 telephone call by a healthcare professional involved in the patients treatment/ care	Not in English language Reports of patient satisfaction by proxy (i.e. by carers or healthcare professionals)
Type of study	Data in relation to any of the outcome concepts will be included (including qualitative studies, RCT's, controlled and uncontrolled studies, theses) from published studies	Individual case studies, conference proceedings
Type of outcomes	Perceptions of patients having received the intervention Reports of acceptability of telephone as a means of support / intervention delivery in any part of the document., Acceptability - for the purpose of this review - is defined as acceptability, acceptance, attitudes, beliefs, experience, impressions, opinions, perceptions, satisfaction with, or views of patients.	

Types of studies

All studies published in English language providing data relating to any of the outcome concepts were included, including RCT's, controlled and uncontrolled studies, qualitative studies, and theses. Conference proceedings were not included based on evidence of variable agreement between conference abstracts and corresponding full-

text publications (Balshem *et al.*, 2013), however attempts were made to contact authors to see if the abstract had been published. Individual case studies were also excluded due to potential for bias in quality and interpretation of the observation (Nissen and Wynn, 2014).

Types of participants

Studies including ≥ 75% of participants aged ≥ 18 years old (no upper limit), independent of gender and diagnosed with cancer (any type) were eligible. Studies included > 75% participants receiving or had received cancer treatment – as defined previously.

Types of interventions

Studies were eligible if they evaluated telephone interventions delivered in the period during or post- cancer treatment only. Interventions providing support for physical or psychosocial issues related to cancer or its treatment were included. For the purpose of this review, support is defined as physical, social, psychological, emotional, information support or monitoring. Interventions were delivered by a qualified healthcare professional, with the intervention including ≥ 1 telephone call initiated by the healthcare professional.

Types of outcomes

Only studies reporting perceptions / opinions of patients on the acceptability of and satisfaction with the telephone intervention within any part of the document were eligible. Acceptability - for the purpose of this review - is defined as acceptability, acceptance, attitudes, beliefs, experience, impressions, opinions, perceptions, satisfaction with, or views of patients.

4.1.5 Search Strategy

In line with guidance from the Cochrane Collaboration (Lefebvre *et al.*, 2011), a search strategy was developed, and facet analysis used – a process by which the topic is deconstructed into its component parts, facets or basic components (Spiteri, 1998), in order to analyse the subject and synthesize concepts to describe the subject (Fugmann, 1993), and select appropriate search terms. Other terms were identified using MeSH subheadings. Truncation was used e.g. oncolog* to account for variant word endings.

To ensure specificity of the search, the Boolean term AND was used to ensure all literature included the key search terms identified. Some databases did not allow use of a complex number of search terms (TRIP, UKCRN Clinical Trials Portfolio, NIH Clinical Trials Database), so more generic search terms were used.

A wide selection of databases were used to conduct the searches in order to capture all relevant literature available across a variety of multidisciplinary fields. Databases searcher were: PUBMED, EMBASE, PsychINFO, MEDLINE, CINAHL, British Nursing Index, Cochrane Library, Web of Knowledge, Applied Social Sciences Index and Abstracts, Allied and Complementary Medicine Database – which includes palliative care, TRIP (Turning Research into Practice) Database, UKCRN clinical trials portfolio and NIH Clinical trials database (Table 4). The UKCRN Clinical Trials Portfolio and NIH Clinical Trials Database were included as a means of identifying current studies underway and the Principal Investigator was contacted for further information. Reference lists of articles were checked in order to identify eligible studies. All searches took place between February and March 2012, and an updated search was performed between September and October 2014. Full details of the search strategies, terms used and specific dates of individual searches are in Appendix 3.

Table 4 – Databases searched for the systematic review

Database
AMED (Allied and Complementary Medicine Database – includes palliative care)
ASSIA (Applied Social Sciences Index and Abstracts)
British Nursing Index (1985 to present)
CINAHL (1981 to present)
Cochrane Library
EMBASE (1974 to present)
MEDLINE (1948 to present)
NIH Clinical trials database
PsychINFO (1989 to present)
PUBMED
TRIP (Turning Research into Practice) Database
UKCRN clinical trials portfolio
Web of Knowledge

4.1.6 Study selection

The title and abstract of studies resulting from the search were examined for eligibility by the author. Where there was missing data or insufficient information reported to verify eligibility, an attempt was made to contact the study author for further clarification. Following the initial screening, the full text of potentially eligible articles was obtained. Full text articles identified as eligible for inclusion by the author were independently reviewed by the supervisory team to verify eligibility. A sample of 'rejected' studies were also reviewed by the supervisory team to ensure adherence to the study protocol.

4.1.7 Data extraction

The purpose of the systematic review was to investigate current literature in relation to the specific question of patients' perceptions of acceptability of telephone-based interventions. With this in mind, a specific data extraction form was devised *a priori* to extrapolate key data of interest. It had three main functions – verification of study eligibility, a transparent record of data extraction and interpretation, and data to be analysed (Meade and Richardson, 1997). The form was created after revision of the Cochrane Collaboration (Higgins and Deeks, 2011), CONSORT Guidance (Boutron *et al.*, 2008), and CASP checklists (2010), and initially piloted with 3 studies. Data was extracted by the author and members of the supervisory team, with a view to ensuring extraction of only appropriate data. Modifications were made until a consensus was reached for the final version (Appendix 4). These were double blind extracted to ensure accuracy.

4.1.8 Quality appraisal of studies within the systematic review

In determining the approach to quality appraisal for the acceptability or satisfaction outcome data, the gold standard for studies examining intervention acceptability was discussed at length with the supervisory team. For the purpose of this review it was defined as qualitative inquiry or use of open-ended questioning allowing participants to express opinions without imposed restrictions. Studies adopting closed-question questionnaire methods to inform findings were determined to be of lower quality due to the reduced opportunity for additional patient-centred issues or opinions to arise. Studies were assessed on the basis of whether a qualitative approach to data collection or open-ended questions was employed, and whether sufficient data was reported to

support the findings. Studies where fulfilling both of these criteria were regarded as potentially higher quality. A critical appraisal of individual study quality was then undertaken of those studies deemed to be within the higher quality category (i.e. explicitly stated to be qualitative studies).

The systematic review performed included studies providing both quantitative and qualitative data and as such, methods to appraise quality were defined prior to evaluation. In order to critically appraise the individual quality of studies providing quantitative data, the Cochrane Collaboration Risk Bias of Assessment Tool for RCT's (Higgins and Green, 2011) was used to assess the methodological quality of randomised controlled trials reporting patient satisfaction outcomes in both intervention and comparison arms. The Cochrane guidance (Higgins and Green, 2011) was used for assessment of methodological quality in non-RCT's (nRCT), single group designs. Where intervention group data only for the intervention arm within the context of an RCT or nRCT, studies were treated as single-group designs. For the appraisal of studies providing qualitative data, the CASP Qualitative research appraisal tool (2013) was used which includes assessment of aims and rationale for the study, the appropriateness of the methodological design, sampling, patient characteristics, data collection, relationship between researcher and participants, ethical considerations, rigour of data analysis, findings and their credibility. However as the CASP tool is said to be lacking in addressing validity (Hannes *et al.*, 2010), it was used in combination with the validity assessment of the Evaluation Tool for Qualitative Studies (HCPRDU, 2009).
Where studies were of mixed methods providing both qualitative and quantitative data, the assessment of methodological quality of the study was performed using both qualitative and quantitative assessment tools fitting with the study design, as described above.

4.1.9 Data analysis

The articles included in the review provided both qualitative and quantitative data. Analysis was performed based on the type of acceptability/ satisfaction data reported. Qualitative data analysis was performed from the data provided within the primary studies, eliciting patterns from reported findings. Quantitative data analysis was performed from the data provided within the primary studies, focusing on the methodology and instruments employed in data collection, and reported results.

4.1.10 Data synthesis

As the studies provided both qualitative and quantitative data, a segregated framework for the mixed methods review was performed (Sandelowski *et al.,* 2006), with individual syntheses of qualitative and quantitative data being conducted prior to a concluding 'mixed method' synthesis, in order to identify complementary or contrasting evidence.

For studies providing qualitative data, a thematic synthesis was performed in order to identify themes revealed from the text by means of coding from themes identified within the original studies, organisation into descriptive themes and development of analytical themes (Thomas and Harden, 2008) to describe patients perceptions. With regards to quantitative data, while meta-analysis is described as having a fundamental role in evidence-based medicine (Haidich, 2010), this approach to data analysis is based on the combination of similar studies. As there was significant variability in both the populations and measurements used to collect quantitative data, it was not possible to perform a meta-analysis. A narrative synthesis of quantitative data was performed following Consumers and Communication Review Group guidance (Ryan, 2013), by analysing the studies for correlation and diversity in findings and determination of patterns from the data. For mixed methods studies, a multi-level synthesis was performed, initially as a separate synthesis of qualitative and quantitative evidence. The data in each section were different and not double counted.

The final mixed methods synthesis of qualitative and quantitative data was descriptive based on the qualitative thematic synthesis (themes identified) and quantitative narrative synthesis (numerical) from the primary studies, in order to compare and contrast findings. In this way triangulation is employed as a means to check the similarity or diversity results according to the methodological approach used and potentially increase confidence that the 'true' response to the research question is gained (Harden and Thomas, 2005).

4.1.11 Ensuring rigour in the systematic literature review

Several steps were taken to establish rigour within the review suggested by Vickers *et al.* (1995), outlined in section 3.2.4. The protocol was written outlining the process for

undertaking the systematic literature review (Appendix 2). The purpose of the review and research question were stated with associated aims and objectives. An exhaustive search of relevant studies over pertinent databases was performed adhering to explicit inclusion and exclusion criteria to ensure a transparent and replicable search, with process details and results presented. Studies for inclusion were evaluated by the author as well as a sample of both included and excluded studies by the supervisory team in order to check adherence to the inclusion / exclusion criteria. Data extraction was performed systematically by use of a data extraction sheet, with extraction also being performed by the supervisory team in order to reduce bias. The methodological quality of studies included were evaluated using existing published criteria and author evaluation presented. The quality of acceptability data was determined by the author and supervisory team, providing a rationale for the decisions made.

4.2 Section two: Results

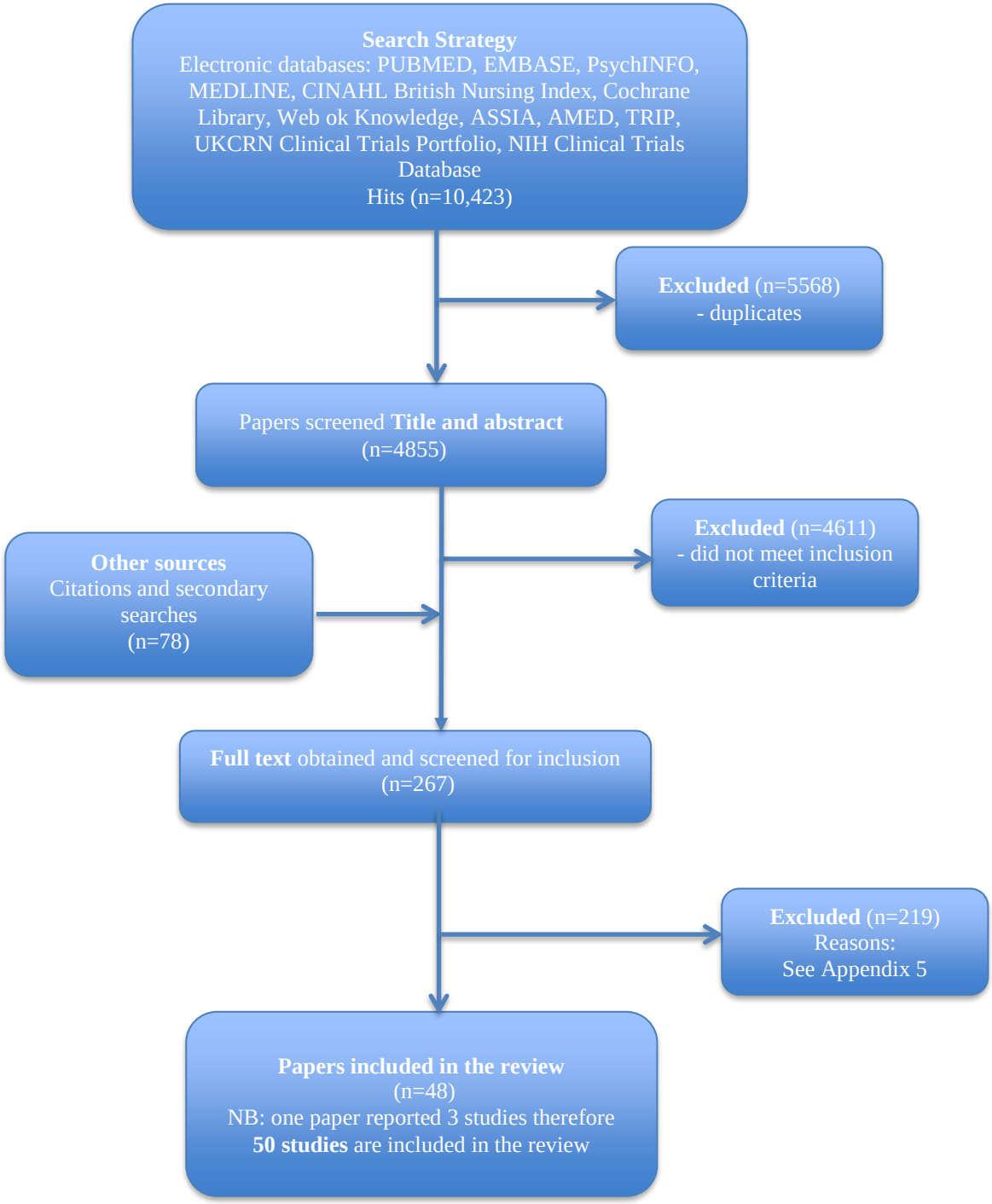
The search was performed on 14th November 2012. The initial search generated 8825 papers of which 4829 were duplicates and were excluded. Of the remaining 3996, following title and abstract screening 3826 were excluded because they were irrelevant and the full text of the remaining 170 abstracts was gained in order to evaluate inclusion. Seventy-eight articles were identified following hand search and reference review, of which 55 were rejected because they did not meet the inclusion criteria. The full text of the remaining 23 articles were gained for evaluation. Of the total 193 full text papers, a further 158 papers were excluded due to lack of coherence with the inclusion criteria.

The search was updated on 17th September 2014 and generated 1538 papers of which 739 were duplicates and were excluded. Of the remaining 859, 785 were excluded because they were irrelevant and the full text of the remaining 74 abstracts was gained in order to evaluate inclusion. A further 61 papers were excluded due to lack of coherence with the inclusion criteria. Rationale for exclusion of full text articles from the searches are provided in Appendix 5.

Full text of 267 articles were reviewed, leading to rejection of a further 219, with the remaining 48 articles eligible for inclusion. One article described a series of three studies involving different patient populations (Heidrich *et al.,* 2009), which were included in the review, each being treated separately. Two articles (Zhang *et al.,* 2013;

Zheng *et al.*, 2013) provided qualitative and quantitative data in relation to the same intervention. The authors clarified that studies had an overlapping time frame of recruitment, and that a small number of patients provided data for both studies. As the data was both different and complementary, both studies were included in the review. Figure 7 shows the study selection process.

Figure 7 – Systematic review study selection process (Liptrott *et al.*, 2017)



4.2.1 Study Characteristics

Fifty studies (from 48 articles) met the inclusion criteria and were included in the review. A summary of the key characteristics of the studies is provided in Appendix 6 (Liptrott *et al.,* 2017). The majority of studies reported quantitative acceptability data (n=39), and 24 studies provided qualitative data. With regards to studies providing quantitative data, 17 were RCT's and 16 were single-group designs. The majority of qualitative data came from stand-alone, single-group designs (*n* = 11) or nested process evaluations (*n* = 4).

4.2.2 Quality appraisal

An overall quality appraisal of the methodology of the studies included in the review is provided in Appendix 7 (Tables 1, 2 and 3 – Liptrott *et al.,* 2017).

Six of the 24 studies, which provided qualitative data, were determined to be of high methodological quality (Archer *et al.,* 2014; Beaver *et al.,* 2010; Campbell *et al.,* 2007b; Donnelly *et al.,* 2013; Wilmoth *et al.,* 2006; Zheng *et al.,* 2013), employing methods such as focus groups, well-conducted interviews, and open-ended questioning (Appendix 7, Table 3). An additional 3 studies also reported interview data, however insufficient detail was provided in terms of study methods or data completeness, and as such these studies were deemed lower, or at best of unclear, quality (Kilbourn *et al.,* 2013; Livingston *et al.,* 2010; Young *et al.,* 2013).

A further fifteen studies provided qualitative data collected through a variety of methods including open-ended questions focusing on a single pre-defined aspect of the intervention (Badger *et al.,* 2013), and/or use of written questionnaires, feedback or comments, with insufficient evidence to confirm completeness of data reporting (Alter *et al.,* 1996; Badger *et al.,* 2013; Booker *et al.,* 2004; Cimprich *et al.,* 2005; Cox *et al.,* 2008; Dixon, 2010; Hafiji *et al.,* 2012; Hagopian and Rubenstein, 1990; Inman *et al.,* 2011; Kelly *et al.,* 1999; Smithies *et al.,* 2009; Steginga *et al.,* 2008; Young *et al.,* 2010). These studies were also considered to provide lower quality data.

The majority of the studies provided quantitative data (n= 39), with only two studies used validated measures—the Ware's Patient Satisfaction Questionnaire III (Kimman *et al.,* 2010b) and the Satisfaction and Experience of Care Questionnaire (Cox *et al.,*

2008). The remaining studies (*n* = 37) used adapted scales (Beaver *et al.,* 2012; Cox *et al.,* 2005, Leahy *et al.,* 2013; Salonen *et al.,* 2009) or unvalidated tools, which had been specifically designed for the study (*n* = 34, 87%). The use of Likert scales was common (21/39 studies - 54%), requiring respondents to identify their agreement or disagreement to pre-set statements using ordinal scales. Twenty-four studies (62%) gave the number of items used to assess satisfaction, with the median being four items per outcome measure (range 1–42). The majority of studies provided either detail of the questions asked (11/39, 28%) or information about topics covered (24/39, 62%); however these were pre-conceived by research teams without evidence of patient-led question development. The quality of acceptability and satisfaction data quality is summarized in Appendix 8 (Liptrott *et al.,* 2017).

4.2.3 Sample sizes

The aim of this review was to systematically evaluate the existing literature surrounding patient reported acceptability and satisfaction of telephone delivered supportive interventions. The RE_AIM framework is a model initially used in the evaluation of health research findings, highlighting internal and external validity, and issues with generalizability and research dissemination (Glasgow *et al.,* 1999). One of the dimensions if that of 'reach', being described as the number, proportion and representativeness of individuals who are willing to participate in an initiative. It is therefore fitting that in an evaluation of acceptability, the level of reach to some extent, symbolizes the intervention acceptability, giving insight into potential participant selection bias in study samples.

However, within the studies included in the review, participation rates and sample representativeness were inconsistently reported. Definitions of sample size varied, and it was often ambiguous whether participant numbers referred to the total number of patients approached to participate in the intervention, the number who consented, received the intervention or provided data on intervention acceptability.

Just over half (26/50 – 52%) of studies presented acceptability data for all participants receiving the intervention, with ten studies (20%) providing acceptability data for less than 75% of the sample. Of significance, two studies provided data for less than half of the participants (49% - Sardell *et al,,* 2000, and 41% - Archer *et al.,* 2014), with several patients in the latter study declining to participate in an evaluation of acceptability.

In studies providing quantitative satisfaction data (*n* = 39), the median number of participants receiving interventions and therefore potentially providing satisfaction data was 38 (range 9 to 387). In studies providing qualitative acceptability data (*n* = 24), the median number of participants receiving the intervention was 30.5 (range 8 to 187). The high sample size in this category (*n* = 187) was within a study reporting feedback and qualitative comments in relation to the intervention (Hafiji *et al.,* 2012), however it is unclear from how many participants comments were collected.

4.2.4 Participant characteristics

Almost all of the studies (*n* = 43) were focused on a single cancer type, in particular breast cancer (*n* = 16), colorectal cancer (*n* = 11) or prostate cancer (*n* = 7). Mixed samples including patients with different cancer diagnoses were reported in seven studies. All participants had received or were still receiving treatment for cancer, including surgery, chemotherapy, targeted agents, radiotherapy or hormone therapy. In almost half of the studies (48%), gender and age demographics were described in terms of the total sample size and were not specific for those either having received the intervention, or who provided data relating to acceptability of the intervention. Forty-one studies provided data for participants' age, with the mean being 60.2 years old (*SD* 6.98). With the majority of studies targeting female gender cancers, there was a potential for gender bias. In studies targeting non gender specific cancers, 60% of participants were male.

4.2.5 Intervention characteristics

Three key intervention categories were observed within the data, although there was significant variability in interventions, in terms of content, objectives, design, duration and structure.

The largest category described telephone interventions directed towards side effect and toxicity monitoring (*n* = 23), delivered during and after cancer treatment. A small number incorporated side-effect management and coping strategies and/or elements of education and information provision. The majority of interventions were nurse led, being delivered to a variety of cancer patients receiving a diversity of treatments. The timing of the intervention varied according to the nature of the treatment being received. Whilst being predominantly interventions supplementary to standard care (Cirillo *et al.,*

2014; Cox *et al.,* 2008; Delaney *et al.,* 2009; Dixon, 2010; Hagopian and Rubenstein, 1990; Heidrich *et al.,* 2009; Inman *et al.,* 2011; Jefford *et al.,* 2011; Jensen *et al.,* 2011; Mordenti *et al.,* 2013; Munro *et al.,* 1994; Sardell *et al.,* 2000; Smithies *et al.,* 2009; Young *et al.,* 2010; Young *et al.,* 2013; Zhang *et al.,* 2013; Zheng *et al.,* 2013), four were described as standard of care interventions (Archer *et al.,* 2014; Craven *et al.,* 2013; Hafiji *et al.,* 2012; Kelly *et al.,* 1999).

The second category (n = 21) described heterogeneous psycho-educational interventions, delivered by a variety of healthcare professionals (psychologists, physiotherapists, social workers, counselors and health educators), with predominantly nurses. Fourteen studies reported psychological interventions which included counselling (Alter *et al.,* 1996; Badger *et al.,* 2013; Barsevick *et al.,* 2002; Kim *et al.,* 2011; Marcus *et al.,* 1993; Marcus *et al.,* 2010), coping strategies and skills training (Campbell *et al.,* 2007b; Kilbourn *et al.,* 2013), problem solving (Hegel *et al.,* 2011; Steginga *et al.,* 2008), self-management (Cimprich *et al.,* 2005), cognitive behavioural skills training (Sandgren *et al.,* 2000) or intimacy enhancement programs (Reese *et al.,* 2012; Reese *et al.,* 2014). Educational and supportive interventions were described in seven studies, varying greatly in timing and duration (Cox *et al.,* 2005; Donnelly *et al.,* 2013; Garrett *et al.,* 2013; Kimman *et al.,* 2010b; Livingston *et al.,* 2010; Salonen *et al.,* 2009; Wilmoth *et al.,* 2006).

The third category was telephone follow-up (TFU) in lieu of standard hospital follow-up. These interventions involved general and cancer symptom monitoring with information and support following diagnosis and treatment (n = 6). The content and timing of the intervention reflected standard of care follow-up – changing only the mode of service delivery. All interventions were nurse-led and seen within specific patient groups - breast (Beaver *et al.,* 2009; Beaver *et al.,* 2010), colorectal (Beaver *et al.,* 2012) and prostate cancer (Anderson, 2010; Booker *et al.,* 2004; Leahy *et al.,* 2013).

4.2.6 Acceptability outcome data

Outcome data has been summarised in Appendix 9 (Liptrott *et al.,* 2017). This table is intended to demonstrate the range of factors potentially impacting on the acceptability of the intervention, according to data type and quality. Scales and quantitative data provided more generic information directed at positive aspects of interventions

including convenience, accessibility, overall satisfaction and the patient-HCP relationship. In contrast, qualitative data gave further insight into opinions of intervention-specific components and negative perceptions of aspects of the interventions. Consistency of findings across studies has been indicated.

4.2.6.1 Consistent findings across intervention categories

High-quality evidence frequently supported the view of convenience provided by telephone-based interventions in terms of aiding personal organisation (Beaver *et al.*, 2010), saving on time and travel (Campbell *et al.*, 2007b; Jefford *et al.*, 2011), and surmounting participation restrictions (Campbell *et al.*, 2007b). Seven studies providing lower quality data confirmed these findings (Alter *et al.*, 1996; Anderson, 2010, Booker *et al,*, 2004; Cox *et al.*, 2008; Hafiji *et al.*, 2012; Hegel *et al.;* 2011, Sardell *et al.*, 2000). Positive experiences of the intervention process were apparent in both higher and lower quality evidence across the three intervention categories (Beaver *et al.*, 2010; Donnelly *et al.*, 2013; Jefford *et al.*, 2011; Zheng *et al,*, 2013), including reports of patient acceptance (Zheng *et al.*, 2013) and call appreciation (Donnelly *et al.*, 2013). Lower quality evidence mirrored these findings in 18 studies suggesting helpfulness or usefulness of the intervention (Barsevick *et al.*, 2002; Cimprich *et al.*, 2005; Delaney *et al.*, 2009; Garrett *et al.*, 2013; Hafiji *et al.*, 2012; Hagopian and Rubenstein, 1990; Heidrich *et al.*, 2009; Inman *et al.*, 2011; Kelly *et al.*, 1999; Kim *et al.*, 2011; Livingston *et al.*, 2010; Marcus *et al.*, 2010; Mordenti *et al.*, 2013; Munro *et al.*, 1994; Reese *et al.*, 2012; Reese *et al.*, 2014; Salonen *et al.*, 2009; Steginga *et al,*. 2008), ease of participation (Reese *et al.*, 2012; Reese *et al.*, 2014) and appreciation for the calls (Dixon, 2010).

High levels of overall satisfaction was prominent in low-quality evidence across the intervention categories (Alter *et al.*, 1996; Anderson, 2010; Badger *et al.*, 2013; Beaver *et al.*, 2009; Booker *et al.*, 2004; Cox *et al.*, 2005; Craven *et al.*, 2013; Garrett *et al.*, 2013; Hafiji *et al.*, 2012; Hagopian and Rubenstein, 1990; Hegel *et al.*, 2011; Heidrich *et al.*, 2009; Jensen *et al.*, 2011; Kilbourn *et al.*, 2013; Kimman *et al.*, 2010b; Leahy *et al.*, 2013; Sardell *et al.*, 2000; Steginga *et al.*, 2008; Zhang *et al.*, 2013). Comparative control group analysis in three studies provided confirmation of a statistically significant greater satisfaction with telephone-based intervention in comparison with standard hospital care (Beaver *et al.*, 2009; Jensen *et al.*, 2011; Zhang *et al.*, 2013).

4.2.6.2 Treatment side-effect/ toxicity monitoring

High quality data in side-effect and post-treatment monitoring interventions suggested the telephone-based method as more comfortable (Jefford *et al.,* 2011), providing timely access to HCPs who could address concerns (Jefford *et al.,* 2011), a finding echoed within lower quality data (Delaney *et al.,* 2009; Hafiji *et al.,* 2012; Inman *et al.,* 2011; Kelly, 1999). Of note, high-quality evidence from post-surgical monitoring interventions highlighted continuity of care - aiding in the transition from hospital to home (Archer *et al.,* 2014), facilitating the return to a "normal life" (Zheng *et al.,* 2013) and promoting mutual communication (Archer *et al.,* 2014). While one study illustrated high-quality evidence of psychological support (Zheng *et al.,* 2013), lower quality evidence encapsulated concepts with more emotive terminology. This included the advantage of having someone to talk to (Smithies *et al.,* 2009), being listened to (Dixon, 2010), cared for (Hafiji *et al.,* 2012; Hagopian and Rubenstein, 1990), calls showing concern (Inman *et al.,* 2011) and reducing the sense of isolation (Kelly *et al.,* 1999), especially in interventions of a longer duration. Interestingly, support provided was not always deemed necessary, especially in cases where personal support systems were already existent (Young *et al.,* 2013).

There was conflicting evidence of the impact of the telephone intervention on the patient–HCP relationship. High-quality findings highlighted difficulties in dealing with emotions by telephone (Jefford *et al.,* 2011), with agreement from low-quality evidence, where a lack of emotional support (Young *et al.,* 2013), a lack of "enhanced care giving" (Mordenti *et al.,* 2013) and generally poorer understanding of the patient's situation (Young *et al.,* 2013) were described. In contrast, other lower quality evidence stated positive opinions of the patient–HCP relationship (Cirillo *et al.,* 2014; Cox *et al.,* 2008; Dixon, 2010; Sardell *et al.,* 2000; Young *et al.,* 2013). Lower-quality evidence made reference to components of the intervention structure that appeared to be key in its success. These included the need to ensure appropriate call timing (Sardell *et al.,* 2000; Young *et al.,* 2010), the frequency of calls (Hafiji *et al.,* 2012; Kelly *et al.,* 1999), the importance of patient choice to receive the intervention (Hafiji *et al.,* 2012), and consideration of and potential solutions for dealing with language difficulties in telephone based interventions (Young *et al.,* 2010).

4.2.6.3 Psycho-educational interventions

Evidence from high-quality data regarding psycho-educational interventions suggested a telephone-based approach was useful especially when dealing with sensitive subjects (Campbell *et al.,* 2007b), providing a sense of control (Wilmoth *et al.,* 2006). Low-quality data findings described the availability of support (Cimprich et al, 2005), the availability of someone to talk to (Salonen *et al.,* 2009), providing reassurance (Livingston *et al.,* 2010), and having access to a responsive HCP who understands and cares (Marcus *et al.,* 2010). Significant numbers of participants reported contact by telephone to be the most valuable component of the intervention (Marcus *et al.,* 2010). Preference for a telephone-based intervention was not the same for all, with one study revealing the impersonal nature of the method (Kilbourn *et al.,* 2013) as a barrier to discussions.

The structure of the intervention was a recurring theme within psycho-educational interventions, with high-quality data eliciting the utility of a structured intervention to aid memory (Wilmoth *et al.,* 2006), encouraging patient motivation and accountability within the context of an exercise and diet programme (Donnelly *et al.,* 2013). While lower quality evidence suggested that on the whole, calls were appropriately timed for these interventions during the patients pathway (Cimprich *et al.,* 2005; Donnelly *et al.,* 2013, Kilbourn *et al.,* 2013, Kim *et al.,* 2011; Salonen *et al.,* 2009; Sandgren *et al.,* 2000), lack of control over call timing was highlighted (Sandgren *et al.,* 2000), as well as treatment side effects impacting on the feasibility to participate in counselling calls (Kilbourn *et al.,* 2013).

Lower quality evidence raised the issue of appropriateness of a telephone intervention as a blanket measure for all patients, challenging this on the basis of the temporal and variable nature of individuals needs (Zheng *et al.,* 2013). Alternative methods of support were preferable for some patients such as group sessions (Cimprich *et al.,* 2005) or face-to-face contact (Sandgren *et al.,* 2000), with some participants reporting the intervention as unhelpful due to already existent support (Kilbourn *et al.,* 2013). Despite these findings, positive perceptions of the patient–HCP relationship such as good rapport were stated (Reese *et al.,* 2014). There was also high satisfaction with technical competence (Kimman *et al.,* 2010b; Reese *et al.,* 2014), and high levels of preference for telephone-based interventions (Kilbourn *et al.,* 2013; Reese *et al.,* 2012; Reese *et al.,* 2014). Interestingly, two studies reported preference as an interpretation of negatively

worded indicators—with participants "not at all" worried about calls (Livingston *et al.,* 2010), and 0% of patients "complained about the interview to the interviewer" (Marcus *et al.,* 1993).

4.2.6.4 Telephone follow-up interventions

With regard to TFU as a replacement to routine hospital follow-up, high-quality evidence highlighted the importance of access to HCPs, in order to deal with issues in a timely manner (Beaver *et al.,* 2010). The "normality" of telephone based communication made this easier (Beaver *et al.,* 2010), and use of a structured intervention facilitated organization of thoughts and review of topics (Beaver *et al.,* 2010). Despite this, some participants missed peer contact and reassurance provided by a physical examination, with consultations by telephone said to be rushed and impersonal.

4.3 Section three: Discussion

This systematic review addressed the need to identify and synthesis evidence in relation to patients perceptions of acceptability and satisfaction with telephone-based supportive interventions during or post treatment for cancer.

4.3.1 Summary of findings

A systematic review of the acceptability of telephone-based interventions for adult cancer patients was conducted. This review identified 48 articles which reported on 50 studies. As determined by appropriate and validated quality appraisal tools, the overall quality of the existing evidence base was not high.

Primary research only was included in the review included with notable variability in sample size. "Pilot" or "feasibility" studies were of smaller sample sizes whilst larger samples were evident in service evaluations. Self-selection of participants was evident, highlighting possible selection bias. The challenge in comprehending total numbers of patients approached and subsequently accepting to participate in the intervention is ambiguous for the majority of studies. Similarly clarity of participant characteristics was marred by inconsistent reporting of data in relation to those participating in the evaluation and their representativeness of the total group.

Short quantitative questionnaires were the most frequent method of acceptability and satisfaction evaluation, the majority of which were neither standardized nor validated. This provides at best generalized, preliminary findings. It is acknowledged that quantitative outcome assessment can be patient-centred, particularly if developed from rigorous qualitative insight, however findings in this review demonstrated that the scales used did not always reflect the complexity and breadth of patient identified concerns highlighted with more open-ended designs. This was especially evident where intervention specific issues arose and in permitting negative opinions of the intervention.

In order to address such issues, quantitative tools should be developed enabling respondents to be critical, as well as positive about their experience, incorporating components that explore patient perceptions of the intervention utility, convenience, accessibility, timing, and communication preferences. It is recognized that patients tend towards positive responses on such instruments (Bradley *et al.*, 2007), and therefore reliance exclusively on quantitative data may cause unintentional bias in findings. Similarly the potential for a ceiling effect, makes differentiation of clustered upper end results challenging to interpret (Dell-Kuster *et al.*, 2014). Engaging in mixed methods research or qualitative approach may, as such, be more appropriate.

Qualitative research permits in-depth exploration of patient perceptions, with acceptability defined according to the patient own priorities and concerns. The aims and objectives of the study will however direct the conduct of the research. Stand-alone studies may explore intervention acceptability from a neutral standpoint, whilst a nested process evaluation is often motivated by the aim to understand positive or negative intervention effects. The specific objectives will therefore determine to a degree the reporting of strengths or limitations of such an intervention. Stringent development of evidence-based interventions requires consideration of all viewpoints. With this in mind, eligible qualitative studies were included in the review, irrespective of design or primary objective.

A number of consistent and potentially important findings were unveiled from the review despite heterogeneity in the intervention categories and data collection methods. Convenience was a key factor of telephone-delivered interventions and prominent

across all intervention and data types. Positive personal experiences were also recounted across intervention types, being particularly evident in side-effect/ post-treatment monitoring and psycho-educational interventions, where such enhanced communication was an additional component to standard care. TFU as a replacement to routine hospital follow-up received more negative feedback, leaving some patients lacking assurance. These differences infer that the intervention nature and context may be influential on patients perceptions of acceptability and satisfaction.

Side-effect and post-treatment monitoring interventions emphasized the importance of accessibility to care. Telephone-based interventions were commonly reported as a source of timely reassurance and continuity of care. Calls also provided information to deal with practical issues, recognized within the literature as one of the most important factors of supportive care throughout the cancer trajectory (Husson *et al.,* 2013). Some patients, described difficulty in receiving emotional support during the interventions, which may be due to a lack of discussion around psychosocial well-being issues in general terms (Taylor *et al.,* 2011). The incorporation of psychosocial component and a more holistic approach may facilitate in addressing this practice gap.

Patient choice is apparent throughout the review, in terms of satisfaction with the composition of the intervention, but especially in recurrent findings relating to a lack of choice over the method of intervention delivery and call timing. Higher and lower quality data suggest intervention utility can be enhanced where framed by and responsive to individual patients needs rather than as a one size fits all approach. Participation and involvement of patients in care planning is identified as a core element of patient-centred care (Kitson *et al.,* 2013), without which, may lead to wasteful application of services and resources. Distinct identification of individual patients' needs at specific time points and giving choice of access to services may aid in providing a more patient-centred approach to care.

The majority of studies indicated the potential positive effect of telephone-delivered interventions on patient–HCP relationships and communication with the healthcare team, however a small number alluded to a negative impact, and patient preferences for alternative methods of contact. Whilst these findings were predominantly evident in lower quality quantitative data, they were also mirrored in some studies providing

higher quality qualitative data. The data does not however provide detailed information with regards to motivators for such responses. The impact of the telephone as a method of intervention delivery and its impact on the HCP–patient relationships is one area that may benefit from more in-depth qualitative investigation into different stakeholder perspectives.

High levels of overall satisfaction were reported within this review, however, it is important to highlight the context of the evaluation when interpreting these results. Often findings from low-quality data were given during the delivery of the telephone intervention, with potential for respondent and social desirability biases impacting on the liberty to express true perceptions. Despite overall satisfaction being a "comforting" indicator, it does not provide ample detail to enable key features of intervention designs to be identified and therefore expanded upon.

4.3.2 Strengths and limitations

This systematic review is the first to the authors knowledge investigating published literature surrounding patients' acceptability and satisfaction of telephone-delivered for cancer patients both during and following treatment. Data from various research strategies has been included in the review. The methodological approach to the systematic review was comprehensive and transparent, employing a protocol for the review and a detailed search strategy permitting identification of the majority of articles meeting the inclusion criteria. The decision to include both qualitative (nested and non-nested) and quantitative designs increases the probability that the full extent of responses to acceptability of telephone-based care is included within this synthesis. Correlation between data from stand-alone and nested process evaluations supports the significance of such components determining acceptability in practice.

There are limitations to the review which are also acknowledged. While it is recognized that telephone based supportive care interventions may be provided by non-qualified HCP's (e.g. peer support), only interventions delivered by HCPs were included within this review in order to have a more homogenous level of educational training. This review excluded studies that were not published in English, and although a detailed protocol was developed for the review, it is recognized that there is the potential for relevant studies to have been unintentionally missed. It is also acknowledged that the

quality appraisal of acceptability outcome data was based on criteria developed following in-depth discussion between the author and supervisory team, and not based on published tools. Whilst the rationale are given for qualitative investigation or open-ended questioning as the 'gold-standard' for reporting, this may be seen as introducing bias. The attempt to synthesise acceptability data from such diverse approaches to both qualitative and quantitative data collection, meant that neither a meta-synthesis nor meta-analysis were feasible. The thematic synthesis performed with qualitative data and narrative synthesis of quantitative data in relation to each of the identified intervention categories, was performed in order to give meaning to findings within the specific category context itself.

4.3.3 Conclusions

In conclusion, this systematic review provides insight into current published research pertaining to patients' perceptions of acceptability and satisfaction with telephone based interventions to provide support during or after treatment for cancer. Telephone based interventions are a means to improve accessibility of healthcare initiatives to a variety of patients, and therefore deserves further investigation. Whilst the use of telephone delivered interventions has expended, particularly in the form of smaller 'pilot' or 'feasibility' studies, often participants' perspectives are not explicit within the study aims and subsequently not part of a rigorous study design, which has resulted in several reports of low quality qualitative data derived by means of post hoc comments or informal feedback.

Suggestions for subsequent research should consider incorporating a high quality qualitative component, so as to ensure participant individuality and personal experiences are captured. Although there is difficulty in generalising findings due to the disease-specific nature of the majority of studies and variability in the nature of the interventions, some consistent data has emerged permitting a constructive understanding of patients' perceptions. Current evidence in relation to the acceptability and satisfaction of support delivered by telephone for cancer patients during or after therapy suggests it is convenient, provides significantly positive personal experiences, and enhances patients' accessibility to HCP's, allowing for a familiar environment to facilitate sensitive healthcare discussions. The data synthesis suggests greater need for a clearer and in-depth understanding of patients needs in order to develop patient-centred interventions that reflect the individual's needs and choices.

Chapter 5: Study 1 - Exploration of the needs of haemato-oncology patients and experiences of a telephone intervention for support and symptom management

This chapter describes the working methods and findings from Phase 1 of the research: Study 1 – semi-structured interviews with patients. There are three sections to the chapter.

Section one contains the working methods including aims, study design, sampling strategy, data collection and analysis methods.

Section two provides the analysis and resulting themes from the qualitative data.

Section three discusses the findings and examines the strengths and limitations of the research.

5.1 Section One: Working Methods

5.1.1 Background to the study

As described in Chapter 1, a routine service of telephone support was provided on an as required basis by nursing staff, for patients with haemato-oncological malignancies whom were felt needed further support after leaving the hospital. Patients were called by an experienced nurse from the inpatient unit, but not necessarily a nurse directly involved in the patients' care. Calls were performed 2-3 days after therapy or discharge, to see if they had any problems, needs or questions.

In developing services for patients, feedback is crucial and satisfaction with care and services is central in evaluating quality (Martin *et al.*, 2007). Anecdotal feedback from patients suggested that the intervention was useful and increased perceptions of safety at home, however a more rigorous evaluation and high quality evidence of acceptability for patients in the intervention was lacking. This indicated a need to understand perceptions and experiences of patients having received telephone-based intervention to address their needs, and provide support. In order to gain a more detailed insight into this area, facilitate understanding of the utility of the service for patients and identify any potential areas for improvement, qualitative methods were employed.

5.1.2 Aims of the study

The aims of the study were to:

- determine the needs of haemato-oncology patients during treatment and post-treatment phases of the cancer trajectory.
- explore patients perceptions of the telephone intervention
- examine potential barriers and facilitators to their participation in a telephone support intervention

5.1.3 Study design

The purpose of this phase of research was to investigate the perceived needs of patients and their perceptions and experience of the telephone intervention, and what makes this method acceptable or unacceptable. A qualitative approach to research was chosen employing semi-structured interviews with patients, in order to enhance comprehension of the topic by means of in-depth exploration through patient centred data of the meanings and experiences for patients.

5.1.4 Ethical approval

A research ethics committee application was submitted in October 2014 to the European Institute of Oncology ethics committee; a favourable opinion was obtained in November 2014 (Ref: R164/14 IEO175) (Appendix 5.1). Subsequently an application was submitted to the University of Manchester Committees on the Ethics of Research on Human Beings in 01/2015; where amendments were requested. These amendments were re-submitted for ethical approval to the European Institute of Oncology ethics committee 06/2015 (Amendment 1), who then requested an agreement for data sharing which was drafted by the author and after modifications by both the European Institute of Oncology and University of Manchester legal teams, both gave approval and signatures.

The application was resubmitted to the European Institute of Oncology in June 2015; a favourable opinion was obtained in June 2015 (Ref: IEO 175 RE545/1) (Appendix 11). Subsequently an application was submitted to the University of Manchester Committees on the Ethics of Research on Human Beings in 01/2015 (Amendment 1); where a favourable opinion was obtained in 07/2015 (Ref: ethics/15005) (Appendix 12).

A research ethics committee application was submitted in 10/2015 to the European Institute of Oncology ethics committee for an amendment to the inclusion criteria (Amendment 2); a favourable opinion was obtained in 12/2015 (Ref: IEO 175 RE682/2) (Appendix 13). Subsequently an application was submitted to the University of Manchester Committees on the Ethics of Research on Human Beings in 12/2015; a favourable ethical opinion was obtained in 01/2016 (Ref: 15005) (Appendix 14).

5.1.5 Sample

As the issue of importance for this study were the needs of patients undergoing or having undergone treatment for their malignancy, and experiences related to a telephone intervention, this leads to focus on a specific cohort of patients. In this case, the sampling frame – the population from which the sample was drawn (Trochim, 2006), included all patients with haematological malignancies treated at the European Institute of Oncology (EIO), who received the telephone intervention.

However, although a homogenous sample can reduce variation and allow for a simpler analysis (Polgar and Thomas, 2008), this limits the capture of experiences in a wider group of patients. Using maximum variation would address this, yet there were felt to be particular characteristics of interest, which stemmed from the initial investigation of the literature, which needed to be prioritised

Stratified sampling was therefore chosen with sampling sub-groups being informed by the literature – gender (male / female), age ($\leq$30years old / >30 years old) and distance from the EIO (within the local region (Lombardy) or outside of local region (non-Lombardy)) (Table 5). The aim was to capture a diversity of perspectives, yet allow for some comparison between sub groups. The sample size was determined to reflect the stratified sampling approach of 24 patients, with each sub-group consisting of 3 patients, in order to facilitate a comparison between groups.

Table 5 – Study 1: Sampling matrix

	Patient characteristics							
Gender	Male				Female			
Age	≤30		>30		≤30		>30	
Locality	L	NL	L	NL	L	NL	L	NL
Number of patients	3	3	3	3	3	3	3	3

L – Lombardy, NL – Non-Lombardy

During the early stages of data collection, identification of potentially eligible participants highlighted a significant number of patients were either no longer treated at the hospital, or deceased. Moreover, many eligible patients approached did not remember having received the telephone intervention. It was evident that the potential for recruitment to the proposed subgroups was not feasible, in particular patients under 30 years of age. For this reason, it was decided by the author and agreed with the supervisory team to amend the protocol, modifying the sampling frame to include all patients with haematological malignancies treated at the European Institute of Oncology (EIO), who received the telephone intervention. The proposed sub group analysis in relation to participants age, was therefore not feasible, however for the purpose of the analysis, the sub group analyses were therefore extended to ≤ 40 and > 40 years of age in order to facilitate the comparison of younger and older patients perspectives.

5.1.5.1 Inclusion and exclusion criteria

Patients were eligible if they had a histologically confirmed diagnosis of a haematological malignancy, had received treatment within the Division of Haematology at the European Institute of Oncology (EIO), had received at least one telephone call providing support / information from the haemato-oncology nurses from the Division during or after their treatment, were aged ≥ 18 years at time of telephone support, and had provided written informed consent. Patients were ineligible if they were participating in (at the time of seeking consent) or had participated in a clinical trial at the time of the telephone support provided (observational and retrospective studies involving data collection only were permitted).

5.1.6 Recruitment procedures

Potential participants were identified by the author from existing telephone support records. The author gained permission from the Consultant responsible to approach patients and following agreement, patients were provided with an Italian version of a Patient Information Sheet and Consent Form (Appendix 15: Italian version, Appendix 16: English Version). Patients were then given the opportunity to read the consent form and speak with the author, who provided further information as necessary. The voluntary nature of participation was stressed, and the patients right to withdraw at any time. Patients were offered at least 24 hours to read the Patient Information Sheet and Consent Form, and consider whether they wished to participate in the research study. Although the majority provided written consent at least 24 hours prior to the interview, some patients wished to provide written consent in the same day as having been approached and then be interviewed. This was often due to logistical reasons as they lived some distance from the hospital, and did not wish to return or conduct the interview by telephone. Patients were given the opportunity to decide if they preferred the interview as face-to-face in a dedicated private room at the hospital or by telephone.

5.1.7 Data collection

Demographic data was collected after obtaining written informed consent from clinical notes and existing telephone support records on the data collection sheet, defined for the study (Appendix 17). Qualitative data was collected by means of in-depth interviews with patients, focusing on individuals needs during and after treatment, and their views of the telephone support intervention received, in order to gain "*as complete a description as possible of the experience that a participant has lived through*" (Giorgi, 2009, p. 122), ensuring confidentiality and allowing for focus on the individual. For patients agreeing to take part, and after obtaining written consent, patients were offered the possibility to participate in the interview at their convenience, either face-to-face within a private room in the hospital, or via telephone. The interviews were undertaken in the patients' native Italian language, digitally recorded and transcribed verbatim by the author into Italian and then into English language. It was agreed by the author and supervisory team that the author perform the dual role of researcher/ translator for this study for several reasons. Firstly, the author was fluent in both Italian and English language, being native a English speaker, and having worked directly with haemato-oncology patients in Italy since 2006. Whilst it is acknowledged that there is an

argument for back translation to ensure the text is concordant with the translated version (Edwards, 1998), both time and funding issues were limiting factors making this unfeasible. It was also felt that as the author was fluent in both languages, the author as translator had the opportunity to deal with issues of meaning equivalence and interpretation within the research process (Temple and Young, 2004), beginning from the point of data collection in the patients native language. Translation of the full transcript took place before any analysis or coding was performed. Although it is recognised that this severs the link between the language and the identity/ culture (Temple and Young, 2004), it was necessary for the supervisory team to have access to the full transcript data in order to provide feedback during the data analysis process. Language considerations in qualitative research are discussed in Section 3.3.5.4. Field notes were also made during the interviews as an aide memoir to the context of patients comments.

A semi-structured approach was used (Patton, 1990), asking key questions, yet allowing the patient to expand in further detail or bring in new areas of personal importance. A topic guide was developed, the detail of which was based on findings from the literature regarding needs of cancer patients, and the synthesis and findings from the systematic review (Appendix 18a). This involved a series of open-ended questions, beginning with generalised questions about the patients' diagnosis and treatment, then moving on to more specific questions about the telephone intervention. As the interviews were transcribed and made available to the supervisory team for review, the interview schedule was adapted to reflect further areas of interest and focus for the interviews (Appendix 18b).

In order to safeguard patients' rights and privacy, patients were made aware of the voluntariness of participation and could withdraw consent at any time. In all cases, interviews were recorded and transcribed verbatim by the author, with identifiable data anonymised by use of a Unique Participant Number (UPN). Recordings were transferred onto CD's, and together with the transcriptions were filed in a locked cabinet at the European Institute of Oncology. Translated transcriptions sent by email to supervisors were sent as password protected documents via password-protected computers. It was acknowledged that participation and sharing of somewhat sensitive information may be a cause of distress and patients were encouraged to signal any

questions they did not wish to answer. Measures were also devised to ensure patient support both during and after the interview by means of an interviewee distress protocol (Appendix 19), with referral to the psycho-oncology department, provision of further information where appropriate, and/or referral to a member of the haematology medical team as appropriate.

Whilst the sample size of 24 was set initially to reflect the sampling subgroups, it was acknowledged that the sample size was indicative and the aim was to achieve saturation of data. For the purpose of this study data saturation defined following guidance from Guest *et al*. (2006) where no additional new information is attained from interviews.

5.1.8 Data analysis

The theoretical approach for this study was applied qualitative research or data driven approach as described in section 3.3.4.2. In this study, data collection and analysis were carried out simultaneously as recruitment and interviewing took place.

The analysis was aimed at addressing the specific question about patients' needs and perceptions of a telephone intervention, in order to identify what makes this method of support provision acceptable or unacceptable. With this in mind, Framework Analysis is the appropriate approach of applied research, which can aid in informing practice (Ward *et al.,* 2013). The flexible yet structured approach also assists in providing a clear and comprehensive approach to the research process, ensuring transparency of the decision making process (Swallow *et al.,* 2011) in data analysis.

Data analysis followed the steps of the Framework Analysis respecting the key stages of familiarization; coding; developing and applying a working analytical framework; charting, and interpretation (Gale *et al.,* 2013).

Transcripts were analysed line by line to identify patients' needs, and their experiences and views surrounding the telephone intervention received and means to improve such a service. Excel spread sheets were used in the management of data. Codes were derived from the data and grouped into coherent themes. Coding was performed by the author and checked by 2 supervisors, giving feedback during all stages of data analysis. Disparities in coding were discussed and resolved between the author and supervisors.

5.1.9 Ensuring rigour within the study

Several measures were employed to safeguard rigour within the study. In order to address the need to demonstrate credibility, the sample of patients interviewed were patients having been diagnosed with a haemato-oncological disease and having received a telephone intervention. These patients were therefore suited to provide in-depth insight into the issues of interest.

Data collection was performed by the author (moderator) for all interviews using semi-structured topic guide to facilitate consistency enhancing reliability and equivalence, yet allow individual exploration of important topics. Member checking (Denzin and Lincoln, 1994) was undertaken during the interviews where the author paraphrased issues arising so as to verify the patients thoughts of the authors comprehension.

All interviews were performed in Italian language, and transcribed verbatim. All interviews were then translated following a semantic and context equivalent approach into English language by the author prior to analysis, in order to ensure the supervisory team could review all interviews. The rationale for the author as translator has been discussed in further detail in section 5.1.7 of this chapter. The subsequent development of codes, sub-themes and themes was undertaken by the author, so as to enhance internal consistency of coding, but transcripts and coding were reviewed by the supervisory team, facilitating recognition of the researchers potential biases in the analysis of data.

Reflexivity

Within the context of this study, it is acknowledged that interactions with patients and personal professional experiences, background and prior assumptions may be influential on interviews performed. Rigour was ensured through the reflexivity of the author as researcher.

The author has been working in clinical settings as a Registered Nurse in oncology for 20 years and more specifically in haemato-oncology for 17 years. Her work has included various roles including ward based Staff Nurse, Clinical Nurse Specialist and more recently Research Nurse, working both in the UK and in Italy, obtaining an MSc in Clinical Nursing in 2008. During the PhD, the author has been employed as a Research Nurse within the Division of Haemato-oncology at the European Institute of Oncology in Italy, a role that encompasses both clinical and nurse-led research. In a

variety of her roles, the author has personally used the telephone as a means of communication and support provision for patients with haematological malignancies on an ad hoc basis. Investigation of patients needs, and their experiences and opinions of the telephone support received were of interest to the author in order to explore the patients perceptions of such service initiatives, and whether these are really addressing patients needs.
Prior to undertaking the PhD, the author did not have experience in performing interviews with patients. The supervisory team provided support throughout the process, being extremely experienced in qualitative data collection methods. Furthermore, the authors previous experience of data analysis was limited and was supported by the supervisory team.

As discussed within the methodology section earlier, the experiences of the researcher may influence the way in which data is collected, analysed, and its interpretation. For example, the authors prior knowledge and experience of healthcare services in two very different countries may influence expectations and interpretation of the data. Exposure to different cultural contexts may also impact on the authors interpretation of data. The interaction between the researcher-author and patient may also be influenced due to the fact that she is a nurse with extensive experience in haemato-oncology, but also is part of the same hospital Division where patients still attend for follow-up visits. Whilst it was acknowledged that an empathic approach was employed taking into account an understanding of the perspectives, feelings, experiences and views of respondents (Patton, 1990), the author was not to become a 'nurse therapist', but should maintain boundaries with the study participants (Murray, 2003). To ensure reflexivity, field notes were taken during interviews and supervision with the supervisory team was held at monthly intervals. Discussions with the supervisory team assisted in reflection of potential influences from the researchers current role and challenges to obtaining critical insights of patients.

An attempt was made to avoid relationship bias through an existing professional relationship between patients and the author. Exclusion of participants who had or were participating in clinical trials was evidenced for 2 reasons – firstly, the author was working as a Research Nurse within the Haemato-oncology Unit and may have provided support for patients who participated in clinical trials – here there is a potential

bias in interviewing patients with whom there is a direct clinical relationship, and secondly, patients within clinical trials do not receive standard care but by the nature of trial participation, are contacted on a regular basis by different clinical research team members.

5.2 Section Two: Results

Section two of this chapter presents the results of the interviews with haemato-oncology patients who had received a telephone intervention. Total sample size, demographic data and intervention data are reported. Themes and subthemes emerging from the data are also presented.

5.2.1 Patients and demographic data

Recruitment took place from October 2015 to February 2017. A total of 134 patients records identified those potentially eligible for the study, 50 were invited to participate in the study (84 patients were no longer in care at the institute or had died). 25 of the invited participants did not recall the telephone intervention, and 4 patients declined to participate. A total of 21 patients agreed to participate in the study. One patient at interview said that he did not remember receiving any telephone call from the department and therefore the interview did not go ahead. A total of 20 interviews were performed. The mean duration of the interviews was 43 minutes (range 18 to 66). Twelve interviews were conducted by telephone and eight face to face. In one case the patient wished for his wife to be present at the interview and she stayed in the room during the interview but did not comment. Summary demographic data is detailed in Table 6.

Table 6 - Study 1: Patient demographics

	Patient characteristics
Gender	Male n=11 Female n=9
Age at telephone contact	Mean 54 years old (range 25 – 69)
Diagnosis	Acute Leukaemia n=2 Indolent NHL n=2 Aggressive NHL n=14 HL n=2
Residence	Lombardy n=12 Non –Lombardy n=8
Call timing	Following discharge from autologous SCT n=7 Following discharge from allogeneic SCT n=3 During chemotherapy treatment n=8 During follow-up (post treatment) n=4
Total number of calls	Median 2 (range 1-20) Incomplete records for 10 patients

HL – Hodgkin Lymphoma, NHL – Non Hodgkin Lymphoma, SCT – Stem Cell Transplant

A total of 20 patients were interviewed, 11 male and 9 female with 12 from the local region and 8 being resident outside of the local region. The age of patients at the time of the call ranged from 25 to 69 years old, the mean being 54 years. Seven patients were $\leq$ 40 years of age while the remaining 13 patients were > 40.

Patients interviewed had received the intervention calls 2 to 6 years before. At the time of the calls, ten patients had been recently discharged from hospital following autologous SCT (n=7) or allogeneic SCT (n=3), and eight patients were still receiving chemotherapy. Four patients were contacted for follow up of late onset complications that had been noted in the outpatient clinic.

Documentation of telephone contact was incomplete for ten patients. For those where documentation existed this ranged from 1 to 20 and was a median of 2 per patient. A total number of 75 calls were documented, providing evidence of monitoring: generalised, symptom monitoring, medication adherence. There was also evidence of information provision in terms of symptom management advice and education for self-care and preventative practices, as well as organisational information for appointments and investigations. Emotional support was also documented.

5.2.2 Themes from the interviews with patients

During the interviews, patients were asked to reflect on their individual needs during treatment and post- treatment phases of the cancer trajectory, and their perceptions of the telephone intervention they had received. They were also asked to examine potential barriers and facilitators to their participation in such an intervention and whether this

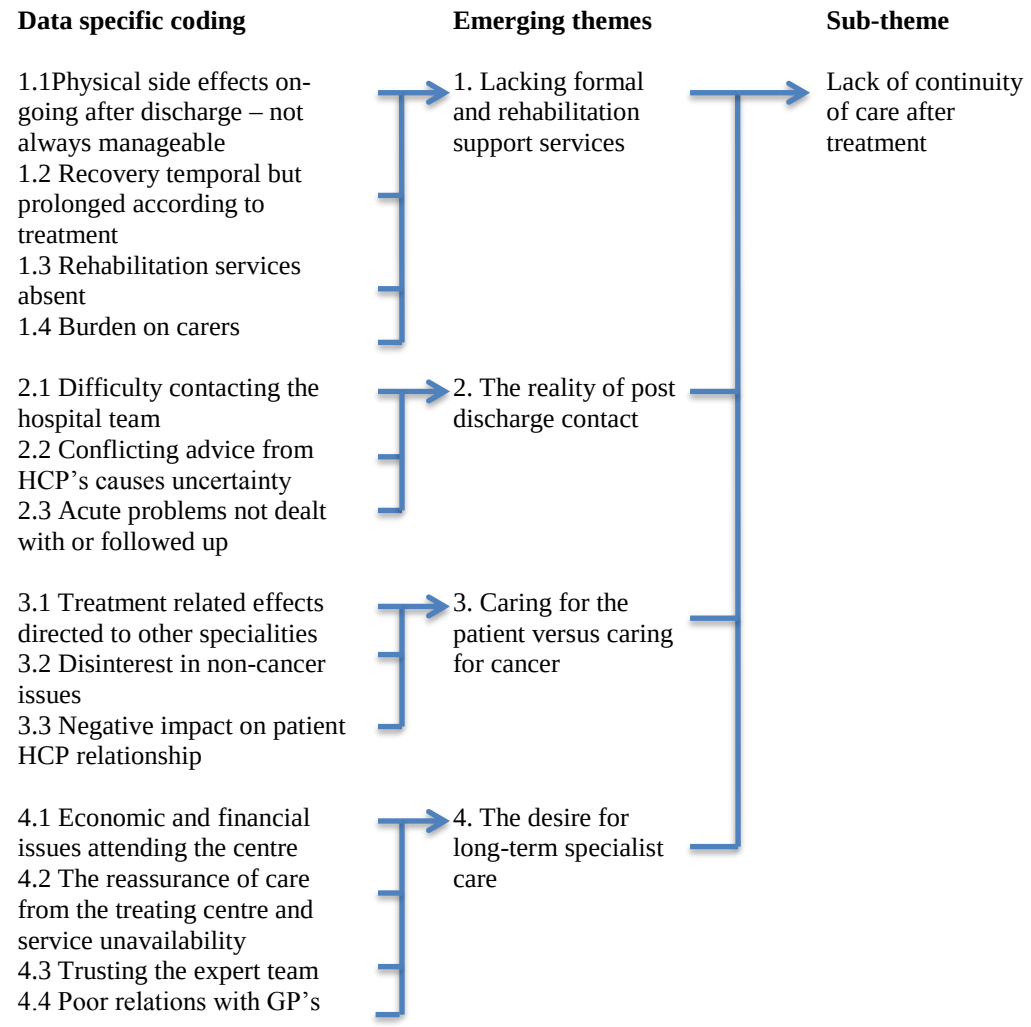
could be improved in any way. The interviews were analysed using a Framework Analysis with several sub themes being developed. These supported the development of three broad themes emerging from the analysis (Table 7).

Table 7 – Study 1: Conceptual framework outlining the main themes and subthemes from the qualitative study with patients

Main theme	Sub theme
1. Personal emotional distress and coping strategies	i. Experiences of personal emotional distress ii. Adaptive coping strategies iii. Maladaptive coping strategies and their contributors
2. Unmet needs of patients	i. Unmet psychological and emotional needs ii. Lack of continuity in care after treatment iii. Unmet information needs
3. Meeting patients' needs via the telephone intervention	i. The extent to which the intervention addresses patients' needs ii. The acceptability of the telephone as a method for addressing need iii. Refining the intervention to reflect patients' perceptions

Thematic charts were developed for the main themes and related sub-themes. An example excerpt from the thematic analysis coding tree is provided in Figure 8. A complete example of a thematic chart is provided in Appendix 20. A discussion of the main themes and sub-themes are presented below.

Figure 8 – Study 1: Example excerpt from the thematic analysis coding tree – Sub Theme 2.2: Lack of continuity of care after treatment



5.2.2.1 Theme 1: Personal emotional distress and coping strategies

One main theme surrounded patients' experiences of personal emotional distress and the coping strategies adopted to deal with this.

5.2.2.1.1 Experiences of personal emotional distress

Variable and fluctuating emotions were reported across the cancer pathway being time point dependent. Specific issues were highlighted in relation to the challenge of the unknown, feelings of loss and the link between physical and psychological well-being.

Personal emotional distress was evident across the cancer pathway where patients were challenged with unfamiliar situations, especially where uncertainty existed. In patients'

accounts of events leading up to diagnosis, emotional distress was common. One patient considered attending a 'cancer centre' as devastating, emphasising the seriousness of the situation, which was followed by a sense of 'limbo' waiting for results. While for one patient diagnostic confirmation of cancer provided relief after protracted uncertainty, the majority of patients felt this was a significantly stressful time experiencing a range of negative emotions including shock, despair, fear, defeat, and confusion. Patients recounted their uncertainties for the future - whether the cancer could be treated, cured, the outcome and their fear of dying. The wait for treatment was also stressful, filled with apprehension and anxious expectations of treatment side effects. Patients without prior experience of hospital admissions reported even the prospect of being in hospital as traumatic. Similarly, impromptu clinical events or minor complications and their effects on treatment effectiveness were also a source of distress.

> *"…even if you're cured, found the right hospital, it's always the person that is hit by this thing here, it's always tragic"* (P15, F, age 63, Lombardy)

In addition, for patients being discharged following chemotherapy as an inpatient, emotional distress was linked to the shift of care. Leaving the security of the hospital environment for home, brought a sense of increased risk, which was exacerbated in those living far from the hospital. Patients discharged following SCT and instructed on self-care behaviours in order to minimise complications, found themselves in states of anxiety generated by confusion and uncertainty regarding permitted activities, taking medication, and participating in social activities which carried a perceived increased risk of infective complications. Although anxiety and distress were seen to be temporal and in general reducing over time, the majority of patients agreed that fears persisted in relation to periodic check-ups and fear of relapse especially where impromptu events or illnesses occur.

> *"you have the chemo, done, you go home…but now, I'm at home I'm agitated, I don't know what to do, I don't know what to take…"* (P08, M, age 33, Lombardy)

A recurrent theme through the pathways was that of patients sense of loss. In the early stages, this was described in relation to lifestyle, freedom and long-term plans that had been made, as the impact of diagnosis and treatment on both their own lives and the lives of significant others was contemplated. Some patients gave examples of identity

loss, moving from their status as 'citizen', 'parent', 'breadwinner' and entering into the realm of 'cancer patient', challenging performance of these roles. Socio-economic factors were also a cause of distress with some patients living outside of the region remarking on angst in relation to lost ability to work and financial concerns in terms of lost income and increased expenses for travel and accommodation to stay near the hospital, a finding reported particularly in patients with young families to support. Having cancer was believed to be an imposed situation, with patients loss of autonomy causing them to depict themselves as burdensome for family and healthcare professionals alike, requiring assistance for basic activities of daily living such as washing and cleaning. Limitations on restricted 'normal' activities, and isolation following SCT were particularly distressing.

> *"I was very autonomous as a person, very independent...and the fact of delegating ...not being able to do things… made me feel really bad .. 'now I'm a burden', I really felt that they're making a huge sacrifice for me"* (P01, F, age 32, Lombardy)

> "*I work so, I also had economic repercussions…so I had to face this thought as well, then fortunately I had a… an employer that was very… understanding… that helped me in every way, but not everyone has this fortune. There are people that lose their jobs."* (P04, F, age 44, Non-Lombardy)

In the long-term period following treatment, some patients expressed persistent emotional distress feeling fragile vulnerable, describing a cumulative lack of emotional strength, as well as significant feelings of loss due to time stolen by disease and treatment instead of fulfilling personal goals, and losing a 'normal' relationship with life that is not punctuated by treatment and tests, One patient experienced the death of a close relative during their treatment, highlighting the reality of additional external factors in emotional distress.

> *"…they take away your…normal relationship with life… I've become much less …sociable I happily stay alone more…because you can't always say to friends .. you know I don't feel like it I have to have a CT scan…or I don't want to because I'm waiting for the results…it gets a bit…arduous…so I prefer to stay on my own a bit more…the only bad thing this disease has left me is this"* (P09, F, age 66, Non-Lombardy)

Treatment for all patients involved the administration of chemotherapy delivered on either an outpatient or inpatient basis depending on the regime and whether the treatment was part of a stem cell transplant - involving a more prolonged period of hospital recovery. While emotions during this period were said to fluctuate, it was evident that physical well-being and psychological well-being during the treatment period were seen to have a linear relationship with positive physical well-being corresponding with better psychological well-being. Fewer disease and treatment related side effects and effective management strategies were important factors. The majority of patients did however experience emotional distress during the treatment period. Patients with physical side effects or complications from treatment still on-going after discharge described significant distress, feeling disheartened, abandoned, and often mentioned the frustration of imposed physical limitations. Patients also described a loss of self-confidence due to changes in physical appearance. In the later post-treatment period however, continuing physical improvements were seen positively, with several patients identifying a shift towards their previous life, leaving that of the 'patient' identity and returning to normal.

> *"…they sent me home and they gave me the impression that I'd been abandoned…like saying there's nothing else we can do, we'll send her home"* (P16, F, age 55, Lombardy)

5.2.2.1.2 Adaptive coping strategies

Patients were seen to have used a variety of personal adaptive coping techniques to deal with their emotional distress. Evidence of external coping assistance was also apparent, as well as issues surrounding accessibility and the desire for external support.

Personal adaptive coping strategies

Problem focused coping techniques targeted the cause of stress, and followed particular time points within the cancer pathway. Several patients described adoption of a pragmatic approach throughout this period, involving reasoned and logical thinking in terms of accepting the diagnosis, need for treatment, lack of outcome guarantees, short-term and long-term effects of treatment, and limitations to everyday activities. During the follow up period, it was accepted that fears persisted with hospital visits, tests and the possibility of relapse. Such events were seen as a necessary part of the pathway.

"it's not a walk in the park…but you know this…you're patient." (P03, M, age 67, Lombardy)

In contrast, some patients focused on a more proactive approach. Treatment was seen as a step towards combating the disease, feeling strength and hope. Some patients also told of their adaptation as a means to coping with cancer and treatment by devising 'new' routines when facing the inpatient stay and frequent outpatient visits. In some cases, adaptation meant taking on a more proactive role in self-care through dietary intake and medication management. For one patient, a more proactive and pragmatic approach meant preparation and organisation of practical aspects of a funeral and preparing others to be self-sufficient after her death.

"..going there (referring to the hospital) *was a habit, that day, at that hour you had to be there… so that's something that, yes you are alone but it's like your job, because it is a daily commitment, one day yes, one day no, I'd be here"* (P17, M, age 40, Non-Lombardy)

"…I thought they weren't able to face certain things so I…already started organising things to that if anything happened to me, at least they'd have some time, have the house clean so I did this, and did that…I taught them to cook, I taught my husband to do this and do that…because they weren't able to use even the washing machine…" (P16, F, age 55, Lombardy)

Emotion-focused coping techniques were evident where patients' sense of control had been challenged. Positive techniques such as cognitive reframing included focusing on the transient nature of problems, survival, remaining optimistic, and comparing oneself more positively against other patients in similar situations.

Patients also used meaning-focused coping techniques in order to gain significance from their experience, noted particularly within an older patient group. Although cancer was said to be life changing, some patients detailed how their experience enabled them to be more empathic to others in the future, feeling both personally and emotionally stronger. Patients also described how events had caused them to reflect and re-focus as well as re-prioritise aspects of their life including friendships.

"…this thing here it has to teach you something, to overcome everything…this thing means that you've touched with your hands, with your heart, all this

problem…and… you have to be above it…trivial things you put aside" (P05, F, age 57, Non-Lombardy)

External sources of coping assistance

In addition to individual coping strategies, both formal and informal sources of support were defined as a key feature in facilitating adaptive personal coping throughout the cancer pathway.

Prior to diagnosis, emotional support was prominent from informal sources such as family, friends and the religious community. At diagnosis, the majority of patients told of how external support from both informal and formal sources (the healthcare team), had been necessary in order to accept the disease, aid in adjusting to a new reality and to get reassurance. Both informal and formal sources of emotional and practical support were illustrated during the treatment period. A few patients received support from a psychologist, providing constant and personalised support and facilitating use of more complex coping techniques such as accepting the need for help, delegating, and learning self-value. This formal support was portrayed as being especially useful where family support was lacking. In particular, medical and nursing staff were illustrated to be fundamental in facilitating coping during treatment, providing reassurance and encouragement for treatment side effects.

"I always had…doctors, nurses that…helped because…during the hospital stay I was alone, I didn't have family err….they were indispensable for me (laughs) …" (P04, F, age 44, Non-Lombardy)

"the doctors came running…the psychologist came…the nurse that gave me the chemo… they all came, they made me reason, they made me let it out, open up and from that moment there, they calmed me down, they were really useful because after, I continued to have my chemo…they were interested, wanted to know if it had passed" (P15, F, age 63, Lombardy)

Following treatment and attending follow-up appointments, coping was facilitated through formal support seeking from the clinical team. Their expert opinion was highly valued, providing reassurance. Effective communication was also seen as a key factor in promoting support-seeking behaviours, especially in terms of positive communication and encouragement, facilitating open discussions about issues of importance to patients.

Similarly a positive relationship between the healthcare professional and patient was critical in building trust, with patients feeling more comfortable to seek support in contexts where they felt followed and perceived a genuine interest in their well-being.

> *" ...the people that we…have to lean on, so there's so much trust..and it's a reciprocal trust."* (P04, F, age 44, Non-Lombardy)

Support-seeking as a coping strategy was seen to be promoted by ease of access to the healthcare team via telephone outside of hospital visits. Positive experiences of gaining time sensitive advice and reassurance for a variety of complications were reported including fevers, pneumonia and thrombosis, appearing to enhance the sense of availability. One patient recounted how empowerment through shared responsibility with healthcare professionals following early discharge had also promoted perceived access to support.

> *"I called as well sometimes, it's contact…there was contact and contact is really important, you know if you have any problem you can call and they'll respond* (referring to the hospital staff)*"* (P15, F, age 63, Lombardy)

Despite some patients describing support from others as unnecessary when they had returned to normal and there were no perceived dangers, some felt on-going physical problems meant they hadn't returned to 'normal'. In one case this was viewed with disappointment but acceptance and was not something that the patient wanted support for. Interestingly, one patient describing support provision being the need of others to give support rather than the patients to receive it.

> *"It's not that I'm fine here…but I'm fine on my own so…don't worry…but…it was their thing rather than mine* (referring to family members)*"* (P02, M, age 30, Lombardy)

5.2.2.1.3 Maladaptive coping strategies and their contributors

Maladaptive coping strategies were also significant within the data. Specific issues related to self-preservation, reluctance to seek informal and formal support, and prior negative experiences influencing support seeking.

In some cases maladaptive coping was part of the patients chosen approach in self-preservation, manifesting terms of resignation where the responsibility for decision-

making was openly delegated to the healthcare team. Some patients chose to avoid using words such as 'cancer' or 'chemotherapy' so as to down grade the seriousness of events. For others, distractions such as work and social engagements were seen as important, as was maintaining control and a sense of 'normality' during the cancer trajectory - an important factor in preserving psychological well-being.

> *"…if it had stopped me doing those things, probably psychologically I wouldn't…I'd have felt…well ill…someone else…I'd have felt a...a stronger effect of the disease on the course of my life"* (P20, F, age 25, Lombardy)

Maladaptive coping was sometimes a result of patients' own reticence to seek support from informal sources. Patients were often reluctant to ask for help, as this would cause worry for others. This was particularly evident where patients were themselves carers for disabled family members or relatives with health problems that they felt would be exacerbated with increased stress. Patients commonly stated that they themselves were providers of support and reassurance for frightened and tearful relatives, hiding emotions and illness so as to protect their loved ones, who were unable to cope with the diagnosis and situation, In some cases this was accompanied by self-blame for causing the ill health of others. Such behaviours often resulted in personal and social withdrawal to hide anxieties and for self-preservation, commonly focusing on other people's problems.

> *" when the chemo was finished I came home, I did it even without my husband knowing where I was, what I'd done, my husband thought that I was at work…in the afternoon… I let my children see that I.. I was ok like so they wouldn't worry"*

The patient went on to describe her motivation for such behaviors

> *"one day I burst out crying, because I said 'goodness, my husband is ill and I'm here, I have to be well"* (P15, F, age 63, Lombardy)

While in some cases, patients were not initially averse to seeking support from informal sources such as family and friends, their own experiences had led them to employ avoidance techniques and distancing from stressful situations, turning towards personal and social isolation. Family members were described as causing greater stress for patients, and a number of patients were disinclined to accept support where family had become paternalistic, blocking patients' autonomy and reinforcing the 'patient' role.

Similarly, peer support was avoided after listening to other patients' negative experiences, which were felt to breed negativity within the patient. One patients poor physical condition meant her desire for informal support from social events was impossible and future social events were subsequently avoided. Some patients also described how family and friends lacked an understanding of the disease, and were reluctant to provide the support patients required, which also resulted in further patient withdrawal.

> *"often you find those family members that…even if they offer help, they don't want to give it…there are people that understand the disease, people that think that you've got a common cold"* (P04, F, age 44, Non-Lombardy)

Patients also indicated their unwillingness to seek formal support to aid in coping. They were reluctant to ask healthcare professionals for support, perceiving their concerns to be trivial, and only contacting the team when they were really afraid. They often did not want to be perceived as a burden to doctors seeing this as waste of their time, but would have gladly spoken to a nurse. Their adversity to asking questions was also influenced by the individual healthcare professional they were communicating with. Some patients rejected formal support from psychologists as a personal preference, while a few patients on reflection regretted not accepting or asking for support at a later time.

> *"I called only when I couldn't carry on anymore* (laughs)*…because you're really afraid...really scared…no you don't call…you hold back don't you?"* (P12, M, age 51, Lombardy)

5.2.2.2 Theme 2: Unmet needs of patients

Several unmet needs of patients were reported.

5.2.2.2.1 Unmet psychological and emotional needs

Patients described unmet needs for psychological support throughout the cancer pathway. Specific issues were evidenced in relation to the perceived lack of formal psychological and emotional support, and barriers to support from healthcare professionals. Suggestions for improvements were also provided.

A minority of patients spoke of healthcare professionals providing symptom control and emotional support prior to diagnosis, however the majority were critical of the lack of psychological support, seen as fuelled by professionals lack of interest where there was still no confirmed diagnosis. While a few patients stated they did not wish to receive formal psychological or emotional support, for the majority diagnosis was a key time point. Again psychological support was felt to be lacking – preferred by one patient to be from a psychologist, with similar reports during the treatment and early post-discharge periods. Not all patients felt they had access to a formal service, describing their need for greater emotional protection, and this service shortfall as leaving patients abandoned. Others wished for psychological support from the clinical team for patients needing to talk and those who felt alone. One suggestion was having access to a healthcare professional to talk to for support and further reassurance.

> *"…it'd be enough just to have a chat if someone needed it… for…with a professional…sometimes, even just knowing what the treatment's like, stops you worrying…"* (P18, M, age 35, Non-Lombardy)

The provision of psychological and emotional support from the clinical team was felt to be at the mercy of a variety of factors. One patient described how a shifting relationship with healthcare professionals as a result of relapsed disease, had blocked emotional support, where initial relationships were familial and protective, this had remained professional but become impersonal and detached. A person-focused approach to care was said to be lacking, creating a barrier to gaining the support desired. It was suggested that provision of psychological support also depended on the individual healthcare professional in terms of personality and skill. Likewise, patients described healthcare professionals as 'going through the motions' with visits being overtaken by bureaucracy rather than talking to patients.

> *"…I didn't have… I had a the sensation of being a bit like a car being repaired…almost like an object .. "*

the patient went on to elaborate:

> *"…I had the feeling that I was in the hands of professionals, but… I was a…a machin… good mechanics but I felt that it lacked a bit of humanity"* (P13, M, age 64, Lombardy)

Patients felt that in order to improve support and meet their needs, care should be individualised, taking into account existing support networks. Holistic support was essential, caring for the patient as a person, not solely based on a professional relationship but with a humane element and warmth. Communication was also key to providing psychological and emotional support, warranting improvement to allow patients to discuss issues that were pertinent to them. One example provided was that of problems with sexual intimacy, said to require privacy, and one-to-one communication separate from family members attending appointments. The need for awareness of both verbal and non-verbal communication was also highlighted where the healthcare professionals choice of words were seen to be a cause for concern for patients and tone of voice or a brusque manner escalated patients suffering. Instead, patients wanted communication that was genuine rather than superficial, and humanised.

> *"…even just your smile…does a lot…it can also be a…a touch...it's not just the medicine that makes…it's…the medicine that works when all around there's a context in which…tries to make it work…if one sees it from the others point of view, it's… the desire to do your best, and take off the white coat…it's really important"* (P04, F, age 44, Non-Lombardy)

5.2.2.2.2 Lack of continuity of care after treatment

One sub theme focused on patients descriptions of lacking continuity of care in terms of formal support and rehabilitation after discharge, the reality of post-discharge contact with the hospital, caring for the patient versus the cancer, and the desire for long term care from the specialist team.

In the immediate post discharge phase a number of patients were discharged from the hospital with conditions still on-going, the most common being treatment related side effects including fatigue, gastro intestinal disturbances such as appetite loss, taste changes and nausea, vomiting and dehydration, and alopecia. Some patients argued they had been unable to cope with side effects at home desiring the input of medical or nursing support. Whilst physical recovery was recognised as temporal, it was also acknowledged that the period of recovery was more prolonged for patients having undergone SCT. These patients reported that formal rehabilitation services such as physiotherapists and dieticians were lacking but necessary following discharge. The majority of patients also described limitations on everyday physical activities after

treatment such as walking, cooking, performing household chores and employed work, which meant that they required more practical support, with the burden falling on close family members and friends.

> *"I asked for the physiotherapist because I had to do some exercises on my own and I couldn't manage…one thing really lacking was physical support, because the ward had a physiotherapist… going home ... I didn't know what exercises to do"* (P01, F, age 32, Lombardy)

Patients were told that the healthcare team were still available after discharge and were advised to telephone in with problems or concerns, however their experiences did not always reflect the continuity that was suggested. Some reported difficulty in gaining access to the health care team via telephone, and when contact was made, conversations between the patient and several different healthcare professionals giving conflicting advice caused a sense of insecurity. Some side effects were medically more serious and also unpredictable in nature requiring prompt medical attention. Patients often described incidences of calling in with acute problems and being directed to local emergency services. This was because no Accident & Emergency service existed within the hospital and patients were often living over 100km away. This was however seen as a lack of continued support from the hospital and abandonment. Similarly, when problems had been reported to the hospital team, patients felt there was no follow up or interest from the team to ask about progress or improvements.

> *"…if I needed them they were there, however it wasn't like that because…in the moment of need, they told me to go to accident and emergency"* (P07, F, age 65, Lombardy)

Moreover, late effects as a result of cancer treatment were felt to be dismissed by the hospital team, seen as problems to be dealt with by other medical specialities. It was suggested that the clinical team focused only on the cancer – perceived by patients to be a lack of holistic care. Patients sensed healthcare professionals were generally disinterested in patients after discharge. In one case, this culminated in a lack of trust in the team and the patient no longer seeking help from the hospital, instead returning to the GP for support with longer term issues.

"…I realized something, that they look at their sector…then for the damage that's caused by the chemo and anything that's…the surrounding things… they don't…they're not interested…" (P16, F, age 55, Lombardy)

It was evident for the majority of patients that the hospital remained a key point of reference in the context of long term follow-up. Patients wished for economic and financial support to deal with travel and hotel costs to enable them to attend appointments. Patients sought to book scans and investigations within the cancer centre perceiving the services at the centre to be more reassuring however the lack of availability was unsatisfactory. The importance of the expert team was further encouraged by mistrust in non-specialist healthcare professionals due to previous negative experiences where delayed diagnosis had taken place, or where care in other hospitals was felt to be lacking. Similarly, the challenge of 3-way care involving patients, the GP, and the treating hospital, had left patients feeling as go-betweens, with the treating hospital directing patients to the GP and the GP directing patients to the hospital. This affirmed patients' desire for continued care from the treating hospital.

"I feel abandoned, by the fact that, I can't, I can't in any way, have a CT scan there (referring to the hospital), *where I trust them. To me having a CT scan in a hospital near home – let's be clear…maybe they are… perfect…but for me it was there* (refers to treating centre) *that saved my life …"* (P07, F, age 65, Lombardy)

5.2.2.2.3 Unmet information needs

Information was a key component in coping for many patients, however information needs were not always addressed, and the subsequent impact on coping and adjustment was highlighted. Suggestions to improve information giving were also given.

Patients need for information altered according to the situation and what information they already had access to. Information was felt to be crucial in the earlier stages of their disease, even prior to diagnosis with patients recognising they had more questions to ask. Information was sourced mainly from healthcare professionals with one patient describing reluctance to engage in informal help seeking via internet or talking with peers, prioritising information from the doctor. Others acquired information from other patients regarding side effects of treatment and tips for management. The majority of

patients acknowledged receiving information from healthcare professionals in relation to their treatment type, expected outcomes, its schedule, potential side effects, symptom management strategies and behavioural measures for patients to undertake in order to minimise the risk of complications such as infections or bleeding. Information in relation to high cure rates and remission impacted positively on psychological well-being, whilst information anticipating unpleasant or disturbing investigations, or isolation following SCT, helped in psychological preparation. Information also empowered patients, encouraging self-care in medication management at home, and aiding planning and personal organisation. Patients also commented that the ability to obtain ad hoc information in relation to unexpected events such as unexplained myelosuppression, dietary advice, and late effects of treatment, gave important reassurance.

> *"...you know what they're going to do, you're prepared...you don't get a surprise, you know that ...it's a necessary test to exclude the fact that the tumour has struck the marrow and it's important that it gets done, so in the moment they explain all these things... I think...it's better..."* (P20, F, age 25, Lombardy)

While a few patients did not wish to know about their treatment, due to preconceived ideas and perceptions that knowledge of side effects would increase fear, the majority wanted more information than had been given and suggested that not all information needs had been addressed. Some patients highlighted the desire for further information about treatment and potential side effects, while some felt deceived by this shortfall. One patient attributed this to the underlying assumption that he had already spoken with the doctor, and was therefore completely informed, whilst others considered staff workload dictated whether healthcare professionals had time to give information. On reflection, some patients held that information received concerning treatment and side effects did not match with their experiences, which were sometimes depicted to be much worse. On-going information regarding dietary advice were also seen as missing, as well as a paucity of information in relation to the future and life after treatment. One patient also described a lack of information regarding late effects of treatment on sexuality and intimacy, having many unanswered questions and gaining support from her partner rather than the healthcare team.

" …I would have liked to have known something more about what they were doing and then what would happen afterwards…what was going to happen… " (P13, M, age 64, Lombardy)

Lack of information was seen to have had a significant impact for patients. Absence of clarity and uncertainty of what to expect caused fear for patients particularly in relation to undergoing invasive procedures, and isolation after autologous stem cell transplant – an expectation reported to be much worse than the experience itself. The capacity for self-care was also impeded in some patients with examples including inadequate preparation to self-administer injections or being uninformed of what medications were 'allowed' for treating commonplace problems, necessitating permission seeking by patients. Rigid instructions were often given at discharge to transplant patients for behaviours to minimise infections and complications. These did not appear to be revisited, with patients often describing the lack of information and practical advice regarding protective behaviours meant self-imposing restrictions that were actually unnecessary. This was felt to have hampered recovery and return to normal social and daily activities.

"…I stopped myself for six months, I followed to the letter what I was told because I was afraid...of making a mess… to take something… and I followed to the letter what they told me … even if I could have done something more … like eating out ...we could have done ...but I didn't...because I didn't know exactly…how much I could do… and so I said 'no', avoid it… avoid problems " (P01, F, age 32, Lombardy)

Patients offered some proposals to improve the practice of information provision. One patient alluded to the potential for treatment information to precipitate depression and advocated a stepped approach to communication, especially when sharing information perceived as limiting everyday activities. While patients having undergone SCT acknowledged that they needed to be aware of continuing restrictions regarding activity and diet so as to avoid complications, they saw information framed in a negative way describing only limitations as inducing fear. A suggestion was to shift to a more positive presentation of what one could do instead. The desire for healthcare professionals to take more time to explain and the reiteration of information were also expressed, with a particular note on accessibility of the healthcare professional and

recognition that patients' need for information often arose outside of hospital appointments. In one case, a patient thought that the healthcare professional should take a proactive approach to information provision, as patients were often afraid to ask or did not know what to ask.

> *"…they told me things a bit at a time…so much so that I didn't know exactly what I was going up against, probably… thinking about it, I think it's really a normal practice this…someone like me… even if I've been strong, I would have dropped like a lead weight into a depression… saying things a bit at a time… it was better"* (P05, F, age 57, Non-Lombardy)

5.2.2.3 Theme 3: Meeting patients' needs via the telephone intervention

Another main theme surrounded the telephone intervention that patients had received.

5.2.2.3.1 An intervention addressing patients needs

One sub theme was the extent to which the telephone intervention had been able to meet patients' needs in terms of emotional and psychological support, patient focused continued care and addressing information needs.

The need for emotional and psychological support was evident within the data, and some patients felt that the telephone intervention had been an important resource in addressing this need, also providing words of encouragement. Patients had earlier described the importance of reassurance from the healthcare professional throughout their pathway. The telephone intervention was said to provide reassurance, an outlet and a sense of security and protection especially for those living at a distance from the hospital, and far from family support. Interestingly one patient believed that even just the opportunity to talk about physical problems promoted better psychological well-being.

> *"…that's the beautiful thing, that out of the blue it's like a friend calls you 'how are you?'…so it was beautiful because anyway it's support…when someone thinks about you… you haven't got your family nearby and you get this call, you feel good.. even if your unwell.. it picks you up.."* (P17, M, age 40, Non-Lombardy)

"I felt it inside, I felt lifted, reassured.. I felt…not worried…even if I had to do a lot of, well miles from home when I was…but hearing them (referring to the nurses who had called)*, that were interested …hearing them, I got back the enthusiasm to live, to carry on…to be strong…"* (P19, M, age 62, Non-Lombardy)

It was also seen to provide a more patient focused approach to care which the majority of patients greatly appreciated, reporting calls to be useful, important, pleasurable, and providing a sense of the importance of the patient as an individual and not a number. Patients also sensed that the calls meant they were cared for beyond the hospital setting, that someone was interested in them, ready to listen to their concerns and provide support in early periods of adjustment. Calls were also regarded as providing continuity of care following discharge with patients reporting that they had not felt alone or abandoned, and were still being followed at home.

"…the fact that someone is interested…it's really really important… I'm glad that someone is interested about things in your life…comes into your life a bit" (P10, M, age 48, Lombardy)

" …even a voice…someone is interested in me…that I'm looked after, I'm not abandoned…" (P16, F, age 55, Lombardy)

Patients also described the calls as an opportunity to address information needs. Information reiterated following hospital visits and discharge was welcomed, as well as the opportunity to ask questions. They appreciated the opportunity to gain access to real time information to address their worries or concerns.

"I asked what I felt like, what came from inside" (P12, M, age 51, Lombardy)

"this is a…a very positive thing because…it allows you to have…human contact with someone who's in the hospital, that knows your situation well and can give you indications, advice or… so surely I think it's something, something positive" (P20, F, age 25, Lombardy)

5.2.2.3.2 Acceptability of telephone method for the intervention

One important sub theme was patients perceptions of the telephone as a method to provide the intervention highlighting the perceived benefits, individual preferences, feasibility, and barriers to the use of the telephone.

For the majority of patients, the telephone as a means of communication to access support for their needs was described as acceptable providing a number of benefits. It allowed communication that was more personalised rather than being influenced by the clinical environment, saving time and money, and providing a quick resolution to problems. It was also seen as more convenient with some patients suggesting that their physical condition and distance from hospital meant that gaining support would not be feasible for them by other means. A telephone call was felt to be sufficient for some and a supplementary support between treatments, which already meant frequent hospital visits. A significant number of patients suggested that talking on the telephone was not a problem for them with regards to discussing sensitive or personal issues, a fact that was facilitated by having an already established relationship with the nurse caller.

> *"…the phone becomes…an important means, you avoid going to the place…it's a very formal thing if I come there, I have to wait… I have to go into the room like all the others…it becomes something about the hospital"* (P10, M, age 48, Lombardy)

Not all patients however gave a clear preference for a telephone-based intervention, with some being indifferent whether support was telephone-based. A small number of patients stated their personal preference was a face to face intervention for support as this would give the opportunity to ask more questions and explore more personal issues, however this was not a feasible option for them living so far from the hospital.

> *"..it's obvious that speaking face to face with someone is one thing, speaking by telephone is another, but…I obviously couldn't come because…I live in (*town outside of the local area*) and I couldn't think about having a face to face discussion"* (P14, M, age 61, Non-Lombardy)

Other patients felt that some topics were incompatible with telephone conversations such as receiving a cancer diagnosis by telephone or complex information such as the SCT process and isolation, which required physical presence to calm patients concerns.

Similarly formal psychological support with a psychologist was also seen as inappropriate as privacy was not guaranteed. Patient related barriers were also highlighted in relation to the utility the of telephone. One patient said being severely unwell had been a barrier to talking on the phone, whilst another described how feelings of depression led to personal withdrawal including the inability to talk on the phone.

> *"I was fed up of having the chemo… I didn't want to live anymore…I wanted a coffin - …I didn't want to speak to anyone…"* (P15, F, age 63, Lombardy)

5.2.2.3.3 Refining the intervention

One sub theme focused on patients suggestions to refine and improve the intervention such as the need for patient choice and patient selection, providing a more individualised and patient focused content, recommendations for call timing, frequency and planning, as well as the preferred characteristics of the caller and the role of the intervention as a supplementary element of care.

Identifying those in need of additional support

The routine service of telephone support was provided for patients deemed to be in need of further assistance by treating doctors and nurses, and whilst this was perceived positively and desirable for most patients, it was clear within the data that not all patients wanted such contact. For two patients, calls were actually seen as distressing, viewed as a reminder of the need to return hospital, and that a more serious clinical situation was afoot. For other patients calls were not indispensable as they felt they had adequate self-management strategies and did not require external support. Whilst it was suggested that calls should be proactive from the hospital team, engagement and agreement from the individual was said to be a question of individual choice as its success would be influenced by the patients willingness to participate. Despite this, supportive calls were felt to be more indicated in some situations such as where patients had physical problems ongoing, in follow up of clinical conditions, and for those living significant distances from the hospital.

> *"I wouldn't want a call to arrive, someone call me and say…instead of thinking it would be something to help me, I'd have another thought…who knows what I've got that this one keeps calling me…"* (P06, F, age 69, Non-Lombardy)

Intervention content

Calls had provided organisational information about appointments and admissions, asked about general well-being, and were used to identify needs and problems. They were often however, felt to be led by the needs of the healthcare team for symptom monitoring and to check patient comprehension of instructions, rather than focusing on patients needs. Calls were described as being brief and not of an in-depth nature, however this was not perceived negatively, rather it was the contact itself that was held as important. Patients agreed with some aspects of the existing content in their preferences for the intervention, such as enquiry of general well-being, reiteration of information and opportunity to ask questions, but suggested other aspects should be enhanced or incorporated such as greater reassurance, understanding the individuals psychological well-being and provision of greater psychological support, especially where physical issues are ongoing. More specifically, patients also wanted further behavioral advice from the intervention about activity and diet, and guidance for the future and management of long-term problems.

> *"…instead knowing that there's a person, 'look I feel like this at the moment, is it normal?, can I take anything?', that there would be really good*" (P09, F, age 66, Non-Lombardy)

It was suggested that individual experiences required individualized support, reflecting issues of pertinence to the patient at that time through evaluation of individual needs. A more person-focused approach was recommended, shifting away from a focus solely on healthcare professionals interests and treatment, towards a more improvised flexible approach. One patient hinted that calls may be beneficial not only to the patient, but also pleasurable for the healthcare professional as a follow-up and continuity for them after discharge.

> *"there's advice, and the need to see what patients need at that time.. that maybe could be done every so often"* (P01, F, age 32, Lombardy)

Call timing, frequency and organisation

The timing of the calls that were received were also determined by the nurses calling patients, and more often this was shortly after a treatment cycle, or following hospital discharge, which was described as acceptable for many. Suggestions for optimal timing for calls providing support were seen to be unpredictable and dependent on individual

need, however others highlighted a variety of different time points across the trajectory where they felt additional support of this manner had a role, including at diagnosis, whilst waiting to start treatment, and during treatment. In the early period after discharge, calls were felt to be necessary, especially following prolonged in patient stays, and where there was protracted time between hospital visits, and where patients have undergone allogeneic SCT, support was described as preferable for a few months. There was however some disagreement as to whether supportive calls were necessary longer term following treatment. While one patient would have liked to continue receiving calls for support, the majority felt calls were unnecessary, in particular as patients saw this period as having overcome the cancer and its treatment.

> *"its not a bad idea to be called to ask …an extra support, you see…it's clear that after the first…the first times that maybe they tell you something, afterwards you learn…but it's clear that the first times, absolutely, it's important to know what's happening to you"* (P05, F, age 57, Non-Lombardy)

Similarly, the frequency of the calls was variable, some being every 2-3 days whilst symptoms were ongoing, following each treatment or discharge whilst others were 2 or 3 calls over a period of months. For those who made recommendations, they suggested that in general calls could be performed monthly but the ideal frequency really depended on the individual's needs.

> *"I don't think it's something that you need continually, but even after the discharge even a call could be sufficient I think…one or two…if one has a hospital admission that's a bit longer though…I don't think it's necessary to have more frequent calls..."* (P18, M, age 35, Non-Lombardy)

Most calls were unexpected and for some the timing of the call was not ideal with patients highlighting the necessity to adapt to the nurse callers availability. When asked if there was any preference for organised appointments for such calls, choice seemed to be individual with some preferring a fixed time and date, whilst others felt this was unnecessary.

Caller characteristics

Patients recognised that it was a senior nurse that was calling, describing them as experts, humane, and an individual known to the patient making communication easier.

For some patients, the fact that they were speaking to a nurse rather than a doctor meant the possibility to talk about issues truly pertinent to patients. Patients wanted this intervention to be delivered by an experienced healthcare professional, as a single point of contact with understanding of the clinical pathway able to offer practical advice, with some patients preferring a nurse that they already knew, providing continuity and trust. It was also felt important that the caller was someone who believed in the delivery and importance of the intervention.

> *"…with them* (referring to the nurse caller)*, I could speak about…well symptoms …about pain…other things like this…instead with the doctor….he spoke more about the treatment in general and how it was going etc….it's also useful to be able to speak about…the little pain, about feeling tired…maybe more everyday things…that you don't…that you don't speak about much with the doctor and…to have the possibility to ask these nurses that follow you even by telephone"* (P20, M, age 25, Lombardy)

Calls as an additional component to care

Whilst the service provided left patients with a more positive perception of the hospital as an organisation, one clear factor coming from the data was that the service should not be a replacement for providing patients with the possibility to call into the hospital.

> *"I preferred to have a number where I could call when I needed something...maybe many times they call, and you haven't…or you're not available or there's something like you're busy and you're not even…instead I'd prefer to have a key person where I can say 'ok, I feel like this, I can call and I know there's a person that can give me an explanation"* (P09, F, age 66, Non-Lombardy)

5.3 Section Three: Discussion

5.3.1 Summary of findings

This study addressed the need for a more detailed understanding of haemato-oncological patients' needs during their cancer pathway, and the perceptions and experiences of the telephone-based intervention to address these needs and provide support.

Three key messages were evident from the analysis:

- personal emotional distress is evident throughout the pathway with a variety of coping strategies employed (sometimes imposed) to manage situations;
- despite existing support, patients continue to report unmet needs particularly in the post treatment phase;
- the provision of an effective and useful telephone intervention as perceived by patients requires acknowledgement of individual preferences for support and a more individualised patient focused content to guide structure and delivery.

The first theme highlighted patients' personal emotional distress as evident across the cancer pathway and the various coping mechanisms employed to deal with such. Reports of distress entering into a new realm surrounded by unfamiliarity and uncertainty were common. Fear of the unknown is described as the oldest and strongest kind of fear (Joshi and Schultz, 2001), and a basic concept of anxiety (Carleton *et al.,* 2007). It is therefore comprehensible that an array of negative emotional responses were recounted not only at diagnosis but evident in periods of transition where situational stability and familiarity were absent, findings mirrored in both cancer survivors (Hoffman *et al.,* 2009; Norton *et al.,* 2004) as well as survivors of haemato-oncological malignancies (Jones *et al.,* 2015a; Jones *et al.,* 2015b). Distress was also perceived in terms of loss of control, autonomy and personal identity especially where role reversals meant dependence on carers and feelings of burden and the longer-term impact of lost time and life goal achievements, with this data supporting evidence from the literature (Gagliese *et al.,* 2009; Harden *et al.,* 2006). Physical health is recognised to directly impact on emotional health and quality of life (Naughton and Weaver, 2014), and similarly, emotional distress was also seen to be closely linked to physical well-being within this group of patients. Fewer well-managed physical symptoms during treatment, and longer-term physical recovery to a pre-cancer 'normal' status, meant greater psychological well-being and limited reports of emotional distress. Focusing on symptom management and supportive care to address physical needs could therefore be a target to improving psychological well-being in patients.

There was evidence of use of a variety of resources for coping with emotional distress in line with the 4 categories of intrapersonal, interpersonal, information and tangible resources as suggested by Andrykowski *et al.* (2008). Patients often used multiple methods, changing across the trajectory and according to stressors faced, and resources

available. Support from family members and friends was felt to be of significant importance throughout the cancer pathway, and is recognised as a key factor in improved coping (Parker *et al.,* 2003; Kornblith *et al.,* 2001), however this was not always accessed or available for a variety of reasons. The Family Systems Theory acknowledges the role of the individual as part of the family, where change in one will affect all members (Mehta *et al.,* 2009), with the family as a whole adjusting to maintain the balance between change and stability (Wright and Leahey, 2005). One possible explanation for patients' reluctance to share their physical or psychological distress is to avoid causing further disturbance to the family unit, especially in the context of a newly established equilibrium following a cancer diagnosis.

The key findings within this theme here are reminiscent of the Social-Cognitive Transition Model of Adjustment - a framework which endeavours to elucidate both positive and negative adjustment in cancer patients (Brennan, 2001). It describes how the individuals core assumptions of self, life philosophy and relationships are affected by the disease, and posits that the social context has significant role on adjustment. Brennan (2001) suggests that healthcare professionals can reassure patients about their experiences through recognition of what are 'normal' adaptation processes and personal transition. However where insufficient interpersonal resources or social support are identified these could be areas for healthcare professionals to target to improve support so as to avoid maladaptive coping where possible.

The second theme surrounded the perceived unmet needs of patients interviewed. Patients with unmet needs experience greater incidences of symptom-related and psychological distress (Dyson *et al.,* 2012; Hewitt *et al.,* 2006), and whilst acknowledging emotional and psychological support from the healthcare team, it was evident that gaps in support remained for these patients, a finding consistent within the literature (Hall *et al.,* 2013; Lobb *et al.,* 2009; Swash *et al.,* 2014). The availability of the healthcare professional to provide emotional support was challenged through the lack of a person centred approach and poor inter-relational skills leaving patients feeling that some could not or would not meet these needs. Barriers to patients expressing their concerns were also highlighted which confirms findings reported by other authors including healthcare professionals behaviour (Henselmans *et al.,* 2012), limited time to discuss concerns (Okuyama *et al.,* 2008) and legitimacy of expressing concerns and

time wasting (Henselmans *et al.,* 2012; Okuyama *et al.,* 2008). Communication skills training has been shown to improve supportive skills (Moore et al, 2013) and may be beneficial in this setting. While some studies have highlighted age differences with younger patients reporting higher unmet needs in dealing with emotional problems (Parry *et al.,* 2012), such differences were not seen within this patient group.

There is agreement that the traditional approach to follow-up with the oncologist and specialist cancer centre is unfeasible in the long term (Howell *et al.,* 2012), and services must be developed or redefined in order to meet the increasing numbers of cancer survivors. Whilst there has been a shift of care from hospital based to early discharge and home care (van Tiel *et al.,* 2005), not all patients in this study felt ready or able to cope with on-going side effects of treatment at home. These findings are similar to those seen within the literature (Parry *et al.,* 2011), with patients reporting confusion and distress in the end of treatment transition period. Formal services supporting recovery and rehabilitation were also felt to be lacking after discharge, and despite reassurance of continued care and availability of the specialist team after discharge, there was evidence of difficulty accessing and gaining consistent support, leading to insecurity. Similarly, where long-term effects were dismissed as being the problem of other clinical specialities this reinforced the perceived lack of holistic care following discharge. Some patients spoke emotively about such experiences suggesting an imprinted memory, which had clearly marked their cancer experience. The dependency created through treatment at the specialist centre was symbolised by the desire to be treated only by specialists within the cancer centre however service availability did not meet patients' needs, and relationships with GP's were often strained or inexistent, sustaining dependency. Patient preparation for transition, as well as reassurance of sustained high quality care and a clear concise plan for survivorship care are some suggestions to aid the shift from cancer centre to primary care (Franco *et al.,* 2016), and are worth investigating as the pressure on services and patient dissatisfaction persists.

Patients received significant amounts of information, describing this as being helpful especially in the early stages of diagnosis in reducing stress, preparing for treatment, and in promoting control and self care behaviours – echoing findings by other authors (Collins *et al.,* 2009; Husson *et al.,* 2013). However similar to psychological support, whilst there was satisfaction with information received, patients still desired more, a

finding congruent with other studies (Faller *et al.*, 2016; Hall *et al.*, 2013). Information resources are a key element in psychological health with increased education associated with better psychological health (Parker *et al.*, 2003), in fact patients in this study described how the lack of information had impeded self-care, and personal recovery. Specific examples of information needs were quite different across the group, reinforcing the need for tailored individualised information (NBC/NCCI, 2003), in which needs alter over time (Gansler *et al.*, 2010). A proactive stepped approach by healthcare professionals, communicating positively, dedicating adequate time to provide information as well as revisiting issues, and being accessible to answer further queries as they arose were also seen as advantageous.

The third theme surrounded patients' perceptions and opinions of the telephone intervention that they had received. The majority of patients described how the intervention had addressed some of their identified needs, in particular by providing emotional support during and post treatment, and given access to the healthcare professional providing reassurance, especially for those who lived some distance from the hospital or were staying far from family. It provided a person-centred approach, described in terms of a variety of positive emotions including feeling cared for, having someone interested and providing continuity of care. It was also seen as a source of information and an opportunity to ask questions.

As reported within other studies (Beaver *et al.*, 2010; Jefford *et al.*, 2011), the majority of patients within this study described the method of telephone for intervention delivery as acceptable due to its convenience, and time and money savings, as well as preferable due to the comfort of being away from the clinical environment. Convenience and savings were significantly true for those living outside of the local area, as evidenced in studies caring for patients living in regional, remote and rural areas (McGrath, 2000). Telephone support was not the first choice of all patients with some preferring face-to-face support but in cases where distance created such a barrier it was seen as an acceptable alternative. The data provided evidence that for some patients telephone was not an acceptable method of support provision – either for personal dislike of talking on the phone, or perceived unacceptability of telephone to discuss identified topics such as diagnosis, complex treatments or for psychological support. In these cases personal interaction was felt to be more appropriate.

Patient-centeredness postulates that healthcare should be tailored and responsive to the needs of patients (Institute of Medicine, 2001), and individual choice to participate in the intervention was felt to be an overwhelming factor cited by patients. It was clear from the data that while the majority of patients had appreciated calls, for some they were seen as unnecessary or even undesirable, and as such call acceptance was seen as a prerequisite to engagement and its success. This is fitting with discussions surrounding receptivity and the desire or ability of the individual to participate in supportive care services designed to meet their needs (McGrath, 2013). Interestingly patients did not feel that this should be a replacement to the possibility to call in, rather as an additional component to care.

With regards to the nature of the intervention, checking on general well-being, and symptom experience were considered appropriate components, but patients favoured a more individualised call providing reassurance and emotional support. As with other studies (Parry *et al.,* 2012), research demonstrated evidence of unmet needs in a variety of domains, suggesting that support has to be multifunctional, flexible and individualised. Poor information recall (Kessels, 2003) and its links to anxiety (Jacobsen *et al.,* 1993) would suggest that reiteration of tailored information and giving the opportunity to ask questions, would contribute to the recovery process (Braun *et al.,* 2009). Numerous instruments are available for patient needs assessment, which are conducive to patient-centred care (Institute of Medicine, 2008). They should be used to target areas appropriate for service interventions.

Optimal timing and frequency of intervention calls were felt to be indefinable *a priori.* Key points however, were identified where patients had perceived the need for greater support such as prior to diagnosis, whilst waiting for treatment, during treatment, and in the early period following discharge, incorporating a longer period following more intensive treatments such as stem cell transplantation. Timings suggest agreement with those indicated by survivors of haematological malignancies, as being psychological and organisational transition points (Parry *et al.,* 2011), of which, both were evident in this patient group, and can provide a focus for additional support in adjustment. The majority of patients interviewed did not however find that continued support was necessary in the long-term, especially where recovery and return to normality was described.

Patients wanted calls from a healthcare professional that they knew so as to facilitate the care being provided. The importance of continuity in relationships has been described within the literature (Parry *et al.*, 2011), and in this study, the role of the nurse with an existing relationship with the patient was highlighted. The benefits of nurse-patient interactions have been shown in the literature to improve understanding and reduce psychosocial morbidity (NBC/ NCCI, 2003), and in this study patients described support from nurses as more conducive to discussing aspects of importance to the patient and saw them as having more time to dedicate to patients.

The original sampling framework attempted to include and equal proportion of patients that were > 30 years of age and ≤ 30 years of age, based on the assumption that technology is described as central point in young people's lives in terms of modern communication (MORI, 2005), and preferences for older patients remain that of face-to-face communication (Yuan *et al.*, 2016). However differences in age and preference (or not) of a telephone intervention were not evident within this data. This may be due to a series of factors. Firstly, this is a relatively small sample size and as such transferability of findings makes comparisons difficult. Results may also be a reflection of the overwhelming use and integration of telephone as a means of communication, and therefore its acceptance rather than preference.

5.3.2 Strengths and limitations

The strengths of this study are that it provides a deeper insight into the needs of patients spanning their cancer journey. It builds on evidence within the literature and contributes to understanding perspectives of patients from a different country to those previously published as well as expanding on knowledge within the field of haemato-oncology where research is still limited. It also presents the target groups' perceptions and opinions of the telephone intervention to support patients during and post treatment which highlights the potential utility of the intervention in support provision, providing enlightenment of elements where service modifications could make this intervention more acceptable and patient-centred.

It is also recognised that the study also has some limitations. The number of patients recruited to the study was small, however following guidance from Guest *et al.*, (2006), interviews had continued until data saturation was reached with codes identified during the last interviews being a confirmation of those described by earlier patients. The study

was also retrospective in nature, which in itself is not an issue however during the course of the PhD study, nursing staff delivering the intervention were assigned to other duties and this intervention was no longer continued. As a result, the majority of patients interviewed had received the intervention a significant period of time ago, which may have reflected on their memory of the intervention and perceptions of such. All patients had received or were receiving chemotherapy during or prior to the intervention, with half of them having undergone SCT, however the diagnosis of these patients was predominantly lymphoma and different disease groups may have provided alternative insights to their needs and perceptions of the intervention.

It is also acknowledged that the author works as a Research Nurse within the Division of Haemato-oncology at the hospital, and while measures were implemented in an attempt to exclude patients that had an existing relationship with the author (patients involved in clinical trials), the fact that the author worked within the Division was made transparent to patients. Professional backgrounds are one aspect said to influence the perceptions of patients as well the outcomes of interviews (Richards and Emlise, 2000), and the relationship between the interviewer as a representative of the hospital potentially incurred bias in patients reporting in a more positive manner. Patients agreeing to participate in the study were also self-selected and therefore more motivated to share their opinions, however in many cases, patients still felt they could be critical of services they received perhaps as a means to improve experiences for the next person. Similarly, where patients opted for face-to-face interviews, logistical limitations meant these were performed in the hospital setting, which again may influence the openness of responses given. Ideally, interviews would have been offered to patients taking into account not only interviewer context, but also the respondent context (Oltman, 2016), offering convenience and patient preference.

5.3.3 Reflection on interviews

On a reflective note, it was challenging for the author not to use words such as ‘we’ and ‘our’ when talking about the hospital, and the services provided especially in relation to what were emotive topics for patients. While it is accepted that the researchers role is not that of a counsellor (Hennink *et al.,* 2011), this was an issue raised within the first interview and discussed with the supervisory team. In subsequent interviews a mental note was made to avoid such terminology so as to keep the role of interviewer and nurse

employed by the hospital as separate as possible, whilst maintaining an empathic approach. Similarly, in some interviews, patients changed the subject to recount personal experiences that were not completely relevant to the aims of the interview. It is suggested that interviewing necessitates interest in and respect for individuals (Thompson, 2000) and as such active and empathic listening took place at this time. These were clearly topics of importance to the individual that they wanted to share, and as such time was left for patients to talk and then appropriately brought back to the focus of the interview.

5.3.4 Conclusion

In conclusion, the present study extends our knowledge of the needs of patients with haematological malignancies during their cancer trajectory, and provides the first comprehensive assessment of this telephone-based intervention to provide supportive care during and post treatment for patients. The growing use of telephone-based interventions for provision of support is evident within the literature, however the uniqueness of such interventions suggesting that each should be evaluated by investigation of participants so as to explore real perceptions and areas for development. By means of in-depth interviews, personal emotional distress and patients coping mechanisms provided insight into key areas where additional support could be targeted, and whilst patients appeared satisfied with components of support received, it was evident that unmet needs still existed. Although the existent telephone intervention addressed some unmet needs, choice of patient participation and the need for a refined approach in terms of a personalised, tailored model of care are evident. This suggests a complex intervention, being more patient-centred - a necessary component for success.

Chapter 6: Study 2 - Investigation of expert nurses perceptions of the needs of haemato-oncology patients and the use of telephone interventions to address needs

This chapter describes the working methods and findings from Phase 1 of the research; Study 2 - focus group data with expert haemato-oncology nurses. There are three sections to the chapter.

Section one details the working methods including aims, study design, sampling strategy, data collection and analysis methods.

Section two provides the themes emerging from the qualitative data.

Section three offers a discussion of the findings and examines the strengths and limitations of the study.

6.1 Section One: Working Methods

6.1.1 Background to the study

Nurses have a pivotal role in caring for patients with haematological malignancies across the duration of their treatment pathway, and as such, have a broad overview of the types of problems and issues that patients may experience. Whilst little is known about nurses' perceptions of patients' needs, and the use of telephone-based approaches to address these needs, nurses remain central to such service developments. This indicates a need to understand nurses perceptions of telephone-based care, both in terms of its role in supporting patients' needs, and the needs of nurses themselves in providing such care. Qualitative methods were employed with the purpose of gaining an in-depth insight into this area.

6.1.2 Aims of the study

The aims of this study were to explore expert haemato-oncology nurses perceptions of:

- the needs of haemato-oncology patients during treatment and post-treatment phases of the cancer trajectory
- telephone-based supportive interventions of patients with haematological malignancies

- whether particular groups of patients with haematological malignancies would benefit from support, and the feasibility of support via telephone
- potential barriers and facilitators for patients in participation in a telephone intervention
- potential barriers and facilitators to nurses in delivery of a telephone intervention

Expert nurses have been defined as nurses practicing within the clinical area for at least five years (Benner, 1984). For the purpose of this study, this definition was adopted and expert nurses (in this case working in the field of haemato-oncology) were selected so as to provide a more developed description of the area of investigation.

6.1.3 Study design

The purpose of this study was to address the specific question regarding expert haemato-oncology nurses perceptions of patients needs and the use of telephone interventions to address these needs. With this in mind, a descriptive qualitative approach to research was selected by means of semi-structured focus groups, in order to enrich understanding of the subject. Focus groups were held during an international conference focusing on haematology and stem cell transplantation (SCT). This approach was selected to maximise participant recruitment in terms of accessibility to expert haemato-oncology nurses working over a wide geographical area and reduce participant attendance costs in terms of time and money.

6.1.4 Ethical approval

A research ethics committee application was submitted in December 2015 to the University of Manchester Committees on the Ethics of Research on Human Beings; following amendments, a favourable ethical opinion was obtained in March 2016 (Ref: ethics/16063) (Appendix 21).

6.1.5 Sample

Experts are said to provide a more comprehensive explanation of variations in opinions in the area of interest, giving in depth information that is valid and reliable (Romney *et al.*, 1986). Expert sampling ideally aims to include all experts so as to provide saturation of information about the phenomenon of interest (Trotter, 2012). In practice, this is not always feasible.

A purposive sampling technique was adopted for this study to focus on opinions from expert nurses in relation to the research question. The focus on this particular group of healthcare professionals was informed by the literature, which highlights nurses as frequent deliverers of telephone interventions. Local and national experience with the delivery of telephone interventions is limited and therefore maximum variation techniques were used by means of international participation to maximise the diversity of experiences in terms of roles, service level responsibilities, geographical location of practice and variation in nursing care contexts.

6.1.5.1 Inclusion and exclusion criteria

Participants were eligible if they were, Registered Nurses, deemed as an expert nurse (practicing in haemato-oncology for at least 5 years), able to attend the location and time of the focus group, and had provided written informed consent to participate. Participants were ineligible of they were unable to communicate in spoken English as evaluated by the author.

6.1.6 Recruitment procedures

The sampling frame for this study were expert haemato-oncology nurses taken from a European haemato-oncology network. Potential participants meeting study eligibility criteria (n=14) were identified by the author and were sent an email 12 days prior to the planned focus groups with a Participant Information Sheet and Consent Form (Appendix 22), inviting them to take part in the study. The email also provided information regarding the dates for the focus groups as well as logistical information in relation to its location. Participants were given the opportunity to read the consent form and to contact the author with any questions, who provided further information as necessary. Measures were also put in place to safeguard participants' rights. They were made aware that participation was voluntary and that they had the right to withdraw their consent at any time. Those wishing to participate were given a choice of 2 dates to attend focus groups, organized in a private room to ensure privacy. Prior to starting the focus groups, written consent was obtained.

6.1.7 Data collection

Qualitative data was collected by means of semi-structured focus groups and participants were provided with dates and times for two focus groups. All but one

participant wished to participate in the second date, and data collection therefore became one focus group and one individual interview. It is recognised that interviews and focus groups have different goals in their approach to qualitative data collection - the former aiming to explore and preserve personal perspectives and the latter aiming to encourage group discussion and dialogue. For the purpose of this study and in order to maximise the possibility of data collection, the interview was provided as an alternative to the willing participant unable to attend the second date. For the purpose of this section, the term focus group(s) is used to refer to both the focus group and individual interview.

The focus group(s) were in English language, digitally recorded and transcribed verbatim by the author. Field notes were made during the interview and focus group as an aide memoir to the context of participants' comments. Self-reported demographic data was collected from participants in relation to their country of practice, and current role.

A topic guide was developed for the focus group(s), which was discussed with the supervisory team and informed by the systematic review of the literature. Subsequent questions were formulated and are provided in Appendix 23. Topics included were:

- perceived needs of patients with haemato-oncology malignancies during treatment and post- treatment phases of the cancer trajectory
- experiences of supportive telephone interventions to address patients needs – including the nature of the intervention, structure and content
- views of needs that may be amenable to a telephone support intervention
- factors influencing feasibility and acceptability of telephone interventions to address patients needs from both a delivery perspective and a patient perspective

Prior to beginning the focus group(s) it was reiterated to participants that if they felt uncomfortable, did not wish to answer particular questions or wished to stop their participation, they could do so. Measures were taken to ensure that if participants were seen to be distressed during or after the focus group(s) by means of a participant distress protocol (Appendix 24), they could speak with the author separately who would aid in accessing appropriate services. In order to protect participants rights, identifiable data was anonymised during recording of the interviews and transcription, by use of a Unique Participant Number (UPN). Recordings were transferred onto CD's, and

together with the transcriptions were filed in a locked cabinet at the University of Manchester. Transcriptions were sent by email to supervisors via password-protected computers, and the documents themselves were password protected.

Whilst saturation of data was not expected from the focus group(s), participants were perceived to be key informants as they were expert nurses with first-hand knowledge of the issues being investigated. Their diversity of clinical areas and countries of origin also allowed for a greater variation of perspectives of the subject matter.

6.1.8 Data analysis

The theoretical approach for this study was applied qualitative research or data driven approach as described in section 3.3.4.2. Framework Analysis, a form of thematic analysis was employed. This is fitting with the inductive nature of the study – investigating expert haemato-oncology nurses perceptions. Data analysis followed the steps of the Framework method respecting the key stages of familiarization; coding; developing and applying a working analytical framework; charting, and interpretation (Gale *et al.*, 2013).

Transcripts were analysed line by line to identify patients' needs as perceived by expert nurses, and their experiences and views surrounding the use of telephone interventions to meet patients' needs. Excel spread sheets were used in the management of data. Codes were derived from the data and grouped into coherent themes (Figure 9). Coding was performed by the author and checked by 2 supervisors, giving feedback during all stages of data analysis. Disparities in coding were discussed and resolved between the author and supervisors.

6.1.9 Ensuring rigour within the study

Several measures were employed to safeguard rigour within the study. To ensure credibility, the composition of focus group participants were expert haemato-oncology nurses, able to provide in-depth insight into the issues of interest.
Data collection was performed by the author for both the focus group and the interview, facilitated by means of a semi-structured topic guide in order to provide a consistent approach to investigation and data collection, enhancing reliability and equivalence. As the focus group would not be reconvened, member checking (Denzin and Lincoln,

1994) was performed during the data collection where the author attempted to summarise key points emerging and gain feedback on participants' perceptions of accuracy of the authors understanding.
The focus group(s) were digitally recorded and transcribed verbatim. The development of codes, sub-themes and themes was undertaken by the author, so as to enhance internal consistency of coding, but transcripts and coding were reviewed by the supervisory team, facilitating recognition of the researchers potential biases in the analysis of data.

Reflexivity

Within the setting of this study, the author recognises that interactions with participants own professional experiences, background and prior assumptions may be influential on the focus group(s). Detail of the authors professional background, academic qualifications, reflection on current clinical role and personal experience with telephone based communication and support for haemato-oncology patients are described fully in section 5.1.9. The experiences and opinions of expert nurses providing support via telephone were of interest to the author in order to explore existing service initiatives to address patients needs and factors influencing success and feasibility of such interventions – seldom reported in the haemato-oncology setting.
Prior to undertaking the PhD, the author did not have experience of moderating focus groups. The author had however experience in performing interviews with patients in Study 1 of the PhD. Support was provided throughout the process by the supervisory team who are extremely experienced in qualitative data collection methods, and whom provided feedback on the process. Similarly with data analysis, the author had limited experience of qualitative data analysis and was supported by the supervisory team.

The author was also a member of the European Blood and Marrow Transplantations Society Nurses Group Research Committee (EBMT NG RC), and Secretary of the Haematology Nurses and Healthcare Professionals Group (HNHCP). Participants within this study included two members of the EBMT NG RC and two members of the HNHCP Board. Although the invitation to participate in the focus groups was the same for everyone, it is recognised that the relationship between the author and some of the participants may have been a source of bias in accepting to participate. The interaction between the researcher-author and participants may be influenced due to the fact that

the experts are known to her through a specialist nursing network, but with each having differing levels of professional collaboration together. An important consideration in interpretation of conclusions is whether the authors role may have influenced participants desire to share experiences and comment openly.

6.2 Section Two: Results

Section two of this chapter presents the results of the focus groups with expert haemato-oncology nurses. Sample numbers and demographic data of expert nurses are reported. Themes and subthemes emerging from the data are also presented.

6.2.1 Study participants (expert nurses) and demographic data

Recruitment took place from March to April 2016. Fourteen expert haemato-oncology nurses with varying roles were invited to participate in one of two focus groups, and 11 agreed to take part and 10 actually attended. One expert nurse who had agreed to participate did not attend – with no reason given. Of those declining the initial invitation to participate, 2 were not attending the international conference during which the focus groups were to be held, and one was not available to participate at the times set for the focus groups.

One expert nurse attended the first 'focus group', which was therefore an individual interview. Nine expert nurses attended the second focus group. The duration of the interview and focus group were 33 and 100 minutes respectively. The interview and focus group were conducted in a dedicated private room with only the expert nurse(s) and author present. Summary demographic data is detailed in Table 8.

Table 8 – Study 2: Participant demographics*

Unique Participant Number	Job Title / Role
E01	Unit Manager
E02	Nurse Specialist
E03	Unit Manager
E04	Staff Nurse
E05	Nurse Specialist
E06	Nurse Specialist
E07	Nurse Specialist
E08	Nurse Specialist
E09	Nurse Specialist
E10	Unit Manager

*Expert nurses came from 7 different European countries. Expert nurses and countries have not been matched to protect their identity.

Three unit managers participated with one directly involved in patient care, the others had significant previous experience of clinical care of haematology patients and service development.

6.2.2 Themes from the qualitative study with expert nurses

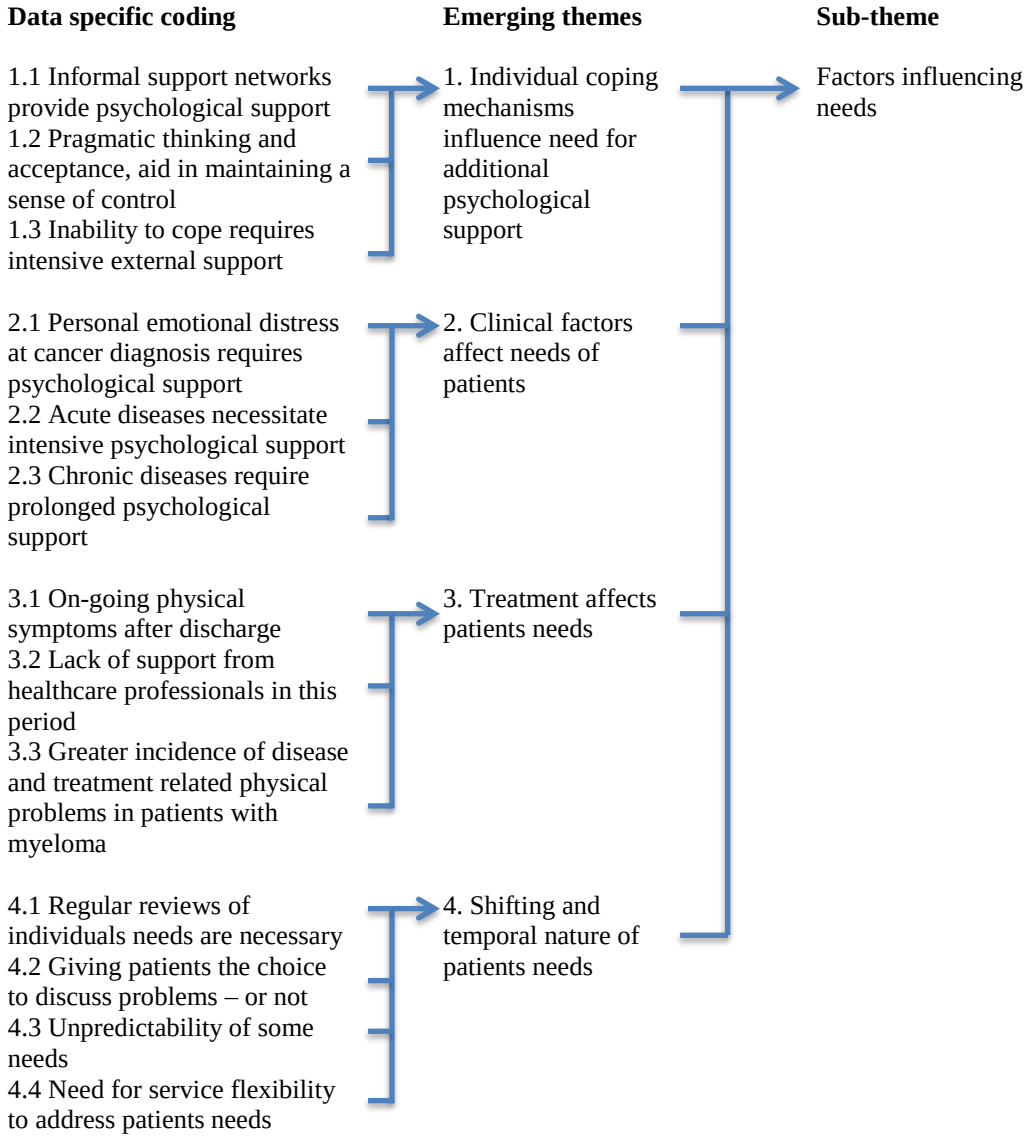
During the focus groups, expert nurses were asked to reflect on their experiences and opinions of haemato-oncology patients' needs, and telephone interventions to address needs. Focus groups and interviews were analysed using Framework Analysis, with the subsequent development of several sub themes, contributing to three broad themes emerging from the analysis (Table 9).

Table 9 – Study 2: Conceptual framework outlining the main themes and subthemes from the qualitative study with expert nurses

Main theme	Sub theme
1. Variability of needs across the cancer trajectory	i. Factors influencing needs ii. Tailored information needs iii. Continuity of care
2. Applicability of support via telephone	i. Meeting patients' needs and service needs ii. Limitations to the application of telephone support
3. Maximising the quality of telephone interventions	i. Shaping the intervention to meet the need ii. Caller characteristics and professional training iii. Organisational support

Thematic charts were developed for the main themes and related sub-themes. An example excerpt from the thematic analysis coding tree is provided in Figure 9. A completed example of a thematic chart is provided in Appendix 25. A discussion of the main themes and sub-themes is presented below.

Figure 9 – Study 2: Example excerpt from the thematic analysis coding tree – Sub Theme 1.1: Factors influencing needs



6.2.2.1 Theme 1: Variability of needs across the cancer trajectory

One theme surrounded the identification of needs within this patient group thus providing a focus for appropriate nursing care interventions.

6.2.2.1.1 Factors influencing needs

Patients needs were seen to be affected by individual, clinical, treatment and time related factors.

Whilst there was agreement amongst expert nurses that key time-points of emotional distress were evident across all patient groups, patients' own coping mechanisms were perceived to influence the need for additional psychological support. They described

patients' use of informal support networks as sources of psychological support, and personal coping strategies including pragmatic thinking and acceptance, as techniques to maintain a sense of control when facing treatment. Techniques were said to aid in coping and dealing with the uncertainty of being able to fulfil familial and societal functioning roles. There was however, a concordant view that not all patients are able to cope alone, with one expert nurse identifying one patients' difficulty in dealing with expectation and uncertainty in relation to a serious clinical situation. In this case, nursing support necessitated adaptation and intensification in order to sustain hope for the patient.

> *"…one of the very important things for the patients is…expectation, building up that expectation, so when you've got a patient coming through to clinic and saying you need to have a transplant…and then you don't find that donor, that is where it's really really difficult because you've got all that psychological impact on the patient...I had a guy...but we couldn't find a donor, and for a whole year, he pretty much phoned me every single day because he was so stressed about knowing he would relapse…"* (E06, Nurse Specialist)

Clinical factors were also stated to affect the needs of patients. Diagnosis clarity was a difficult moment for all patients, often experiencing personal emotional distress at the communication of a potentially life limiting diagnosis, and was unanimously acknowledged as a key moment requiring psychosocial support. Acute or chronic disease characteristics were also factors in determining need. Acute intensive psychological support was thought necessary for those facing aggressive diseases in light of rapid physical changes and illness onset, while in contrast, longer-term psychological support was expressed as necessary for patients with chronic and indolent diseases, facing a more prolonged disease pathway incorporating periods of relapse, remission, treatment and 'watchful-waiting'.

> *"…I think the low grades because they are living with it…they never think it goes away, so I think the anxieties are different…it's very different the support that's needed.. the low-grade's much more psychological erm…that kind of supportive care needed because they are having to live with this.. thing hanging over them all the time… they're equally important* (referring to high grade and low grade disease*) but they're…but it is very different what you're having to tailor to both groups"*
> (E02, Nurse Specialist)

Treatment related issues were particularly evident in influencing patients' needs within the post discharge period following acute leukaemia treatment and autologous SCT, where treatment related physical side effects were often on-going following discharge, requiring management at home. Expert nurses felt there was a lack of support from healthcare professionals in addressing patients needs in this period despite recognition of the significant physical, social and emotional repercussions of treatment. Differences in need were also noted in patients affected by myeloma where the higher incidence of disease related physical problems and symptoms that are present pre-treatment, resulted in a challenge for expert nurses to understand and separate whether problems were disease or treatment related and therefore the ability to address needs appropriately.

> Referring to multiple myeloma: "*...it's also…they get complaints of the disease, they get complaints of the treatment…erm…they get…complaints of the combination, and it's very difficult to know what…what's happening…at that moment?"* (E05, Nurse Specialist)

Expert nurses recognised the shifting and temporal nature of patients' needs, and the call for patient-led support reflecting individual choice. Regular and timely reviews of needs were advocated, by means of a holistic needs assessment, incorporating an element of choice for the patient to discuss, or not, any issues that were of concern to them.

> *"the holistic needs assessment…it's done every six, 6 to 8 weeks, and they'll take it home and fill it in with symptoms, and there's a distress thermometer and what they're feeling and then 'would you like to talk about it at your next visit' yes or no, and they give it to you so you know then…"*

Elaborating on this further, the expert nurse clarified:

> *"…not to give them permission but, to let you know that okay, this is an issue but I'd rather not talk about it"* (E01, Unit Manager)

Whilst some expert nurses used programmed hospital visits to evaluate patients' needs and provide support, it was acknowledged that the need for information and survivorship concerns often arose outside of these appointments. As it was felt impossible to predict exact time points when all issues and questions would arise, expert nurses recognised their patients' need for flexible access to the healthcare team to

address needs, with one expert nurse describing her open access approach to providing support..

" sometimes they come and visit us in the hospital… just to… have a talk…" (E07, Nurse Specialist)

6.2.2.1.2 Tailored information needs

Information provision was considered a key component in patient preparation. Specific issues were described relating to time points of the patients cancer pathway, transition from hospital to home and the return to 'normality', the healthcare professional as gatekeeper to information provision, information retention and on-going information needs.

Differences in need and the type of information required were said to vary according to the point of the patients' trajectory, with the need for knowledge being more evident during periods of transition. Expert nurses commented that in the early stages of diagnosis and treatment, information needs focused on dealing with the 'unknown' and expectations such as side effects of treatment and self-management strategies to aid coping. For patients embarking on stem cell transplantation, having already received chemotherapy, information needs were different, instead focusing on logistical information and expectations of 'return to normal', compatible with a more prolonged period of treatment and interruption to activities of daily living and personal commitments. Here, information providing certainty was considered a facilitator for patient planning and personal organisation.

"...they want to know how do I have to manage and organise my family and they always asked me about the schedule…what can I expect, how chemotherapy cycles and what time do I have to plan…" (E07, Nurse Specialist)

In the transition from hospital to home after autologous SCT, the shift for patients taking on 'new' responsibilities for self-care and self-medication was thought to be a cause of confusion and uncertainty. Poor retention was also described in the post-transplant setting, due to the amount and complexity of information provided at discharge. A greater need for support and information reiteration was perceived within this period.

"…they don't remember nothing…they do mistake or say one thing for another, and so we have to focus, refocus patients…usually they ask about the chemotherapy, if

they have some symptoms, how they can manage family during transplantation, and so on…the food…they focus on the food…what can I eat…"

Elaborating on this further, the expert nurse clarified:

"some did a mistake in the oral intake…or they need something, they miss something they miss some drugs and so on, they phone us" (E04, Staff Nurse)

In a later period of transition where patients were returning to 'normal', expert nurses described different information needs including longer-term projection of self-care, and questions surrounding 'normal' dietary and physical activities. Others described patients' information seeking to deal with everyday challenges such as obtaining holiday insurance and leisure activities such as spa treatments, where conflicting information from healthcare professionals and lay advice was a barrier to a return to normality. Later information needs also included management of persistent side effects including fatigue and cognitive disorders, which were felt to limit patients social reintegration and return to work.

"…the fatigue in lymphoma patients after treatment…the fatigue that is preventing them from…from getting back to work and then…they have this fatigue and they have…cognitive disorders…and then they phone you when they…asking what to do" (E05, Nurse Specialist)

Expert nurses described the basic content of information provided and the timing as being decided by healthcare professionals. During and post treatment, this was focused on the transmission of advice surrounding self-care management to promote well-being, avoid complications and prepare patients. This often meant significant amounts of complex information, and information overload was acknowledged as a source of confusion for patients. Expert nurses cited several examples of fragmented approaches to information giving to address this issue, both in terms of who was providing the information – different healthcare professionals or informal sources, and using a phased approach. There was overall agreement that giving information required an individual tailored component to address individual needs, with mixed methods strategies preferred, being able to provide flexibility and reflect patient preference.

"they visit the area…erm…the doctor is telling a little bit of it…why we want to harvest the stem cells, and I'm going to tell how, and when, so they need planning…I always say.. first this part…the other part about how the

transplantation will be…I'll see the patient when the harvest is…is done, I think 1 or 2 weeks later, I'll see the patients to…tell them all about the clinical transplantation" (E09, Nurse Specialist)

A common view amongst expert nurses was poor information retention influencing continuing information needs. They argued that a critical foundation for information giving was timing, where perceived 'bad news' meant fixation on key words during discussions and poor recall beyond. One expert nurse believed poor retention requiring frequent repetition of identical information was related to the patients disease (myeloma), however expanding further, it was unclear whether poor retention was due to the complexity of information, patient's age, or need for individual reassurance. Although older patients were described as less inquisitive in terms of information needs, their capacity for self-care in relation to treatment toxicity was seen as requiring more intensive support including reiteration of information.

" …giving them information and telling them what to do…if a toxicity occurs…self-management, it's much easier in younger patients, you give them a leaflet and you say, if you get nausea take this or do that, and in older patients you have to keep informing them" (E05, Nurse Specialist)

Interestingly, one expert nurse spoke of potential unmet information needs developing over time, where after longer periods of time and treatment, patients often become less proactive in information seeking, and healthcare professionals assume patients are already adequately informed. On-going information needs were also felt to be subject to the quality of initial information provided. An age dichotomy was also emphasised whereby younger patients verbalised needs more readily compared to older patients who were seen as more passive and acceptant of directions given by healthcare professionals without perhaps voicing on-going concerns. There was general acknowledgement that addressing information needs was an on-going process requiring return to, and active verification of, need, understanding and recall. Expert nurses also felt there was a need to encourage patients to verbalise doubts, concerns and reiterate healthcare staff availability to answer any questions arising.

"…they change as they go along…down to the fact that often, when they've been on treatment for longer…their needs are the same but…I think at times they're scared to ask because…they feel they have been told it, or they should know it…and also I

think there is a little bit of a problem sometimes with us, that because they're further down the road, we feel they…kind of they've been, there they know that, and they don't always" (E02, Nurse Specialist)

6.2.2.1.3 Continuity of care

One important sub-theme of information provision was that of continuity of care. Issues highlighted were the importance of the patient-healthcare professional relationship, trust, security from the specialist team, dependency on the specialist team and the need for reassurance.

Expert nurses recognised the impact of trust on the patient-healthcare professional relationship stemming from early within the patients pathway. Experiences of myeloma patients were described, where delayed diagnosis by GP's led to patients lack of trust in non-disease specialist healthcare professionals. This resulted in increased anxiety in relation to symptoms, and the subsequent need for greater reassurance from the disease specialist team. In such cases the team became the key reference point for patients, with some patient contacts felt by expert nurses to be inappropriate but necessary for patients in order to feel safe.

*"…even things that they should be going to the GP with, they didn't trust them anymore (all participants: 'yes'), so they come back to us because then they feel… they do feel safer and…regardless of whether it's to do with the myeloma or not, they're (*referring to Specialist Nurses*) the only ones now with like the…funnel for everything"* (E10, Unit Manager)

Patients' familiarity over time with treatment, side effects and regular contact with the disease specialist team facilitated interactions and dialogue by building trust and permitting open discussions of issues of importance to patients without reproach. Expert nurses felt that this closeness in the relationship meant there were fewer unmet needs. The majority agreed that access to a key worker or single point of contact for patients in terms of an expert nurse was useful for all patients, both in terms of continuity and accessibility, knowing who could be approached to deal with issues and signpost to other services. However not all countries represented within the data, had access to this type of clinical figure. In these cases, patients would often seek continuity via the ward based nursing team.

" I think it's building trust with the team as well, in being able to trust team and to know that…and to know that, you know, if they phone up with what they may perceive as a really silly question, that it actually isn't and it's very valid and they're not the only one that's suffering with this concern" (E06, Nurse Specialist)

Expert nurses described patients' sense of security when dealing with the disease specialist team and insecurity in the absence of an existing relationship with non-disease specialist healthcare professionals, expressing a clear need for patients to maintain contact with the specialist team, even following discharge. This was particularly evident in shared care situations where patients were treated with more invasive treatments such as SCT within centralised hospitals rather than their local setting following a 'hub and spoke' model of care. In this case, although patients were referred back to the local healthcare team, it was felt unclear for patients who they were supposed to contact for support. Nurse experts from transplant teams described still being contacted for advice and information, as they were still seen to be the key point of contact for a variety of issues.

"it is leaving that bubble isn't it…it's leaving that security, so it's actually having a contact…I think it is the autos that…in some ways they're just, you know, it's just high-dose treatment…so therefore their transplant at that point…a couple of times after we've seen them then they'll be just referred back to their local teams, so they pretty much are just sort of like…that's if you've had it now, you can go back, so it's actually maintaining that contact, and I do still get patients that will phone up post auto, just with a question" (E06, Nurse Specialist)

In contrast, expert nurses described how the trusting relationship between the disease specialist team and patient, was also felt to have created dependency and was a cause of additional pressure on departments and resources. Expert nurses themselves recognised their own role in promoting patient dependence, describing how healthcare professionals taking control in the initial stages of diagnosis and treatment, had establish learned behaviours within their patients by encouraging them to check first and seek permission rather than operating as independent decision-makers. Dependence was further confounded by stigmatisation and reluctance of non disease specialists to care for what were seen as complicated patients, especially those having undergone

stem cell transplant, leading to reinforcement of dependence on the disease specialist team.

> *"…we all talk about self-care, but we still take away…their autonomy, you know, we still…we say 'this is the way you should do things', and yet, you know…they get very reliant on…whatever nursing team or day ward team are looking after them, and they feel that even if they know it, they still have to run and kind of seek permission to do what they think.."* (E02, Nurse Specialist)

The need for reassurance was evident across the various patient groups and time points. Where persistent side effects such as fatigue became a cause for concern, or impromptu events causing minor changes in symptomatology, patients were perceived as needing reassurance from the disease specialist team. Similar findings were voiced in both the immediate and long-term post treatment phase, where fear of relapse was described on a cyclical basis incorporating the anxiety of tests, results, and returning anxiety when check-up time arrives again. Expert nurses described patients' need for more intensive psychological support and reassurance to deal with this.

> *"…once they've had sort of their induction treatment, it's their end of treatment scan and that often is the fear…and of the unknown, of knowing what that PET scan or CT scan is going to show...because you know, they may not have any symptoms but may yet may well still have some disease and I think there's that anxiety, and waiting on that scan result to come back…that sometimes they need that extra psychological support or they need to...you know… just a bit of, a bit of…handholding if you like, and just somebody to be there for them at the end of the phone"* (E06, Nurse Specialist)

6.2.2.2 Theme 2: Applicability of support via telephone

6.2.2.2.1 Meeting patients and service needs

Telephone support was evidenced in meeting both patients and service needs in terms of 'call-in' services, proactive calls to patients on both an ad hoc and structured basis, perceived benefits for patients and organisations, and their role as a tool in patient empowerment.

Prominent within the data was evidence of telephone support to address patients' needs, with expert nurses describing proactive telephone calls by nurses contacting patients, and reactive hospital telephone-based services responding to patients calls. In both cases they described this as a means to providing quick access to the team and timely reassurance, permitting trouble shooting to pre-empt complications.

Two expert nurses described use of generic 24-hour 'hotlines' available for all cancer patients attending the hospital, where calls were dealt with by nurses not necessarily directly involved in the care of the patient calling. Problems were often managed according to pre-defined written protocols, allowing nurses who were unfamiliar with the patient to manage issues. It was remarked that in some cases, symptom management was feasible by telephone, and had reduced hospital visits, improving appropriate clinic resource allocation.

> "*…with a telephone triage system…we've actually in ways cut down on some of the visits to…and people being brought, in because what was happening was people were ringing their CNS and they were saying 'I'm sick, I'm nauseous' or whatever, and because they were running from A to B, they were going booking people into clinic and somebody comes into clinic for something that is solvable in 2 minutes on the phone…so in ways we've actually reduced workload and made it more appropriate…"* (E02, Nurse Specialist)

Expert nurses also described proactive initiatives where hospital-based nurses telephoned patients. One expert nurse described a comprehensive service to all patients beginning chemotherapy treatment within a Day Hospital Unit. Patients had been involved in the development of this nurse-led service, which was aimed at addressing information needs related to treatment. It provided written and verbal educational components as well as a guided visit of the Day Hospital Unit and a follow up phone call shortly after treatment. The unstructured call from the nurse providing earlier education, provided continuity, reiteration of information and opportunity for patients to elicit questions.

> *"one of the things that we do is 24 to 48 hours later, the nurse who has done the pre-chemo assessment should follow that up with a phone call…we don't have a checklist no, no, it's just purely a phone call ..check and see if they have any questions and just to confirm the appointment with them…so really it is a…let's say*

unstructured and also an opportunity if there are any queries to go through that again" (E01, Unit Manager)

Expert nurses also described their use of proactive 'ad hoc' telephone support for patients in a variety of other situations aimed at addressing needs through a more flexible patient-centred approach. Calls were used to provide reassurance for those who were unwell at home awaiting hospitalisation, for symptom monitoring and to evaluate individual coping in the home environment. One example described weekly nurse initiated calls providing support and information at diagnosis and treatment start for patients affected by multiple myeloma, with the need for subsequent calls and support being agreed with the patient. In shared care situations, telephone contacts by the expert nurses ensured continued accessibility to the disease specialist team and provided reassurance. In these cases, calls were supplementary to standard care provision rather than in lieu of visits. Expert nurses described assessment by telephone being feasible as a complementary component to face-to-face consultations in certain settings. Proactive calls were also said to be feasible when replacing hospital appointments where a face-to-face consultation was deemed unnecessary such as in the delivery of palliative care being more convenient for patients and avoiding unnecessary travelling. Expert nurses concurred that such ad hoc proactive calls were unnecessary for all patients; instead patients were individually evaluated by expert nurses involved directly in their care in order to identify the need for more timely reassurance, support, and information provision outside of planned hospital visits.

"not every patient will…or desperately need it, but you can just tell that some of these patients are really really anxious, and want that information sooner than the next clinic appointment, so it's erm…just a bit of reassurance for them…" (E06, Nurse Specialist)

"I think that it saves time.. for the patient then…it's the travel time, then there's quick reassurance rather than then them waiting to come to their next appointment...it saves time for the nurses as well…it's sometimes easier as well to say, you know…to talk to them over the phone and to troubleshoot and make decisions from that as well" (E01, Unit Manager)

Benefits for healthcare professionals and organizations in the use of proactive calls were also described such as time saving for nurses, reducing the number of hospital visits, and streamlining hospital appointments by pre-emptive calls assessing patient symptomatology. One expert nurse reported use of calls in order to verify patient adherence to self-administration of prescribed growth factor injections for stem cell mobilisation. Whilst side effects experienced are sometimes problematic and alarming, causing patients to suspend treatment, the purpose of these calls was not only to provide reassurance regarding potential symptoms, but also to ensure compliance such that collection of stem cells could be performed, respecting organisational and service planning. Such telephone support mechanisms were considered not only to provide timely responses to patients' queries, but a means to promote patient self-care resulting in a reduction on service pressures.

> *"I think it is about everything…down to the…practical ways of having to manage their symptoms, what to do, what they should do when something happens, or what they can do…what…things that will prevent them being admitted to hospital, things that will prevent them, you know, things that they can manage at home…ways that if there was support, if there were support mechanisms in place that can actually reduce the workload on Day Wards, on inpatient units and on the Clinical Nurse Specialists looking after them…a lot of things around self-care…"* (E02, Nurse Specialist)

Expert nurses acknowledged their role was key in empowering patients to take responsibility for their own care. There was general agreement surrounding the expectation of patients to call in and advise the hospital of any problems, with one expert nurse citing this as their organisational philosophy rather than proactively calling patients. The majority recognised however that some patients were reluctant to call in with concerns due to unwillingness to disclose or share problems, seeing themselves as a burden on the healthcare team or in the hope that clinical situations may improve. Whatever the reason, delayed calls were felt to be inopportune for both nurses and patients in terms of accessibility to medical staff during nocturnal hours and dealing with exacerbated clinical situations. A proactive telephone support was however seen as a means of reiterating the continued availability of the expert nurse as a resource, but also a moment to encourage patients to take responsibility for signalling problems and engaging in further contact with the team as they felt necessary.

"but that's survivorship anyway…I mean that's, the whole point is we've taken all the control away from them, by definition we've had to…when they're in an acute…when they're acutely ill…part of that whole survivorship process is for them to be able to then reengage and sort of retake…get that whole locus of control… back to themselves, so they can be empowered to move forward and use us as a resource (ALL: agree) rather than us nannying and sort of parenting them if you will" (E10, Unit Manager)

"well it depends on your philosophy, so we also have the philosophy…patients have to call us…we don't call them, they have to call us…and also when they don't call early enough we will be angry (ALL laugh)…" (E03, Unit Manager)

6.2.2.2.2 Limitations to the application of telephone support

Telephone-based support was not felt to be without challenges, and limitations to its appropriateness were highlighted based on patient related factors, difficulties in addressing sensitive issues by telephone, lack of visual contact with the patient and the challenges for callers of engaging in a formalised service.

Patient related issues such as poor general well-being impacting on the ability to talk, and language difficulties or problems with verbal communication were seen as potential barriers to effective telephone communication. Patients personal preference was a factor in acceptability as it was understood that communication by telephone is not preferred by all, with some patients being reticent to disclose information and discuss problems in this way. Expert nurses suggested that not all patients wished to have additional contact with the hospital outside of programmed appointments, preferring to manage alone, or seeing calls as an unwelcome reminder of illness and inconvenient where patients were busy or working. It was also described as unsuitable where patients were in frequent face-to-face contact with the clinical team as they were felt to be already well supported. One expert nurse hypothesised about the potential negative impact on patients themselves if they happened to compare the frequency of calls they were receiving with other patients; with more frequent calls being an indicator of a serious clinical situation causing anxiety, whilst less frequent calls an indicator of a 'less important' patient, causing feelings of abandonment.

"…the system falls down because then what happens is you potentially have a patient come back in and saying 'she's getting a call twice a week and I'm not,

why? does that mean she…' or another patients going 'does that mean I'm sicker than they are?', or you know, 'you don't trust me but you trust her' and you know it's…there's difficulties with it" (E02, Nurse Specialist)

Dealing with sensitive issues by telephone was a contentious topic for expert nurses. Whilst some found advantages with telephone communication in terms of facilitating disclosure when discussing sensitive topics, others considered it as impersonal in dealing with supportive care needs and survivorship issues. Interestingly, one expert nurse suggested that where patients initiated conversations about emotional or sensitive topics, it was feasible to discuss issues by telephone, however she felt uneasy about raising such topics in conversation herself, preferring to enter into such conversations during face-to-face consultations.

"…I suppose it could make it easier not to face someone and talk about emotional things but I would imagine that it would be easier to instigate that…that conversation face-to-face with the patient however if they brought it up over the phone, you know, but to bring it up yourself…I don't know…I don't think that would be…" (E01, Unit Manager)

One barrier to telephone support for the expert nurses was that of the inability to physically see the patient. Visual cues were described as a key component of assessment, with some describing the sometimes contradictory verbal and non-verbal communication of patients when discussing even their general their wellbeing. They felt that the lack of a visual element in assessment meant that telephone interventions were insufficient where physical examination and review of visual cues were required such as implementing or modifying clinical interventions, evaluation of cutaneous problems, or where patients had non-specific problems such as feeling 'un-well', fever or malaise.

"yeah I was just thinking about starting interventions by telephone… I am not really fond of it because…I like to see my patients, and so when you start thinking of starting an intervention you need to see your patient, not only hear the patient's voice by phone, but see, see the patient, but to evaluate effectively the intervention…" (E05, Nurse Specialist)

Expert nurses discussed the use of alternative remote methods in patient assessment such as computer 'tablets' and face-time as a means to address limited visual access to

patients. One expert nurse described its implementation in care of older patients as improving resource utilisation and service efficiency. All agreed that while this approach would be comforting for the patient being able to see the healthcare professional, its shortcomings included dependence on a good signal and internet access to be a feasible option.

While expert nurses had described their own primarily ad hoc use of telephone support to address patients' needs, some raised concerns about a more formalized service. They spoke of wasted time and increased stress and concern for themselves if they were unable to contact patients. They also described their work as subject to unpredictable events, potentially impacting on their own availability and reliability to call patients where agreed and the negative impact on trust and anxiety for the patient where a 'promised' call was not received. It was also felt that proactive calls to patients might reinforce the 'patient' identity status, promoting dependency on calls. Elaborating on this point, there was concern over whether dependency meant patients waiting for calls and delay reporting important clinical issues, with potentially harmful consequences. One expert nurse went on to clarify this, saying the concern was a significant factor limiting the applicability of structured proactive calls to patients within the haemato-oncology setting.

> *"I think…the reason a lot of us don't do a very structured approach of it, is that you will have the patient that says 'well they're due to ring me tomorrow so I'm not going to bother doing anything – I'm sitting here and I am feeling really sick or I've got a bit of a temperature, I'm not going to tell anybody about it because (NAME) or (NAME) or whoever, is going to ring me tomorrow morning, so it can wait till then…. so I think that's where particularly within a haematology setting there has been a little bit of a reluctance…"* (E02, Specialist Nurse)

6.2.2.3 Theme 3: Maximising the quality of telephone interventions

Expert nurses identified a number of issues requiring consideration when developing proactive nurse-led telephone interventions to address patients' needs.

6.2.2.3.1 Shaping the intervention to meet the need

It was felt that the design of any intervention should reflect individual needs, with specific issues raised relating to identification of patients who may benefit from a

telephone intervention, components of a service, suggested examples and the need for flexibility of an intervention.

Expert nurses described their own experiences of telephone-based support and its utility in addressing patients needs. However, when asked to identify a specific patient population that may benefit from a proactive telephone intervention, expert nurses felt unable to broadly generalise stating the need to look at individual patients, their specific needs and whether telephone was an appropriate method to provide support in such a setting. Both successful and unsuccessful examples of structurally similar telephone based support initiatives within one hospital for two different patient groups were described, affirming the suggestion that support is not a 'one size fits all' concept. It was widely agreed that identifying patients was the role of a nurse who knew the patient and therefore their individual care needs. Expert nurses also concurred that patient choice was an important factor for consideration and that any intervention should be optional rather than enforced.

> *"…I find that very difficult…it's not very easy to say – right definitely for these ones, because I'm thinking perhaps with…with the older patients, with the elderly patients, that would be more helpful erm…transplant patients as well, but yeah…I find that a very difficult question…it depends on the person, you know.."* (E01, Unit Manager)

Similarly, expert nurses were unable to provide a unique definition of what a proactive telephone intervention would look like in practice, in terms of its content and timing *a priori*. Instead the common opinion was that the nature and structure of any intervention would be dependent on the patient, the need being addressed and also influenced by the treatment and phase of the patients' journey. Interestingly, one expert nurse also reflected over the purpose of the intervention, whether the focus was to address the individuals' needs or those of the healthcare professional calling the patient.

> *"but sometimes…it is very important to…to then think what is <u>his</u> need, and what's your need…there is a difference in, in the needing – do you understand?"* (E09, Nurse Specialist)

Examples were given where a proactive service would be most useful. Calls to patients post-discharge after having received complex treatments were deemed to provide 2-way reassurance for patients and healthcare professionals, where side effects and symptoms

could be monitored, reassurance and advice given, and medication adherence checked. Calls were also felt to be useful to reiterate results, and provide on-going support for patients with chronic diseases. Post treatment calls to older patients was another example using a holistic needs assessment as the basis for side effect evaluation, where reiteration of information and greater support in self-care management could be provided. In these cases, structure was felt to facilitate needs assessment and signposting to other relevant healthcare professionals where necessary.

> *"I think it depends on what type of patient it is, you know, the disease…is it a late effects sort of telephone consultation, is it just after transplant and someone's gone home, then you've got a structured phone call saying 'how's everything going' and you've got a structured checklist to go through with the patient…reassure the patient, reassure yourself erm…that everything is fine…"* (E01, Unit Manager)

Concerns were raised over a solely prescriptive approach to a telephone intervention such as the use of a 'checklist' for symptom monitoring. Expert nurses highlighted the necessity to incorporate an element of flexibility within an intervention in order to explore non-standard items arising. Flexibility was also deemed necessary where patients requiring frequent calls for support were perhaps in greater need of a face-to-face evaluation and as such the management strategy would need to change.

> *"but by such a high need, when a patient calls me every day, I want to see him… (all in agreement) not call every day"* (E03, Unit Manager)
>
> *"there definitely has to be some flexibility to it…if for example a patient would mention something that's not on the checklist obviously as a nurse, you would go through that if you hear…something in their voice that…obviously you would ask further, so I'm thinking of flexibility in, in that way…"* (E01, Unit Manager)

6.2.2.3.2 Caller characteristics and professional training

Caller related considerations focused on identifying who should be providing telephone calls in terms of role, skills and providing continuity of care. Expert nurses all agreed that nurses could provide a holistic approach to the evaluation, identification of issues, prevention and supportive care for patients, and as such, were well placed to deliver such an intervention. They did specify however that providing this type of support was the role of an experienced nurse or a 'Specialist Nurse' having a more global view of the patient and greater experience to deal with telephone-based communication in view

of the absence of visual cues. On further investigation, more specific requisites of the nurse were identified including experience caring for patients with the haemato-oncological condition of note in order to be able to identify potential problems. Similarly, skills such as intuition were thought to be more developed within experienced nurses, and important when dealing with telephone conversations lacking visual cues.

> *"…you just gave that case study of a person where there was nothing concrete and yet you contacted them…that's where the, that's…for me is that safety net isn't it… it's a gut instinct and you're not gonna get that unless you've got that experience"* (E10, Unit Manager)

In terms of providing continuity of care, the need for an existing relationship between the nurse-caller and patient, raised divergent opinions. Although an existing relationship was seen as preferable, it was not felt to be an absolute necessity. Clinically motivated calls investigating symptoms, were argued as feasible where performed by nurses that did not know the individual, however for calls involving a psychological component it was necessary to 'know' the patient. Despite this, expert nurses attributed several benefits to an existing relationship such as familiarity being a facilitator to picking up on nuances and voice changes over the telephone, and conducive to easier interpretation and response. Knowledge of the patient, their experiences and pathway was said to assist in individualising care, decision-making and tailoring support to the individuals coping style. More personalised conversations involving a humanistic approach including non-clinical aspects of the patients' life were also described as helpful to developing a more therapeutic relationship. An established nurse-patient relationship was also perceived as beneficial in increasing patient engagement in the intervention.

> *"…just having somebody who does the follow-up, I don't think you would have the same…buy in by patients…and it comes back to this thing as you said sometimes with the patients, they're not…they need to have…trust and belief in the individual…"* (E02, Specialist Nurse)

The existing skill set of nurses - trained and experienced in care of patients within a haemato-oncology setting - was perceived as a limiting factor in provision of support beyond routine nursing care, with one expert nurse making particular reference to dealing with issues in relation to sexuality. All described the requirement to ensure

mechanisms were in place for callers that aided referral to other healthcare professionals, where callers lacked confidence or skills in dealing with particular issues, or having access to Specialist Nurses who knew the patient. Provision of supplementary training for telephone based communication skills and integration into the role was suggested, however more focused interventions required delivery by experts, to complement and extend support provided by nurses.

> *"in that specific area, I mean erm…because for example I've been working in haematology for…for donkeys years but I wouldn't feel comfortable giving advice on sexuality for example…"* (E01, Unit Manager)

6.2.2.3.3 Organisational support

Organisation support for implementation of any intervention was felt to be a key component of success. One expert nurse within a managerial role, described proactive telephone based interventions as feasible within an organisation where there was evidence of benefit such as replacing hospital visits, or where measurable outcomes could demonstrate improvement of the patient experience. It was suggested that material resources required were minimal - as there was easy access to a telephone and a computer, however all expert nurses raised concerns about nursing resources and the feasibility of initiating a formalised proactive telephone intervention within their current level of workload. Despite their own reports of using proactive telephone based support in an ad hoc manner, it was agreed that in order to formalise such interventions in practice, nurses required this to be a validated aspect of their role with dedicated and protected time both to perform calls, and also to prepare beforehand - understanding the patients previous issues and potential issues to ask about and address.

> *"you would certainly have to have protected time, and it would need to be a…certain afternoon or…right to have two hours a day to do my telephone, or one hour a day, certainly not ad hoc"* (E01, Unit Manager)

6.3 Section Three: Discussion

This study addressed the need for an in-depth understanding of expert nurses' perceptions, experiences and opinions in relation to the needs of patients with haematological malignancies and use of telephone interventions to address these needs.

6.3.1. Summary of findings

Three key messages were evident from the analysis:

- patients' needs are individual and temporal requiring continuity of care;
- telephone interventions to address patients' needs are feasible and acceptable in given situations;
- in order to provide a high quality telephone intervention, appropriate organisational and professional resources are necessary and a clearly defined intervention purpose to guide its format and delivery.

The first theme highlighted expert nurses recognition of the individual and temporal nature of patients' needs. Psychological stressors in relation to cancer are acknowledged to be intertwined with those of physical and social issues (Adler and Page, 2008), and in this study, expert nurses also described patient's individual coping mechanisms as influential in the need for psychological support. Clinical factors also determined differences in need for support at the point of diagnosis and whether dealing with an acute or chronic disease. The perceived physical needs of patients were less prominent in the data, and notably treatment related especially where side-effects were on-going after discharge following intensive prolonged treatment. Expert nurses did however describe how physical problems of myeloma patients were particularly difficult to deal with due to ambiguity of the cause. Whilst it is recognised that decision making in healthcare often involves selecting management strategies where uncertainty exists (Thompson and Yang, 2009), care remained a challenge for these expert nurses. In all cases, patient-led support was championed along with patient choice, as the wish for support cannot be assumed even where levels of distress are high (Merckaert *et al.*, 2010). There was also appreciation for providing support that was both flexible and responsive to patients needs.

Patients' information needs were also described by the expert nurses as being individual and predominant within transition periods across the cancer pathway, findings which mirror the evolution of information needs in patients with haematological cancers reported in other studies (Gansler *et al.,* 2010). Expert nurses in this study gave particular significance to the information needs of SCT patients, perceiving the duration of treatment, on-going physical problems after discharge, and the complexity and responsibility for self-care at home as requiring more intensive information support.

Expert nurses described their own role in provision of information both in deciding content and timing of information provision. A variety of methods to convey information, a staged approach and reiteration were common strategies used to individualise and accommodate addressing patients information needs, as well as revisiting issues and encouraging questions.

Expert nurses felt their patients needed continuity of care, an argument where conflicting discourses emerged. A close relationship between the haemato-oncology specialist healthcare team and patient, and single point of contact for continuity of care, was seen as beneficial in facilitating communication, providing reassurance, building trust and was perceived to reduce unmet needs. However expert nurses shared concerns over the lack of longer-term support for patients, which has been evidenced within the literature in both lymphoma and leukaemia patients (Parry *et al.,* 2011). The specialist team was often seen as irreplaceable, especially in shared care settings and where a delayed cancer diagnosis fuelled subsequent mistrust in non-specialist healthcare professionals. Expert nurses spoke of their own role in fostering dependency on specialist services, how early stages of care had removed aspects of autonomy thus encouraging permission seeking. It was felt further ingrained by non-specialist healthcare professionals reticence to address haemato-oncology patients needs. Approaches such as education and training for community based non-oncology specialist healthcare professionals may be one approach to facilitate skill development and build confidence in patient management (Nekhlyudov *et al.,* 2017), as well as reinforcing the concept of shared care with patients themselves.

The second theme surrounded the applicability of telephone support. Expert nurses recounted their experiences of addressing patients' needs and providing support via telephone both by structured and ad hoc nurse initiated calls and patient initiated calls. Perceptions were prevalently positive with expert nurses describing greater accessibility to the team, convenience, utility for symptom monitoring, evaluating coping at home, as well as reiterating information, providing reassurance, timely advice and giving opportunity for patients to ask questions, which reflects findings within the literature (Cox *et al.,* 2017). These were seen as particularly useful in palliative care settings, following up issues raised in outpatient clinic visits, and providing on-going support especially for patients with chronic diseases. Proactive telephone calls were

complementary to standard care, being used to meet individual patients needs. Organisation benefits were also described, facilitating treatment planning and organisation as well as reducing inappropriate hospital visits and improving use of resources. Nurse initiated calls were not however seen as a necessity for all patients, and instead should be assessed by the nurse familiar with the patient.

Some expert nurses using such telephone interventions described them positively and an argument was also made for proactive calls as a means to empower patients, using the call to encourage patients to take responsibility for signalling problems and instigating further contact with the healthcare team. In contrast, reluctance to implement such a formal telephone intervention within the haemato-oncology setting was attributed to the perceived creation of patient dependence, waiting to receive the call, and the 'emergency' situations that delayed contact may bring.

Limitations to the application of telephone support were identified. Poor physical condition, communication difficulties and personal preferences were said to be potential factors making telephone support inappropriate or unacceptable for patients. Concerns were also raised about addressing sensitive and emotive issues by telephone and the challenge for nurses initiating such conversations, with patient's also perceiving a lack of emotional support from healthcare professionals (Jefford *et al.,* 2011, Mordenti *et al.,* 2013). Similarly, particular clinical situations were not conducive to telephone based evaluation where absence of visual assessment and cues were limiting factors. Expert nurses explored alternative methods of patient assessment to overcome the lack of visual cues such as face-time, but even these were not without problems. Some voiced concerns for the caller in terms of investing time and effort in calls that may not even be answered, wasting time and causing stress. While challenges to communication via telephone are reported within the literature (O'Toole, 2012), expert nurses already delivering such telephone-based interventions did not openly share these challenges possibly due to careful and appropriate selection of patients.

The third theme described considerations in order to maximise the quality of a telephone intervention, developing an appropriate and useful service. There was some difficulty in identifying specific patient groups that would benefit from such support. Overall agreement that knowing the patient was key to identifying who, where, when

and what supportive care would be beneficial to patients and whether telephone was an appropriate method of delivery to address the need. Similarly, content and timing of an intervention were said to be determined by individual need and both patient and clinical factors, concurring with the concept of a complex intervention by the nature of multi-factorial components (MRC, 2006). Suggested focus points for an intervention were - the post-discharge phase after intensive treatment and in providing support for elderly patients. Expert nurses suggested the intervention might include the use of structured checklists for 2-way reassurance but with a 'non-standard' flexible component ensuring an individualised approach to care. Clarity in defining the purpose of the intervention would therefore guide its form.

Expert nurses described nurses as well placed to deliver such supportive interventions having a holistic approach to patient care. The nurse-caller was said to require experience and knowledge of the disease and patients' pathway to facilitate the telephone interaction. A prior relationship between the nurse-caller and patient was not always seen as necessary, where an intervention was solely for symptom monitoring, however it is suggested that patients are reluctant to ask questions or discuss emotional issues with an unknown health professional (Cox and Wilson, 2003). Several benefits to an existing nurse-patient relationship were described such as knowledge of the patient facilitating individualised care, and increased participation in the intervention.

Incorporating new health technologies such as telephone interventions, into routine clinical practice can however be a demanding task. Whilst feasibility of calls was acknowledged, barriers to intervention implementation were described referring to resource implications, and the need for managerial support having dedicated time and recognition of the intervention as a valid part of the nurses role. Other challenges were raised in terms of identifying a clear purpose for the intervention, ensuring personnel training and also intervention appraisal to demonstrate utility or benefit of the service for both the organisation and the patient. These key issues support the wider literature on implementation which studies methods to promote the integration of evidence based practice and research into routine care in order to improve health service care, quality and effectiveness (Eccles and Mittman, 2006). They are particularly reminiscent of the Normalisation Process Theory, which elucidates the components of the implementation process: coherence – purpose, relevance and benefit of the intervention; cognitive

participation – user engagement; collective action – to put the intervention into practice; and reflexive monitoring – appraising the intervention (Murray *et al.*, 2010), all of which map on to findings from the data. Application of such a theory to the implementation of a complex intervention, could therefore aid understanding of the aspects of implementation, and by seeking to address the issues raised, improve staff engagement and facilitate integration of new practices.

6.3.2 Strengths and limitations

The strengths of this study are that this provides an in-depth exploration into expert nurses perceptions and experiences with telephone-based support for haemato-oncological patients, providing evidence in an area where research is limited. It provides insight into the perceived needs of this patient group from the perspective of expert nurses directly involved in patient care, service development initiatives, and also opinions regarding the feasibility, barriers and facilitators to telephone-based care interventions. Expert haemato-oncology nurses from different countries and acting within different roles were selected in order to capture variety in practice and experiences in patient care, also providing in-depth understanding of the advantages and disadvantages of proactive telephone communication with this group of patients.

The study also has limitations that are recognized. Although expert nurses from various countries and nursing roles were incorporated within the qualitative data collection process, it is acknowledged that this does not signify transferability in the extent to which findings can be applied to other contexts (Lincoln and Guba, 1985).

Due to logistical limitations and room availability, no alternatives were offered to expert nurses in terms of the location and timing of the focus groups, and as such, the sample and therefore the results are limited to those who were available at that time. Ideally multiple avenues for participation would have been provided to facilitate participation. Those agreeing to take part in the focus groups were also engaged in a professional conference, being potentially more motivated within in their field of practice and have interest in the topic of the study, leading to possible self-selection bias in the data.

At the outset of the study, multiple methods of data collection were not intended, however where one expert nurse was the only one selecting the first of the two dates given for the focus group, an individual interview was performed. The combination of interview and focus group data collection methods merits reflection on its validity, as it

is suggested that an ad hoc approach to data combination may impact of the trustworthiness of findings (Morse, 2003). The rationale for proceeding with this method of data collection was both practical – to address participant convenience, and pragmatic - determined by the perceived important contribution that the expert nurse could add to the area of investigation. The choice of focus groups for data collection within this study was to gain insight through use of interaction and discussion between participants by participant cross- questioning and remarking on each other's experiences (Duggleby, 2005), so as to inquire further. Whilst lacking such intercourse, the interview contributed to the understanding issues raised, and being performed prior to the focus group, it was used iteratively to identify elements felt to warrant further in-depth investigation during the focus group. In combining these data collection methods, both complementary and contradictory findings were elicited, enhancing the investigation.

Expert nurses were asked to identify the needs of patients with haematological malignancies so as to provide a focus for describing areas where telephone interventions may address need. Whilst within their practice, they have significant experience of patients conditions and symptoms, it is acknowledged that there is a variation in the congruence between proxy reporting by healthcare professionals and patients own rating of their symptoms and burden (Broberger *et al.,* 2005, Petersen *et al.,* 2006) with symptoms often being underestimated (Laugsand *et al.,* 2010). However as expert nurses are often providers of initiating and delivering telephone interventions, it is important to gauge their perceptions of patients needs, and it allows for comparisons with patients self-reported needs and triangulation of results. Other members of the multidisciplinary healthcare team also provide telephone interventions however they were not included within the focus group(s). Although it was felt that a nursing perspective would encompass a holistic approach to evaluation of patients needs, it is acknowledged that medical staff and other healthcare professionals may have differing views on this subject.

6.3.3 Conclusion

In conclusion, this study with expert haemato-oncology nurses provides insight into the perceptions of haemato-oncology patients needs and the use of telephone interventions to address needs. Telephone based interventions are increasingly being used in

healthcare initiatives and the opinions of nurses as service providers in this field requires investigation. Whilst there is acknowledgement that patients' needs are individual and changing, there is evidence that nurses are using telephone interventions to address some of their patients needs. Throughout the focus group, the variability of patients' needs was evident and as such, a single all encompassing model for telephone-based care was not possible to define. A specific model for a telephone intervention would therefore be based on the requirements of the particular situation and need being addressed. However careful and appropriate selection of both patients and the applicability of a telephone intervention to address the need are necessary to make an intervention feasible and successful.

This study has also provided a greater understanding of the prerequisites for a telephone intervention including the need for both organisational support and appropriate resource allocation. While telephone is an accepted method of communication, there needs to be a clear, established and comprehensive infrastructure to successfully add a telephone support intervention to practice.

Chapter 7: Reaching Consensus

This chapter describes the working methods and findings from Phase 2 of the research; consensus group meeting with multi-professional stakeholders. There are three sections to the chapter.

Section one details the working methods including the background to the consensus group meeting, the aims, an outline of the consensus process (including task definition, participant selection and invitation, information provision, and the consensus approach, along with data collection and analysis methods).

Section two reports on the outcomes of the consensus group meeting.

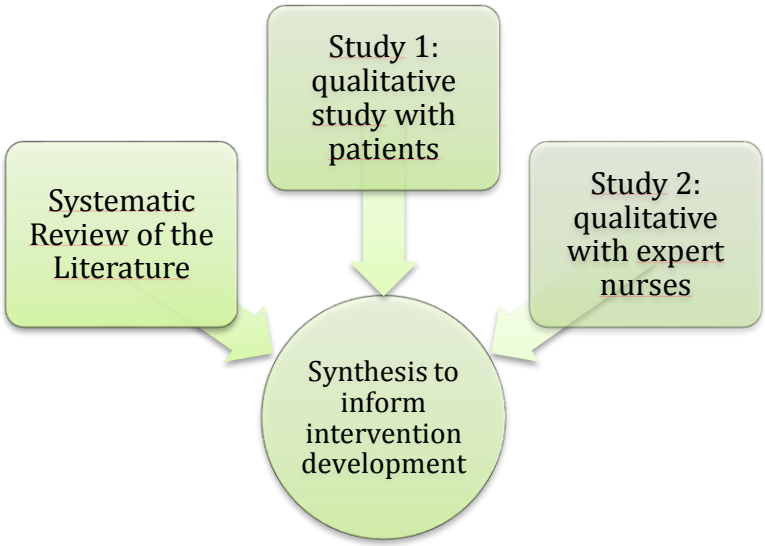
Section three offers a discussion of the outcomes and examines the strengths and limitations of the consensus group meeting.

7.1 Section One: Working Methods

7.1.1 Background to the consensus group meeting

In line with the MRC Guidance for the development and evaluation of complex interventions (Craig *et al.,* 2008), the research performed during the Phase 1 of the PhD provided insight into existing evidence relating to the acceptability of, and satisfaction with, telephone based interventions, among patients and expert nurses. A systematic review of the literature provided insight into existing evidence of the acceptability and satisfaction with telephone-based interventions for cancer patients. Study 1 provided a qualitative evaluation of patients' perceptions of the telephone-based intervention they had received, delivered within a single local setting. Study 2 provided qualitative insight into expert nurses appraisals of the feasibility, usefulness and acceptability of telephone based interventions within the haemato-oncology setting – as the primary service deliverers. The findings from these studies were synthesised (Figure 10), with each of these studies providing complementary and sometimes contradictory data. The synthesis of the data available was then used to inform the following stage of intervention development – modelling – where components of the intervention are identified along with factors impacting on the outcomes (Craig *et al.,* 2013).

Figure 10 - Research undertaken in Phase 1 of the PhD and synthesis



Despite the range of data sources within the first phase of the research, the evidence obtained highlighted areas of ambiguity in relation to:

- the needs of this particular patient group that could be addressed by a telephone intervention
- the overall acceptability of a telephone based intervention to provide support, and
- the nature of such an intervention in terms of content and delivery

A summary of these findings is provided in Appendix 26, 27 and 28. This indicated the need to interpret the evidence available and consider the outstanding ambiguities in order to model the intervention. Factors in relation to the local context where the intervention would be delivered were also to be acknowledged, and a consensus process was employed to perform this task.

7.1.2 Aims of the consensus group meeting

The aims of the consensus group meeting were to:

- review the existing evidence in relation to the unmet needs of haemato-oncology patients during treatment and post-treatment phases of the cancer trajectory, and agree which could and should be met by means of a telephone based intervention

- reach consensus on the core components of the intervention to meet patients needs, based on the available research evidence and/or clinical expert opinion where evidence was lacking
- define the patient group(s) that would benefit most from the intervention (with particular focus on the local context)
- identify resources and infrastructure necessary to implement the agreed intervention (with particular focus on the local context)

7.1.3 Consensus Process

The purpose of the consensus process was to evaluate the evidence available from the previous research undertaken in Phase 1 of the study and to identify and develop recommendations for the detail and content of the intervention where ambiguity was present. With this in mind, a consensus development method as a means to gain and synthesise perspectives of experts and stakeholders (Hutchings and Raine, 2006) was employed. More specifically for this phase of the PhD, the consensus development conference technique was utilised where decision makers are presented with evidence from experts within the field, and following on, make judgements to produce a definitive consensus of opinion (Duncan, 2006; Vakil, 2011). The structure of consensus development followed guidance suggested by Eccles *et al.,* (2012), with 3 inputs (defining the task, identifying and recruiting participants, information), the approach to consensus development and the output.

7.1.3.1 Defining the task

The purpose of the consensus group meeting was to analyse evidence in relation to telephone based interventions and the subsequent development of recommendations where uncertainties remained. The task of the group was therefore to address questions proposed by the author on the basis of the existing information, or lack of. The questions posed to participants at the consensus meeting focused on:

- identifying which unmet needs of haemato-oncology patients could feasibly be addressed by a telephone based intervention
- patients to target with the intervention
- intervention components, and
- organisational needs for intervention implementation

A complete list of questions is provided in Appendix 29.

7.1.3.2 Participant selection and invitation

Whilst an intervention aimed at providing support to address individual patients needs, appears to be an important component in care delivery, it is recognised that the development and implementation of any healthcare intervention takes place within a context of finite healthcare resources, necessitating service evaluation and stakeholder engagement as key elements in its success. With this in mind, participants for the consensus group meeting were invited from the local hospital where the telephone intervention would be performed. A purposive sampling technique was utilized to gain insights from different stakeholders in relation to the intervention development. Maximum variation techniques were applied by means of differing healthcare professionals, within clinical and managerial roles, with differing levels of experience, in order to maximise the range of views. Patients were not included as participants within this stage of the research process as their perceptions and recommendations for intervention modelling had been investigated through Study 1.

The meeting was also held at the local hospital - an approach selected to maximise participation from key stakeholders who were employees within the local hospital and to reduce attendance costs in relation to time out of service and expenses.

Whilst the literature suggests an optimal group size to be between 6 and 12 participants (Fink *et al.,* 1984; Murphy *et al.,* 1998), the invitation was sent to a much greater number of participants, with the rationale that some would not be able to attend due to prior commitments and as such the optimal group size would however be achieved. The potential participants perceived to be key stakeholders in the intervention and invited to attend the consensus group meeting included:

- staff from the Directorate of Nursing (3 in total)
- the Ward Manager from Haemato-oncology inpatient unit (also Area Manager for Medical Oncology and Day Hospital)
- the Deputy Ward Manager
- all nurses from the Haemato-oncology Inpatient Unit (n=17)
- all nurses from the Day Hospital Unit (caring for haemato-oncology patients) (n=2)
- all nurses who delivered the service previously – no longer working in the haemato-oncology unit (n=2)
- staff from the Unit of Clinical Psycho-oncology (n=2)

- medical staff from the Division of Haemato-oncology – representing the 2 units (inpatient and outpatient) and the Quality Manager (n=3)

All potential participants were sent an email 2 weeks prior to the consensus meeting, inviting them to take part, and providing an outline of the meeting in relation to the aims, the synthesis of previous research to be presented, and the subsequent consensus process to gain recommendations. The agenda and logistical information in relation to the meeting location, date and time were also provided. A second email was sent one week before the consensus group meeting, again to all potential participants with a document providing the summaries of Phase 1 of the research – the systematic review of the literature and qualitative Study 1 and Study 2. Further detail of the information provided is in section 7.1.3.3. Opportunity was given to contact the author with any questions, who provided further information as necessary.

Although ethical approval was not necessary for the consensus group meeting, potential participants were informed of the voluntary nature of participation, and that although the meeting would not be digitally recorded, it would be minuted in order to ensure an accurate summary of the points discussed and recommendations made. The consensus meeting was held in a private room to ensure privacy for the group.

7.1.3.3 Information provision

Prior to the meeting, summaries of the research undertaken to date were provided to potential participants. The summary of the literature review included research aims, methods, data summary, key findings, study limitations and what the study added to existing understanding of the topic. Similarly, single page summaries of Study 1: qualitative study with patients, and Study 2: qualitative study with expert nurses, included the research aims, methods, participant summary, key findings, study limitations and what the studies added to existing knowledge.

The purpose of providing information prior to the meeting was twofold. Firstly to orient participants to the topic of discussion, and secondly to provide the opportunity to read and assimilate the evidence and prepare any questions. It is acknowledged that excessive information can be overwhelming within the context of a consensus meeting (Kea and Sun, 2015), however the summaries attempted to provide a balanced overview

of the research performed, including recognition of the limitations of the research undertaken in order to facilitate participant evaluation of the importance reported findings. Information provision also gives participants equal access to data available and a shared foundation for discussion (Murphy *et al.*, 1998).

During the consensus group meeting, a verbal and visual presentation of the research performed to date, covering the 3 studies was performed by the author. This expanded on the single page summaries to provide further information in relation to the research findings and gave the group opportunity to ask and hear other group member questions.

In order to combine the results of the research previously undertaken (systematic review of the literature, Study1: qualitative study with patients, and Study 2: qualitative study with expert nurses), a blank matrix was drafted with each row referring to the core components of the intervention to be discussed, and each column referring to the 3 data sets that were presented. This was given to participants at the beginning of the meeting to allow them to populate the matrix by collating information and personal notes from the presentations in order to provide a practical and visual summary of the findings presented. Participants were then asked to identify where gaps or ambiguity in evidence existed, and further group work was undertaken by means of group discussion, to achieve consensus where gaps existed and recommendations for how the intervention could be applied in a local setting.

7.1.3.4 Consensus approach

A consensus approach may be either implicit or explicit. For the purpose of this consensus group meeting, an implicit approach was used, employing qualitative methods and majority voting to reveal the consensus of opinion (Kea and Sun, 2015). The information provided and the matrix were used to aid group discussion and obtain a summary of recommendations for the intervention. The consensus group meeting was minuted by a secretary, and notes were made by the author.

7.1.3.5 Output

The output of the consensus approaches refers to the dissemination of results and it is suggested that this needs to be considered beforehand (Kea and Sun, 2015). In this case, it was planned that the minutes of the meeting would be circulated to ensure an accurate

recollection of the meeting had been recorded. The feedback from the consensus group meeting would then be analysed, and incorporated to produce a final intervention, which was to be presented to stakeholders as well as patients for their feedback and refinement.

7.1.4 Ensuring rigour

Diverse measures were utilized to ensure rigour within the consensus group meeting. To address the need for credibility, the group was comprised of a variety of participants seen as key stakeholders in such an intervention. Decision makers, nurse managers, experienced senior nurses and staff nurses from the haemato-oncology inpatient and outpatient departments, as well as other healthcare professionals were part of the panel providing recommendations, able to provide insight into the key issues for discussion. As described previously, the minutes of the meeting were circulated as a means of member checking (Denzin and Lincoln, 1994) such that the accuracy of the authors' interpretation of the meeting could be evaluated and feedback from participants gained. The outcomes of the meeting were also found to reflect closely the evidence from the three datasets presented.

Reflexivity

Within the context of the consensus group meeting, the author recognises existing professional relationships with participants, experience, and presumptions may influence the meeting. As previously described, detail of the authors professional background, academic qualifications, reflection on current clinical role and personal experience with telephone based communication and support for haemato-oncology patients are described fully in section 5.1.9. The opinions and recommendations of the participants in the development of the intervention were of interest to the author to explore how an intervention could be modelled to address the identified needs of patients, whilst being feasible and sustainable from an organisational perspective. Before undertaking the PhD, the author did not have experience of moderating consensus group meetings. The author had however experience in conducting focus groups with expert nurses in Study 2 of the PhD. The supervisory team, with significant experience in consensus process for intervention development, provided support throughout the process.

7.2 Section Two: Results

Section two of this chapter presents the results of the consensus group meeting with key stakeholders. A description of participants is reported, along with the recommendations emerging from the data.

7.2.1 Consensus group meeting participants and demographic data

Participants were invited to attend the meeting in February 2017. A total of 31 people were invited to participate – details of those invited to participate are reported in section 7.1.3.2. Ten invitees attended the meeting. Twelve people did not respond to either of the emails, and 9 invitees sent apologies, being unable to attend the meeting for various reasons (in service n=7, on holiday n=2).

The duration of the consensus group meeting was 2.5 hours in total. Summary demographic data is detailed in Table 10.

Table 10 - Consensus group meeting: Participant demographics

Job Title / Role	**Number of participants**
Nursing Directorate staff	3
Haemato-oncology Inpatient Unit Nursing managers	2
Haemato-oncology Inpatient Unit Nurses	2
Unit of Clinical Psycho-oncology staff	1
Nursing Staff from Clinical Research	2
Total	10

7.2.2 Recommendations from the consensus group meeting

During the consensus meeting, the questions proposed by the author (Appendix 29) formed the focus of the task. The task was separated into 3 key areas: the appropriateness of a telephone intervention to meet patients needs, formulating a description of the intervention (to include target patient group, content, delivery details and resource requirements) and methods for intervention evaluation. A summary of the findings from the consensus group meeting are provided in Table 11.

Table 11 - Findings from the consensus group meeting TELECARE intervention core components

	Who should it be provided for?	What should the intervention be?		Who should be the provider? (provider / skills)	How should it be provided?	Where should it be provided?	When and how much should be provided? (timing / frequency / call duration)	Should the intervention be tailored?
	Patient characteristics	**Materials / Additional training**	**Procedures**					
Systematic Review of the Literature	Who depends on intervention type Pts agreeing to calls	Intervention dependent	Individualised component preferable	Intervention dependent	Acceptability of telephone method is personal and content dependent	-	Intervention dependent	Individualised component preferable
Study 1: Qualitative study with patients	• Pts agreeing to calls • In absence of informal support • Pts with on-going physical problems • Pts not local to hospital	-	• Enquire about well-being • Information reiteration • Provide reassurance • Provide psychological support • Behavioural advice including LTSE's and management	<u>Provider</u> Experienced nurse Continuity of care	Acceptability of telephone method is personal and content dependent	-	<u>Timing</u> Diagnosis, waiting for treatment to start, during treatment, early post discharge phase, during protracted visits, for a few months post allogeneic SCT <u>Frequency / duration</u> Needs dependent / monthly <u>Duration</u> Needs dependent	Patient directed component. Give opportunity to ask questions
Study 2: Qualitative study with expert nurses	• Pts agreeing to calls • Older pts • Following complex in-pt treatments (e.g. SCT) • Pts with chronic diseases • Others to be identified by nurse	<u>Materials</u> Access to pts records and a telephone. Holistic needs assessment chart. Dedicated time for intervention <u>Additional training</u> Telephone based communication	• Provide reassurance and advice • Check adherence • Information & results reiteration • Side effect evaluation and self-care management	<u>Provider</u> Experienced nurse Existing relationship preferable for nuances / care individualisation/ pt engagement <u>Skills</u> Intuition where lacking visual cues	Acceptability of telephone method is personal and content dependent	Calls from the hospital Private area to talk	<u>Timing</u> Post discharge after complex treatment (e.g. transplant) FU post clinic with results reiteration <u>Frequency</u> Needs dependent	Responsive to individual needs Flexible to address non-standard issues arising
Consensus Process	Agreement with need to obtain pt consent to call. Disagreement over possibility to identify specific groups 'a priori'.	<u>Materials</u> Agreement with materials required <u>Additional training</u> Agreement with training requirements	Agreement with holistic assessment and components identified. Disagreement over terminology 'psychological support'.	<u>Provider</u> Disagreement with 'experienced' nurse, rather nurse competent in care of the patient. Agreement with continuity in care.	Agreement that patient preference should guide intervention delivery method.	Agreement of need for privacy	Agreement of potential need for support throughout the trajectory for all patients. Agreement that components of frequency and duration are needs dependent.	Agreement of need for flexibility and responsiveness to individuals needs
Incorporated into the intervention	Obtaining and documenting pt consent to receive calls *All patients discharged to be offered calls*	<u>Materials</u> Access to pts records, telephone, private room for call. *Nursing documentation and clinical pathways as basis for intervention.* Protected time for intervention delivery <u>Additional training</u> Telephone based communication	Needs evaluation *using local nursing documentation* Support to include: Symptom monitoring/ management, adherence monitoring, information provision and reiteration, reassurance, *emotional support*, behavioural advice	<u>Provider</u> *Patients Primary Nurse*	*Only a telephone-based intervention in line with resources available.* Patient given choice to receive calls.	Calls from the Ward Managers Office. During working hours.	*Intervention provision in line with resources available.* <u>Timing</u> *Limited to patients from the in-pt unit. Called within 1week of discharge.* <u>Frequency</u> *Maximum 2 calls* <u>Duration</u> *Pt dependent but with introductory phrase to delineate the intervention*	Components of support to provided depending on needs identified (information, emotional etc.) Allowing time for patient questions

FU – Follow-Up, LTSE's –Long Term Side Effect(s), pt/ pts – patient / patients, SCT – Stem Cell Transplantation

NB: *Italics denotes components incorporated into the intervention based on discussions during the Consensus Process, and independent of summary evidence available*

7.2.2.1 The appropriateness of a telephone intervention to meet patients needs

There was general agreement with the evidence that patients needs were individual, temporal, changing in nature and often beginning prior to receiving a cancer diagnosis and spanning across the pathway. There was consensus however that currently available resources meant addressing patients needs across all time points was unfeasible. Participants identified emotionally critical time points for patients (the initial phase beginning treatment and at the end of their treatment, in times of trauma and transition), and agreed that a telephone intervention would be useful to providing support in this periods. Whilst there was agreement that such support should be available for all patients, limitations in terms of nursing staff resources, and a private location to perform such calls, were not available within the Day Hospital (where outpatient treatments are delivered). The consensus of opinion was therefore to provide support for patients that had been in the in-patient unit and had recently been discharged.

There was acknowledgement that post discharge rehabilitation services were lacking however the consensus was that these issues were outside of the scope of a telephone intervention.

7.2.2.2 Formulating a description of the intervention

The description of the intervention included who it should be provided for, what the intervention should be, the provider characteristics, delivery method, intervention timing/ frequency/ duration, and tailoring.

Who should it be provided for?

In agreement with the evidence provided regarding patient choice to receive intervention calls, the group felt that it should be discussed with the patients and consent obtained for the calls. Additional suggestions included provision of a brochure outlining the nature of the intervention and documentation of consent being recorded in the patients electronic notes.

There was disagreement with the evidence provided regarding specific groups of patients who would benefit most from the intervention, with the groups initial discussions suggesting a focus on patients identified as ‘fragile’, having problems with performance of self-care, needing social support, asking for psychological support, or were ‘protected discharge’ patients where continuity of care and assistance was required

in the community setting. The final consensus was to contact all patients agreeing to receive calls following discharge, as support was seen as not only necessary for patients with evident problems. The intervention could not however be offered to patients who did not speak the local language, as financial resources translation services and bureaucratic support were not available.

What should the intervention be?

There was agreement with the evidence that the intervention should be led by a needs evaluation, however there was disagreement with the need for an additional needs assessment tool. The consensus was to use the local nursing care documentation and clinical pathways relevant to the patients experience as these were comprehensive enough to identify symptoms, check medication and self-care adherence, and information deficits. Use of existing documentation also permitted recording of the calls and subsequent support provided.

There was disagreement by the group regarding the provision of 'psychological support' within the intervention. Both staff from the Unit of Clinical Psycho-oncology and nursing staff did not feel the term was appropriate, as it implied formal psychological support from a 'psychology trained' practitioner. It was felt that the term 'support' should be used instead in reference to care of patients experiencing personal emotional distress.

There was agreement with the evidence that additional training for telephone based communication would be beneficial. It was suggested that it should encompass techniques of empathic listening, telephone based communication skills, and simple communication skills, and could be provided by the Unit of Psycho-oncology via educational sessions.

There was also agreement with the evidence provided regarding need for adequate material and personnel resources for the intervention. The group rationalised that there was an estimated three to four patient discharges per week from the in-patient unit as a whole, and consensus of opinion was that the Primary Nurse responsible for the patients care during their inpatient stay, would call the patient. This meant feasible distribution of additional workload (calling patients) and not relying on one individual nurse to perform all calls.

Who should be the provider?

There was agreement with the evidence of the need for continuity of care which was said could be addressed through the Primary Nurse performing the intervention. There was group disagreement however with the suggested need for an 'experienced' nurse. The group elaborated on the role of the Primary Nurse and assignment of patients based on the individual nurses competency, with more experienced nurses caring for more complex patients e.g. those undergoing allogeneic stem cell transplantation. There was a consensus of agreement that the Primary Nurse (independent of their level of 'experience') had been deemed competent in the care of the patient during the inpatient stay, and therefore had the relevant knowledge required to understand both the needs of the patient and the best way to address these needs.

How and where should it be provided?

Whilst there was agreement with the evidence that individual preference may not be for a telephone-based intervention, the final consensus taking into account the resources available, meant that an intervention only by telephone would be offered.

When and how much should be provided?

The group acknowledged the significant variation within the evidence provided and difficulty defining a single rule for the call timing, primarily due to the reason for calling i.e. concerns over self-care or complex medication instructions, would require a call sooner after discharge. The final consensus was that calls should be made within 1 week of discharge - allowing the Primary Nurse to tailor the call timing for both the patient and their own workload.

Similarly, the lack of clear evidence on the duration of calls led the group to agree that the intervention would provide a maximum of two calls following discharge. The rationale given was in order to promote independence and proactiveness of the patient to call in with any problems. It was also suggested that there should be an introductory phrase used at each telephone call in order to frame the context of the call, and clarify the reason for the call. This was to ensure that the call would not be interpreted inappropriately and to delineate the purpose.

Should the intervention be tailored?

There was agreement with the evidence that there should be an individualised component within the intervention, and this could be achieved by an individual assessment and encouraging questions from patients.

7.2.2.3 Methods for intervention evaluation

The group agreed that it was feasible to perform a telephone based supportive care intervention, but it was necessary to evaluate the intervention, both with the patients receiving the intervention and healthcare professionals delivering the intervention, in terms of feasibility as well as efficacy and outcomes. Based on the evidence presented, it was agreed that mixed methods incorporating both qualitative and quantitative approaches should be utilized to ensure the possibility of providing an openly critical evaluation of the service from the perspective of key stakeholders.

7.3 Section Three: Discussion

This consensus meeting addressed the need for interpretation of evidence available and consideration of outstanding issues in order to model a telephone intervention providing support for patients with haematological malignancies.

7.3.1. Summary of findings

Three separate studies were synthesised to develop a theoretical and acceptable intervention, driven by patients and healthcare professionals perspectives. The consensus meeting found that:

- despite agreement with the evidence regarding the need to provide support across the patients cancer trajectory, current resources meant this was unfeasible however additional support via a telephone based intervention could be provided for patients recently discharged from the inpatient unit
- the intervention would monitor patients for any physical, social or psychological needs, to identify and address information needs, and to provide support through individualised care
- the Primary Nurse would deliver the intervention, having a pre-established relationship with the patient and would be equipped with telephone communication skills training to deliver the intervention effectively

- intervention evaluation should include opinions from key stakeholders as well as using mixed methods approaches to ensure an open and fair appraisal

An outline of core components of the intervention is provided in Table 12 following TIDieR intervention reporting guidance (Hoffmann *et al.*, 2014).

Table 12 - The TELECARE intervention

	Item
Brief name	TELEphone CARE Intervention (TELECARE)
Why	To monitor all patients (agreeing to receive telephone calls) post discharge from the haemato-oncology inpatient unit for any physical, social or psychological needs, to identify and address information needs, and to provide support through individualised care
What	Materials: Training – Primary Nurses will be provided with training in relation to telephone based communication from the local Unit of Clinical Psycho-oncology Resources - Electronic nursing documentation and clinical pathways will be used as a basis for patient needs assessment, care planning and documentation of any further intervention. Primary nurses will have access to patients records, a telephone, and a private room in order to perform the intervention Resources for patients - patients will be provided with written information regarding the intervention and its purpose Procedures: Needs evaluation using local nursing documentation Support will be provided which includes (but is not limited to): symptom monitoring/ management, adherence monitoring, information provision and reiteration, reassurance, emotional support, behavioural advice
Who	Intervention to be provided by the patients Primary Nurse
How	Telephone intervention only (Patient and Primary Nurse)
Where	Delivered from the hospital to patients at home (via telephone) during daytime working hours (9am – 5pm)
When and how much	Patients to be called within 1week of discharge Maximum of 2 separate calls to be made Duration of the call (in minutes / hours) - patient dependent but with introductory phrase to delineate the purpose of the intervention
Tailoring	Components of additional support to be provided depending on needs identified (information, emotional etc.) Allowing time for patient questions

7.3.2 Strengths and limitations

The process of modelling within the development of this complex intervention has encompassed evidence from a systematic review of the literature, patients opinions and expert nurses opinions in relation to telephone interventions. This provided a basis for the development of both an evidence based intervention, and one that is patient centred. The evidence provided, was not without areas of ambiguity, and the consensus meeting gave the opportunity to discuss these openly and transparently, tailoring the development of the intervention to the reality of the local setting, a factor suggested to enhance complex interventions rather than a completely standardised approach (Campbell *et al.,* 2007c).

The consensus approach however is not without limitations. The modelling of the intervention was heavily dependent on the consensus group participants, and while the author aimed to encourage opinions from all group members, it is acknowledged that some participants may not have felt at ease expressing all concerns where more senior managerial members of the nursing team were present. The range of professionals that attended the meeting did not include medical staff, nursing staff from the Day Hospital, or nurses that had delivered the intervention previously. These individuals could have provided additional perspectives, highlighting barriers and facilitators to intervention success. The consensus process was also a single meeting limiting accessibility to participants who were available at the time / date set. This was due to time and funding limitations, however plans to detail the intervention and present this to patients, nurses and other key stakeholders for further refinement are planned. It is also recognised that as the purpose of the meeting was to gain consensus on implementation of a telephone intervention within the local haemato-oncology setting, this limits the transferability of the findings to other settings – both in terms of clinical areas and disease groups within the same hospital setting, but also in different external healthcare settings.

7.3.3 Conclusion

While telephone interventions are increasingly used in healthcare provision, the nature and content of interventions is dependent on the needs being addressed. The synthesis of the studies undertaken in relation to telephone support for patients with cancer during and post-treatment, provided both complementary and contradictory findings. The consensus meeting with key multi-professional stakeholders was therefore aimed to

provide consensus on areas of ambiguity – where either evidence was conflicting or absent, in the definition of a supportive care intervention.

Evidence provided was not always incorporated into the intervention due to resource limitations. Key components that were incorporated therefore reflected stakeholders' knowledge of the local context in terms of resources available to provide support. The result was a detailed outline of a telephone intervention to meet patients needs, defining a complex intervention (including the target patient group, content, delivery and resource requirements) and methods for its evaluation.

Chapter 8: Discussion

The aim of the PhD study was to develop a telephone intervention providing support and symptom management that is acceptable to patients undergoing or having undergone treatment for a haematological malignancy, based on the best available evidence. The MRC Framework (Craig *et al.,* 2013) was used as the basis for the development of the intervention.

This chapter provides an overview of the PhD and discussion of the key findings from the studies undertaken. It reflects on the strengths and weaknesses of the thesis, and describes this research in light of current literature in the area, providing recommendations for practice and future research.

8.1 Section one: Identifying the evidence base

Following the MRC framework, the evidence base to inform the development of the intervention was derived from 3 sources – a systematic review of the literature, interviews with patients with haematological malignancies and focus group(s) with expert haematology nurses.

In the systematic review of the literature in relation to patient reported acceptability and satisfaction of telephone delivered support during- or post-therapy for cancer (Chapter 4), there is clear evidence of the application of telephone based interventions in a variety of settings, although very few included patients with haematological malignancies. Heterogeneous approaches to evaluation of intervention acceptability and satisfaction were primarily quantitative measures, which did not always reflect the complexity and concerns of patients in relation to interventions. However, whilst the overall quality of the evidence was not high, telephone interventions were reported to be convenient, providing positive personal experiences, accessibility to the healthcare team, timely reassurance and continuity of care. It was evident however that for some patients, such interventions were undesired and unnecessary, with the telephone method itself seen as inappropriate to meet certain needs.

Study 1 explored the needs of patients with haematological malignancies and their experiences of the then existing telephone intervention for support and symptom management through semi-structured interviews (Chapter 5). The study highlighted the

presence of personal emotional distress for patients throughout the cancer trajectory, and the variety of coping techniques to deal with distress – some of which were imposed, particularly where external coping assistance was perceived as unavailable. Even where existing support was present, unmet needs remained prevalent, especially in the post treatment phase in terms of information needs, and emotional support. Overall perceptions of the telephone intervention were positive, addressing some identified needs. Recommendations for a more effective and useful intervention included acknowledgement of personal preferences for support and a more individualised patient-centred content guiding its structure and delivery.

Study 2 employed focus group(s) methods to investigate the perceptions of expert haematology nurses regarding the needs of patients with haematological malignancies and their use of telephone interventions to address patients needs (Chapter 6). Expert nurses emphasised the individuality and temporal nature of patients needs and the necessity for continuity of care. Telephone interventions to meet patients needs were felt to be both feasible and acceptable where there is a clearly defined intervention purpose to guide delivery and format. It was stressed however that engagement of appropriate organisational and professional resources were imperative for the provision of a sustainable high quality intervention.

The evidence base confirmed the feasibility and acceptability of telephone interventions in the provision of support for patients, however the individuality of patients needs at different time points and measures to address such needs exposed unresolved issues defining the finer detail of the intervention.

8.2 Section two: Reaching consensus

A consensus group meeting to inform and develop a telephone intervention providing support and symptom management that is acceptable to patients undergoing or having undergone treatment for a haematological malignancy was undertaken based on the synthesis of findings from the evidence base (Chapter 7). The consensus group meeting constituted the development/ modelling phase of the MRC complex intervention framework.

The synthesis of research performed to date illustrated areas of persisting ambiguity, in particular which needs could be addressed by a telephone intervention, patients to target, detailed intervention components, and the organisational requirements for intervention implementation. The consensus group meeting was held with key stakeholders from the hospital where the intervention would be provided in order to address local context issues and facilitate implementation. Whilst there was agreement with the research presented, current resources including the lack of a transversal nursing figure within the healthcare team (i.e. Clinical Nurse Specialist) did not permit for such an intervention to cover all time points of the patients trajectory, rather this could only be focused on providing support for patients discharged from the in-patient unit. The result of the consensus group meeting was the definition and outline of an intervention delivered by the Primary Nurse, to monitor patients for physical, social or psychological needs and provide support through individualised care planning. Agreement was reached that the intervention could be trialled in practice and evaluated using mixed methods approached for appraisal.

8.3 Section three: Strengths and limitations of the thesis

8.3.1 Strengths

This study has demonstrated the application of the MRC framework to develop an intervention, through a sound methodological approach to research. This approach encompasses the essence of evidence based medicine, integrating research evidence, patients problems and preferences, and clinical expertise in decision-making for patient care (Sackett *et al.*, 1996).

A transparent and reproducible systematic review of the existing literature has produced insight into the breadth of implementation of telephone interventions in the cancer setting. It highlighted the lack of high quality evidence in evaluation by recipients as to its acceptability and satisfaction, however it provides a valuable understanding of current practice.

The systematic review provided a broad framework of knowledge, which was further refined by multiple method approaches of primary research specific to both the telephone intervention that had been delivered, needs of patients with haematological malignancies, and in the context of supporting these patients via telephone based interventions.

Study 1 involved interviews with patients having received the existing intervention. The ability to perform the interviews in the native language of these patients optimised data richness. Framework methods for data analysis of studies 1 and 2 were transparent and clearly documented. Recurrent themes were evident and data saturation was achieved, enhancing the rigour of these studies.

The combination and integration of findings from the evidence base and involvement of key stakeholders in the consensus group meeting, permitted development of the final intervention tailored to the local setting.

8.3.2 Limitations

Whilst the literature review was rigorous in its methodological approach, participants' perspectives were often not explicit within the study aims and therefore not part of a rigorous study design. This resulted in several reports of low quality qualitative data and frequent use of quantitative questionnaires, which were neither standardised or validated. It is acknowledged that the findings therefore may be limited by the quality of the primary research itself.

A limitation to the qualitative study with patients, which investigated perceived needs (Study 1), was the sample that they were drawn from. This was a single centre study, with the majority of patients diagnosed with lymphoma, including only those having received the telephone intervention. Findings may not therefore be representative of issues for all patients with haematological malignancies as they may differ between disease subgroups. Similarly, patients who had not received the existing intervention (and therefore not seen as requiring additional support) may have different needs.

Another limitation in study 1 was the delay in obtaining ethical approvals to begin the qualitative research with patients. This meant that over the period of time, changes in staffing and resources impacted on the delivery of the existing telephone intervention, which stopped during the course of the PhD, resulting in three key repercussions. Firstly the pool of patients eligible for the study was diminished as many patients had either died or were no longer in follow-up at the treatment centre. Secondly, the time from intervention to interview meant that some patients did not recall receiving the intervention, potentially causing bias in representativeness of the sample. Thirdly, the planned sub-group analysis of patients above and below 30 years old, was no longer feasible. Despite these factors, recruitment for data saturation was achieved, and the suspension of the existing intervention - that had been started as an *ad hoc* service -

gave substance to the argument that research and modelling was necessary to formulate a sustainable service.

Interviews with patients in Study 1 were performed either face-to-face at the hospital or via telephone in order to facilitate accessibility and participation. The geographical distance of patients from the hospital limited the possibility to offer home visits to undertake the interviews, which participants may have preferred. Whilst the author attempted to be reflexive, personal biases may have still influenced data collection. Patients were made aware of the authors current role as research nurse within the Division of Haematology and this may also have had a bearing on responses with patients potentially avoiding criticism of services where they were still being cared for. During the focus group(s) with expert nurses in Study 2, the author aimed to facilitate group interaction, however it is appreciated that some members of the focus group were more verbally expressive than others, which may have directed discussions, and hindered openness of other participants, providing what were socially acceptable responses.

In relation to intervention modelling, consensus group participants were provided with summaries of research performed to date. These summaries whilst being reviewed by the supervisory team for consistency, were summaries and not the complete findings, and as such may be susceptible to bias in data presented on the part of the author. Another limitation of the consensus group meeting was the lack of additional healthcare professionals in this modelling phase – due to the restrictions of a single date and time for the meeting participation was not feasible for all invitees. The views of nurses previously delivering the intervention and medical staff would have enhanced the discussion and modelling process. Similarly, the lack of patient / participant involvement in the modelling phase is a limitation. Although patients perceptions and recommendations for intervention modelling had been investigated previously, it is recognised that patients may have provided further contribution through interaction and debate with other key stakeholders in the final development of the intervention.

8.4 Section four: PhD study in context and recommendations

8.4.1 The PhD study and the current literature

Telephone based interventions for cancer patients have been the subject of several more recent systematic reviews of RCT's reporting on efficacy for pain, depression and quality of life, and psychosocial interventions (Agboola *et al.,* 2015; Okuyama *et al.,* 2015) and both efficacy and acceptability in follow-up in lieu of routine hospital visits (Dickinson *et al.,* 2014). A recent meta analysis reports on 16 studies investigating the effects of nurse-led telephone-based supportive interventions delivered across the cancer trajectory for adults with a variety of cancer diagnoses (Suh and Lee, 2017). Similar to the PhD literature review, a heterogeneous range of interventions were included in the analysis covering follow-up, symptom management, information support, psycho-social support, sex therapy, exercise and diet interventions and coaching for self-care adherence. The analysis suggested that interventions improved self-care and reduced cancer symptoms as well as reducing emotional distress and improving quality of life although to a lesser extent. The breadth of application of telephone interventions in these reviews mirrors findings within the systematic review for the PhD despite the focus on RCTs alone.

Whilst intervention efficacy and improving outcomes for patients is an important component of care for patients with haematological malignancies (NICE, 2016; NICE, 2017), so is the provision and development of services based on patient centred care, recognising patients perspectives (Committee on Quality of Health Care in America, Institute of Medicine, 2001). The investigation of patients' perceptions however, remains less evident within the literature.

Since commencing the PhD and publication of the systematic review focusing on acceptability (Liptrott *et al.*, 2017), a further systematic review has been published by Cox *et al.* (2017). Although studies included a similar patient population, the research question differed in that it focused on solely qualitative evidence of cancer survivors' experiences within a variety of telehealth interventions (comprising telephone and internet). Eleven of the studies appraised telephone-based interventions, with findings consistent with those from the systematic review in terms of: convenience, promoting independence, personalised care in terms of dedicated time and space to focus on concerns, remote reassurance, continuity of contact, being cared for and watched over.

Negative perceptions were also described in terms of the impersonality of telephone interventions especially where patients did not know the caller, and patient related barriers such as hearing difficulties – echoing issues raised by the qualitative findings from PhD studies. Findings would therefore suggest that while telephone interventions are not the perfect solution for all patients, they may go some way to responding to a significant number of needs highlighted by patients.

Intervention acceptability as perceived by patents has been a key component of the PhD work undertaken. Recently Sekhon *et al.* (2017) have proposed a theoretical framework and conceptual definition for acceptability, describing it as:

> *"A multi-faceted construct that reflects the extent to which people delivering or receiving a healthcare intervention consider it to be appropriate, based on anticipated or experienced cognitive and emotional responses to the intervention*." (Sekhon *et al.*, 2017, p. 4)

The systematic review undertaken aimed to capture acceptability, however this concept was often undefined in the literature, rather implied, and measured in terms of participation to, satisfaction with, adherence to, and experience of the intervention of interest. Whilst the PhD studies were not based on this definition, there are areas that reflect components of this theoretical framework. The suggestion that acceptability of a healthcare intervention is dependent not only on the perceptions of those receiving the intervention, but also those delivering the intervention, has been reflected in the approach within the PhD studies where opinions have been sought from both patients, expert nurses and key stakeholders in the intervention modelling phase. Similarly, the element of intervention appropriateness based on cognitive and emotional responses, lends itself to evaluation through qualitative methods – the approach taken both in studies 1 and 2 of the PhD. The availability and application of a conceptual definition and theoretical framework to further research should facilitate a more rigorous and uniform future evaluation of acceptability of healthcare interventions.

A cross-sectional questionnaire survey of unmet supportive care needs in adult haematological cancer patients was performed across 4 Australian states reporting results from 715 respondents, with over 60% diagnosed with lymphoma and a mean 35 months from diagnosis, although it was unclear if patients were actively receiving treatment (Hall *et al.*, 2015). The study described the ten most frequently reported

unmet needs - most of which were linked to emotional health – comprising of fatigue, poor memory/concentration, anxiety, changes in physical ability, lack of patient peer support, expectations of others, stress, inability for long-term planning, affordable parking and the cancer diagnosis itself. Patients within Study 1 of the PhD also perceived unmet needs in psychological support, economic and financial aid, and dealing with physical limitations. In contrast they also alluded to the need for information to facilitate coping and the need for continuity of care. Divergent findings from these studies may be influenced by a number of factors including methodological approaches to the investigation and differences in infrastructure of patient care between countries.

A recent cross-sectional study has been published investigating unmet psychosocial supportive care needs, distress and psychological flexibility in 91 haematological cancer survivors (Swash *et al.,* 2017) via online or mailed questionnaires. Similar to the PhD study 1, the majority of respondents were lymphoma patients having finished treatment. Elevated levels of clinically significant and borderline anxiety and depression, unmet psychological needs and the desire for psychological support were evident. Unmet needs were more common in relation to tiredness, inability to perform activities as before the cancer, uncertainty about the future, concerns for others, anxiety and fear of cancer spreading. A statistically significant correlation between psychological needs and both physical daily living needs and patient care and support needs was observed. Although the methodology differs, these findings confirm those from the qualitative investigation with patients in Study 1 both in terms of areas of need as well as the perceived positive correlation between physical and psychological well-being.

Both of the qualitative studies undertaken for the PhD highlighted the unmet information needs of patients. Atherton *et al.* (2017) recently performed a systematic review of the information needs of adult patients with a range of haematological malignancies at various time points in the cancer trajectory. Quantitative findings highlighted general overall satisfaction with information received, with unmet information needs given a low priority in comparison with other unmet needs. Key areas of need included treatment, disease recurrence, fertility and sexual functioning with clinicians seen as the most important resource for information. Qualitative findings highlighted individual preferences for the amount of information desired, poor recall at

diagnosis, the desire for information to assist with day to day treatment and maintaining hope, and transition from inpatient to ambulatory care. One significant conclusion by the authors was the impact of the relationship between the physician and patient where a caring trusting relationship resulted in greater contentment with information received and needs being met. Unmet information needs appear to be more prominent in Study 1 of the PhD, however several of the findings are consistent. Furthermore, patients in the PhD study also alluded to the impact of information in terms of empowerment and promoting self-care as well as how unmet information needs influenced negatively on coping and adjustment to the cancer and its treatment. This observed difference may be due to the methodological approach employed.

8.4.2 Recommendations for practice

Patients needs are both individual and in a constant state of change. In order to address patients unmet needs, healthcare practitioners should incorporate regular needs assessment into their care, as a means to identify patients needs, but also investigate whether patients actually want support addressing identified needs. Instruments such as the Survivors Unmet Needs Survey (Hall *et al.,* 2014) is a valid and reliable tool tested within haematological cancer survivors and would be fitting for such an assessment. Evaluation and promotion of patient choice for support will promote both a patient-centred personalised approach to care and appropriate use of resources addressing individuals needs.

Local service issues were raised by patients in Study 1, in particular the lack of rehabilitation services such as physiotherapists and psychologists following discharge, and are important matters to consider for future service planning. Another issue was the shift from frequent and close contact with the hospital team to detachment: with mistrust of non-specialist healthcare professionals and the desire to remain under specialist hospital care. One recommendation may be to increase capacity to accommodate all patients however this is probably unrealistic. A more pragmatic solution would be to improve communication and links between the specialist centre, primary care and the patient, fostering and preparing the patient to return to care away from the hospital, whilst not leaving patients feeling abandoned.

The importance of a trusting relationship with the healthcare professional, key resource in information and support provision, has been described in various points throughout the thesis. Findings suggest however that healthcare professionals can themselves be barriers to support seeking behaviours by patients – perceived as too busy, or caring only for their disease speciality. Greater acknowledgement of this responsibility, a humanised approach and self-awareness of personal behaviours are necessary to facilitate a trusting and therapeutic relationship with patients.

The initial development of a telephone intervention to provide support and symptom management for patients with haematological malignancies cared for at a single centre institute, was ultimately unfeasible. Following the MRC Framework guidance in the development of the evidence base, the involvement of stakeholders aided the identification of barriers and facilitators to the implementation of the intervention and its modelling. This approach of stakeholder engagement was both enriching and invaluable in the development of the intervention. Although it is acknowledged that the intervention is designed to reflect the local context, its content, nature and the considerations posed may be of use in other clinical areas to assist in providing telephone-based interventions.

8.4.3 Recommendations for future research

Additional views of healthcare professionals should be sought in the modeling of the intervention. These should be the nursing staff involved in the delivery of the initial telephone intervention delivered and those of hematology medical staff. The nursing staff can provide expert insight into the barriers and facilitators of the telephone intervention, and medical staff may be able to contribute to a greater understanding of the mechanisms by which signaling and reporting of issues raised in the future intervention can be dealt with in a multi-disciplinary approach.

The research undertaken has provided the outline for a refined symptom management and support intervention for patients with hematological malignancies. This should be trialed within a methodologically sound feasibility study, in order to investigate

- acceptability and satisfaction according to stakeholders – nurses delivering the intervention, patients receiving the intervention – incorporating quantitative and qualitative components to research, in order to provide more in-depth data,

- efficacy – including identification of problems, resulting interventions, prevention of re-hospitalization,
- economic evaluation – costs in relation to the intervention and a cost-effectiveness evaluation.

The development of the study should incorporate patient involvement including participation in the project group, protocol elaboration and advising on research materials. To achieve this, collaboration should be sought with national groups such as EUPATI Italia (European Patients' Academy for Therapeutic Innovation).

Based on the success of a feasibility trial, an adequately powered RCT can be performed with cost effectiveness analysis. This would be a larger study facilitating greater subgroup analysis (age, hematological malignancy subgroup, learning needs and learning style, support network), to broaden understanding of issues for a wider variety of haemato-oncology patients.

Despite the intervention being developed for implementation within a local setting, the feasibility and acceptability of this model as a basis for support in other clinical areas could be explored through research.

The evidence from the PhD study also revealed other areas warranting investigation, external to the direct needs of hematology patients themselves. Qualitative data emphasized the importance of support from close family / carers during the patients pathway, and barriers to support seeking caused by concerns for their ability to cope. Further research should be directed towards investigating the needs of carers in this setting and methods to provide support for those caring for patients.

Similarly, in the light of shifting services towards primary care, research should investigate the needs of this group of healthcare professionals as to how they can be best supported to care for this particular group of patients.

8.5 Conclusion

The PhD study has highlighted persisting unmet needs of patients with haematological malignancies. The application of the MRC Framework guidance and robust methodology has provided the evidence base – through a systematic review of the literature and interviews with patients and expert nurses, and consensus group meeting in order to model an intervention providing support and symptom management that is acceptable to haemato-oncology patients undergoing or having undergone treatment.

The study has succeeded in outlining an intervention for patients, which will be refined with further input of healthcare professionals and will be tested within a feasibility trial.

9 References

Adler, N.E., Page, A.E.K. (eds.). (2008). *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington (DC): National Academies Press (US). [Online]. Available at: https://www.ncbi.nlm.nih.gov/books/NBK4011/ (Accessed: 3 April 2017).

Agboola, S.O., Ju, W., Elfiky, A., Kvedar, J.C., Jethwani, K. (2015) 'The effect of technology-based interventions on pain, depression, and quality of life in patients with cancer: a systematic review of randomized controlled trials' *Journal of Medical Internet Research*, 17(3): e65, [Online]. Available at: http://www.jmir.org/2015/3/e65/ (Accessed: 11 April 2017).

AIRTUM. (2017). 'Italian cancer figures – report 2016: Survival of Cancer patients in Italy', *Epidemiologia & Prevenzione*, 41(2): pp.35-43.

Al-Amer, R., Ramjan, L., Glew, P., Darwish, M., Salamonson, Y. (2015). 'Translation of interviews from a source language to a target language: examining issues in cross-cultural health care research', *Journal of Clinical Nursing*, 24: pp.1151–1162.

Alter, C.L., Fleishman, S.B., Kornblith, A.B., Holland, J.C., Biano, D., Levenson, R., Vinciguerra, V., Rai, K.R. (1996). 'Supportive telephone intervention for patients receiving chemotherapy. A pilot study', *Psychosomatics*, 37(5): pp.425-31.

Anderson, B. (2010). 'The benefits to nurse-led telephone follow-up for prostate cancer', *British Journal of Nursing*, 19(17): pp.1085-1090.

Andrykowski, M.A. (1994). 'Psychosocial factors in bone marrow transplantation: a review and recommendations for research', *Bone Marrow Transplantation*, 13(4): pp.357–375.

Andrykowski, M.A., Lykins, E., Floyd, A.(2008). 'Psychological Health in Cancer Survivors,' *Seminars in Oncology Nursing*, 24(3): pp.193–201.

Antman, E.M., Lau, J. Kupelnick, B., Mosteller, F., Chalmers, T.C. (1992). 'A comparison of results of meta-analyses of randomized control trials and recommendations of clinical experts: Treatments for myocardial infarction', *Journal of the American Medical Association*, 268(2): pp.240-248.

Archer, S., Montague, J., Bali, A. (2014). 'Exploring the experience of an enhanced recovery programme for gynecological cancer patients: a qualitative study', *Perioperative Medicine*, 3(1):2.

Armes. J., Crowe, M., Colbourne, L., Morgan, H., Murrells, T., Oakley, C., Palmer, N., Ream, E., Young, A., Richardson, A. (2009). 'Patients' supportive care needs beyond the end of cancer treatment: a prospective, longitudinal survey', *Journal of Clinical Oncology*, 27(36): pp.6172–6179.

Aroni, R., Goeman, D., Stewart, K., Sawyer, S., Abramson, M., Thein, F. (1999). *Concepts of Rigour: When Methodological, Clinical and Ethical Issues Intersect, Vol. 2000*. [Online]. Available at: http://www.aqr.org.au/wp-content/uploads/conference1999/RAroni.htm (Accessed: 22 May 2013).

Atherton, Y., Young, B., Salmon, P. (2017). 'Understanding the information needs of people with haematological cancers. A meta-ethnography of quantitative and qualitative research', *European Journal of Cancer Care*, 26(6): e12647.

Ayres, L., Kavanagh, K., Knafl, K. (2003). 'Within-case and across-case approaches to qualitative data analysis', *Qualitative Health Research*, 13: pp.871–883.

Badger, T., Segrin, C., Pasvogel, A., Lopez, A.M. (2013). 'The effect of psychosocial interventions delivered by telephone and videophone on quality of life in early-stage breast cancer survivors and their supportive partners', *Journal of Telemedicine and Telecare*, 19(5): pp.260-265.

Balneaves, L.G., Van Patten, C., Truant, T.L., Kelly, M.T., Neil, S.E., Campbell, K.L. (2014). 'Breast cancer survivors perspectives on a weight loss and physical activity lifestyle intervention', *Supportive Care in Cancer*, 22(8): pp.2057-2065.

Balshem, H., Stevens, A., Ansari, M., Norris, S., Kansagara, D., Shamliyan, T., Chou, R., Chung, M., Moher, D., Dickersin, K. (2013). Finding grey literature evidence and assessing for outcome and analysis reporting biases when comparing medical interventions: AHRQ and the effective health care program, in *Methods Guide for Effectiveness and Comparative Effectiveness Reviews* [Online]. Rockville (MD): Agency for Healthcare Research and Quality. Available at: https://www.ncbi.nlm.nih.gov/books/NBK174882/?report=printable (Accessed: 25 February 2014).

Barata, A., Wood, W., Choi, S., Jim, H. (2016). 'Unmet needs for psychosocial care in hematologic malignancies and hematopoietic cell transplant', *Current Hematologic Malignancy Reports*, 11(4): pp.280-287.

Barsevick, A.M., Whitmer, K., Sweeney, C., Nail, L.M. (2002). 'A pilot study examining energy conservation for cancer treatment-related fatigue', *Cancer Nursing*, 25(5): pp.333-341.

Beauchamp, T.L., Childress, J.F. (2012). *Principles of Biomedical Ethics*. 7th edn. Oxford: Oxford University Press.

Beaver, K., Campbell, M., Williamson, S., Procter, D., Sheridan, J., Heath, J., Susnerwala, S. (2012). 'An exploratory randomized controlled trial comparing telephone and hospital follow-up after treatment for colorectal cancer', *Colorectal Disease*, 14(10): pp.1201-1209.

Beaver, K., Tysver-Robinson, D., Campbell, M., Twomey, M., Williamson, S., Hindley, A., Susnerwala, S., Dunn, G., Luker, K. (2009). 'Comparing hospital and telephone follow-up after treatment for breast cancer: randomised equivalence trial', *British Medical Journal*, 14(338): a3147.

Beaver, K., Williamson, S., Chalmers, K. (2010) 'Telephone follow-up after treatment for breast cancer: views and experiences of patients and specialist breast care nurses', *Journal of Clinical Nursing,* 19: pp.2916-2924.

Benner, P. (1984). *From Novice to Expert: Excellence and Power in Clinical Nursing Practice*. Menlo Park, CA: Addison-Wesley.

Berger, R. (2015). 'Now I see it, now I don't: researcher's position and reflexivity in qualitative research', *Qualitative Research*, 15(2): pp.219–234.

Bhattacherjee, A. (2012). *Social Science Research: Principles, Methods, and Practices*. Textbooks Collection. Book 3. [Online]. Available at: http://scholarcommons.usf.edu/oa_textbooks/3 (Accessed: 05 June 2014).

Black, E.K., White, C.A. (2005). 'Fear of recurrence, a sense of coherence and post traumatic stress disorder n haematological cancer survivors', *Psycho-Oncology,* 14(6): pp.510-515.

Black, N., Murphy, M., Lamping, D., McKee, M., Sanderson, C., Askham, J., Marteau, T. (1999). 'Consensus development methods: a review of best practice in creating clinical guidelines', *Journal of Health Services Research and Policy*, 4(4): pp.236-248.

Bloor, M., Frankleand, J., Thomas, M., Robson, K. (2001). *Focus groups in social research*. London, Sage Publications.

Booker, J., Eardley, A., Cowan, R., Logue, J., Wylie, J., Caress, A.L. (2004). 'Telephone first post-intervention follow-up for men who have had radical radiotherapy to the prostate: evaluation of a novel service delivery approach', *European Journal of Oncology Nursing,* 8(4): pp.325-333.

Bourke, L., Gilbert, S., Hooper, R., Steed, L.A., Joshi, M., Catto, J.W., Saxton, J.M., Rosario, D.J. (2014). 'Lifestyle changes for improving disease-specific quality of life in sedentary men on long-term androgen-deprivation therapy for advanced prostate cancer: a randomised controlled trial', *European Urology*, 65(5): pp.865-872.

Boutron, I., Moher, D., Altman, D., Scultz, K., Ravaud, P. (2008). 'Extending the CONSORT Statement to randomized trials of nonpharmacologic treatment: explanation and elaboration', *Annals of Internal Medicine,* 148: pp.295-309.

Boyatzis, R. (1998). *Transforming Qualitative Information: Thematic Analysis and Code Development*. Thousand Oaks, California: Sage Publications Ltd.
Bradley, C., Plowright, R., Stewart, J., Valentine, J., Witthaus, E. (2007). 'The Diabetes Treatment Satisfaction Questionnaire change version (DTSQc) evaluated in insulin glargine trials shows greater responsiveness to improvements than the original DTSQ', *Health and Quality of Life Outcomes,* 5: pp.57.

Braun, E., Baidusi, A., Alroy, G., Azzam, Z.S. (2009). 'Telephone follow-up improves patients satisfaction following hospital discharge', *European Journal of Internal Medicine,* 20(2): pp.221-225.

Braun, V., Clarke, V. (2006). 'Using thematic analysis in psychology', *Qualitative Research in Psychology,* 3(2): pp.77-101.

Braun, V., Clarke, V. (2013). *Successful qualitative research: a practical guide for beginners.* London: Sage.

Brennan, J. (2001). 'Adjustment to cancer—coping or personal transition?', *Psycho-Oncology,* 10: pp.1–18.

Britten, N. (1999). Qualitative interviews in healthcare, in Pope, C. and Mays, N. (eds.) *Qualitative Research in Health care*. 2nd edn. London: BMJ Books, pp. 11-19.

Broberger, E., Tishelman, C., von Essen, L. (2005). 'Discrepancies and similarities in how patients with lung cancer and their professional and family caregivers assess symptom occurrence and symptom distress', *Journal of Pain and Symptom Management,* 29: pp.572-583.

Bryant, A., Charmaz, K. (2007). *The SAGE Handbook of Grounded Theory*. London, England: SAGE Publications Ltd.

Bryant, J., Mansfield, E., Hall, A., Waller, A., Boyes, A., Jayakody, A., Dodd, N., Sanson-Fisher, R. (2016). 'The psychosocial outcomes of individuals with hematological cancers: are we doing enough high quality research, and what is it telling us?', *Critical Reviews in Oncology/Hematology,* 101: pp. 21-31.

Bryant, J., Sanson-Fisher, R., Stevenson, W., Smits, R., Henskens, F., Wei, A., Tzelepis, F., D'Este, C., Paul, C., Carey, M. (2015). 'Protocol of a multi-centre randomised controlled trial of a web-based information intervention with nurse-delivered telephone support for haematological cancer patients and their support persons', *BMC Cancer,* 15: pp.295.

Breen, S., Baravelli, C., Schofield, P., Jefford, M., Yates, P., Aranda, S. (2009). 'Is symptom burden a predictor of anxiety and depression in patients with cancer about to commence chemotherapy?', *The Medical Journal of Australia,* 190: S99–104.

Breen, S., Ritchie, D., Schofield, P., Hsueh, Y., Gough, K., Santamaria, N., Kamateros, R., Maguire, R., Kearney, N., Aranda, S. (2015). 'The Patient Remote Intervention and Symptom Management System (PRISMS) – a telehealth mediated intervention enabling real-time monitoring of chemotherapy side-effects in patients with haematological malignancies: study protocol for a randomised controlled trial', *Trials,* 16: pp.472.

Bryman, A. (2008). *Social Research Methods*. 3rd end. Oxford: Open University Press.

Burgess, R.G. (1984). *In the Field: An Introduction to Field Research*. London: Allen & Unwin.

Burke Johnson, R., Onwuegbuzie, A., Turner, L. (2007). 'Towards a definition of mixed methods research', *Journal of Mixed Methods Research,* 1: pp.112.

Campbell, L.C., Keefe, F.J., Scipio, C., McKee, D.C., Edwards, C.L., Herman, S.H., Johnson, L.E., Colvin, O.M., McBride, C.M., Donatucci, C. (2007b). 'Facilitating research participation and improving quality of life for African American prostate cancer survivors and their intimate partners: a pilot study of telephone-based coping skills training', *Cancer,* 109(Suppl 2): pp.414-424.

Campbell, M., Donner, A., Klar, N. (2007c). 'Developments in cluster randomised trials and statistics in medicine', *Statistics in Medicine,* 26: pp.2–19.

Campbell, N., Murray, E., Darbyshire, J., Emery, J., Farmer, A., Griffiths, F., Guthrie, B., Lester, H., Wilson, P., Kinmoth, A. (2007a). 'Designing and evaluating complex interventions to improve healthcare', *British Medical Journal*, 334: pp.455 – 459.

Car, J., Sheik, A. (2003). 'Telephone consultations', *British Medical Journal*, 326: pp.966–999.

Carleton, R.N., Sharpe, D., Asmundson, G.J.G. (2007). 'Anxiety sensitivity and intolerance of uncertainty: requisites of the fundamental fears?', *Behavior Research and Therapy,* 45: pp.2307–2316.

Carr, L.T. (1994). 'The strengths and weaknesses of quantitative and qualitative research: what method for nursing?', *Journal of Advanced Nursing*, 20: pp.716-721.

Centre for Reviews and Dissemination, CRD. (2008). *Systematic Reviews: CRD's guidance for undertaking reviews in health care.* York: NHS Centre for Reviews and Dissemination, University of York.

Cheung, M., Imrie, K., Friedlich, J., Buckstein, R., Lathia,N., Mittman, N. (2009). 'The impact of follicular (FL) and other indolent non-Hodgkin's lymphomas (NHL) on work productivity–A preliminary analysis', *Psycho-Oncology,* 18(5): pp.554–559.

Cimprich, B., Janz, N.K., Northouse, L., Wren, P.A., Given, B., Given, C.W. (2005). 'Taking CHARGE: A self-management program for women following breast cancer treatment', *Psycho-Oncology,* 14(9): pp.704-717.

Cirillo, M., Lunardi, G., Coati, F., Ciccarelli, L., Alestra, S., Mariotto, M., Micheloni, B., Cassandrini, P.A., Inno, A., Magarotto, R., Nicodemo, M., Picece, V., Turazza, M., Gori, S., Venturini, M. (2014). 'Management of oral anticancer drugs: feasibility and patient approval of a specific monitoring program*', Tumori*, 100(3): pp.243-248.

Clarke, J. (2011). 'What is a systematic review?', *Evidence Based Nursing,* 14(3): pp.64.

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences*. Hillsdale: Lawrence Erlbaum Associates.

Collins, E.D., Moore, C.P., Clay, K.F., Kearing, S.A., O'Connor, A.M., Llewellyn-Thomas, H.A., Barth, R.J., Sepucha, K.R. (2009). 'Can women with early-stage breast cancer make an informed decision for mastectomy?', *Journal of Clinical Oncology*, 27: pp.519–525.

Collins, J.A., Fauser, B.C.J.M. (2005). 'Balancing the strengths of systematic and narrative reviews', *Human Reproduction Update,* 11(2): pp.103–104.

Committee on Quality of Health Care in America, Institute of Medicine. (2001). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Washington, DC: National Academy Press.

Compaci, G., Rueter, M., Lamy, S., Oberic, L., Recher, C., Lapeyre-Mestre, M., Laurent, G., Despas, F. (2015). 'Ambulatory Medical Assistance - After Cancer (AMA-AC): A model for an early trajectory survivorship survey of lymphoma patients treated with anthracycline-based chemotherapy', *BMC Cancer*, 15: pp.781.

Cook, T.D., Campbell, D.T. (1979). *Quasi-experimentation – Design and Analysis Issues for Field Settings*. Boston: Houghton Mifflin Company.

Cooke, L., Gemmill, R., Kravits, K., Grant, M. (2009). 'Psychological issues of stem cell transplant, *Seminars in Oncology Nursing'*, 25(2): pp.139-150.

Cormack, D. (1991). *The Research Process in Nursing*. 2nd edn. Oxford: Blackwell Scientific.

Coryn, C.L.S., Noakes, L.A., Westine, C.D., Schröter, D.C. (2011). 'A systematic review of theory-driven evaluation practice from 1990 to 2009', *American Journal of Evaluation,* 32: pp.199–226.

Cox, K., Wilson, E. (2003). 'Follow up for people with cancer: nurse led services and telephone interventions', *Journal of Advanced Nursing,* 43(1): pp.12.

Cox, A., Bull, E., Cockle-Hearne, J., Knibb, W., Potter, C., Faithfull, S. (2008). 'Nurse led telephone follow up in ovarian cancer: a psychosocial perspective', *European Journal of Oncology Nursing,* 12(5): pp.412-417.

Cox, A., Lucas, G., Marcu, A., Piano, M., Grosvenor, W., Mold, F., Maguire, R., Ream, E. (2017). 'Cancer survivors' experience with telehealth: a systematic review and thematic synthesis', *Journal of Medical Internet Research,* 19(1): e11.

Cox, K., Wilson, E., Arthur, A., Elkan, R., Armstrong, S. (2005). 'A randomised controlled trial of nurse-managed trial conclusion following early phase cancer trial participation', *British Journal of Cancer,* 93(1): pp.41-45.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M. (2008). 'Developing and evaluating complex interventions: the new Medical Research Council guidance', *British Medical Journal*, 337: a1655.

Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., Petticrew, M. (2013). 'Developing and evaluating complex interventions: the new Medical Research Council guidance', *International Journal of Nursing Studies*, 50(5), pp.587-92.

Craven, O., Hughes, C.A., Burton, A., Saunders, M.P., Molassiotis, A. (2013). 'Is a nurse-led telephone intervention a viable alternative to nurse-led home care and standard care for patients receiving oral capecitabine? Results from a large prospective audit in patients with colorectal cancer', *European Journal of Cancer Care* (England), 22(3): pp.413-419.

Crawford, J., Foote, M., Morstyn, G. (1999). 'Hematopoietic growth factors in cancer chemotherapy', *Cancer Chemotherapy and Biological Response Modifiers.* 18: pp.250-267.

Creswell, J.W. (2003). *Research Design: Qualitative, quantitative and mixed methods approaches*. 2nd edn. Thousand Oaks: Sage.

Creswell, J.. (2008). Mixed methods research, in Given, L.M. (ed) *The Sage Encyclopedia of Qualitative Research Methods*. Los Angeles, California: Sage Publications, pp.527-530.

Creswell, J.W., Miller, D.L. (2000). 'Determining validity in qualitative inquiry', *Theory into Practice,* 39(3):pp.124-130.

Critical Appraisal Skills Programme. (2010). *CASP Checklists*. [Online]. Available at: http://www.casp-uk.net/casp-tools-checklists (Accessed: 25 February 2014).

Critical Appraisal Skills Programme. (2013). *Qualitative Research Checklist*. [Online] Available at: http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf (Accessed 05 June 2014).

Curry, L., Nunez-Smith, M. (2015). *Mixed Methods in Health Sciences Research: A Practical Primer*. Thousand Oaks, California: Sage Publications Inc.

Cusack, M., Taylor, C. (2010). 'A literature review of the potential of telephone follow-up in colorectal cancer', *Journal of Clinical Nursing*, 19: pp.2394–2405.

Datta J., Peticrew, M. (2013). 'Challenges to evaluating complex interventions: a content analysis of published papers'. *BMC Public Health*, 13: 568. [Online]. Available at: http://www.biomedcentral.com/1471-2458/13/568 (Accessed: 31 May 2016).

Davalos, M.E., French, M.T., Burdick, A.E., Simmons, S.C. (2009). 'Economic evaluation of telemedicine: Review of the literature and research guidelines for benefit-cost analysis'. *Telemedicine Journal and e-Health*, 15(10): pp. 933–948.

Davoodi, S., Mohammadzadeh, Z., Safdari, R. (2016). 'Mobile phone based system opportunities to home-based managing of chemotherapy side effects', *Acta Informatica Medica,* 24(3): pp193-196.

Delaney, L., Chambers, C., Roldán, G., De Robles, P., Cairncross, G., Forsyth, P., Easaw, J. (2009). 'A feasibility study to assess the integration of a pharmacist into neurooncology clinic', *Journal of Oncology Pharmacy Practice*, 15(2): pp.79-85.

Dell-Kuster, S., Sanjuan, E., Todorov, A., Weber, H., Heberer, M., Rosenthal, R.

(2014). 'Designing questionnaires: Healthcare survey to compare two different response scales', *BMC Medical Research Methodology*, 14: pp.96.

Denzin, N.K., Lincoln, Y.S. (1994). *Handbook of Qualitative Research*. Thousand Oaks, CA: Sage Publications.

Department of Health. (2005). *Research Governance Framework for Health and Social Care.* London: Department of Health.

Dickinson, R., Hall, S., Sinclair, J., Bond, C., Murchie, P. (2014). 'Using technology to deliver cancer follow-up: a systematic review', *BMC Cancer*, 14(1): 311.

Dixon, W. (2010). 'The feasibility of telephone follow-up led by a radiation therapist: experience in a multidisciplinary bone metastases clinic'. *Journal of Medical Imaging and Radiation Sciences*, 41(4): pp.175-179.

Dixon-Woods, M., Shaw, R.L., Agarwal, S., Smith, J.A. (2004). The problem of appraising qualitative research, *Quality & Safety in Health Care*, 13:pp.223-225.

Drabble, L., Trocki, K.F., Salcendo, B., Walker, P.C., Korcha, R.A. (2016). 'Conducting qualitative interviews by telephone: Lessons learned from a study of alcohol use among sexual minority and heterosexual women', *Qualitative Social Work*, 15(1): pp.118-133.

Donnelly, C.M., Lowe-Strong, A., Rankin, J.P., Campbell, A., Blaney, J.M., Gracey, J.H. (2013). 'A focus group study exploring gynecological cancer survivors' experiences and perceptions of participating in a RCT testing the efficacy of a home-based physical activity intervention', *Supportive Care in Cancer*, 21(6): pp.1697-1708.

Dudovskiy, J. (2016). *The ultimate guide to writing a Dissertation in Business Studies: A Step-by Step Assistance* [Online]. Available at: http://researchmethodology.net/researchphilosophy (Accessed: 25 May 2016).

Duffy, M.E. (1986). 'Quantitative and qualitative research antagonistic or complementary', *Nursing and Health Care*, 8(6): pp.356-357.

Duggleby, W. (2005). 'What about focus group interaction data?', *Qualitative Health Research.* 15(6): pp.832–840.

DuHamel, K.N., Mosher, C.E., Winkel, G., Labay, L.E., Rini, C., Meschian, Y.M, Austin, J., Greene, P.B., Lawsin, C.R., Rusiewicz, A., Grosskreutz, C.L., Isola, L., Moskowitz, C.H., Papadopoulos, E.B., Rowley, S., Scigliano, E., Burkhalter, J.E., Hurley, K.E., Bollinger, A. R., Redd, W.H. (2010). 'Randomized clinical trial of telephone-administered cognitive-behavioral therapy to reduce post-traumatic stress disorder and distress symptoms after hematopoietic stem-cell transplantation', *Journal of Clinical Oncology*, 28(22): 3754-3761.

Duncan, E. (2006). The nature and use of consensus methodology in practice, in, Kielhofner, G. (ed) *Research in Occupational Therapy: Methods of Inquiry for Enhancing Practice*. Philadelphia PA: FA Davis.

Dyson, G.J., Thompson, K., Palmer, S., Thomas, D.M., Schofield, P. (2012). 'The relationship between unmet needs and distress amongst young people with cancer', *Supportive Care in Cancer*, 20: pp.75-85.

Eakin, E.G., Hayes, S.C., Haas, M.R., Reeves, M.M., Vardy, J.L., Boyle, F., Hiller, J.E., Mishra, G.D., Goode, A.D., Jefford, M., Koczwara, B., Saunders, C.M., Demark-Wahnefried, W., Courneya, K.S., Schmitz, K.H., Girgis, A., White, K., Chapman, K., Boltong, A.G., Lane, K., McKiernan, S., Millar, L., O'Brien, L., Sharplin, G., Baldwin, P., Robson, E.L. (2015). 'Healthy Living after Cancer: a dissemination and implementation study evaluating a telephone-delivered healthy lifestyle program for cancer survivors', *BMC Cancer*, 15: pp.992.

Eccles, M.P., Grimshaw, J.M., Shekelle, P., Schunemann, H.J., Woolf, S. (2012). 'Developing clinical practice guidelines: target audiences, identifying topics for guidelines, guideline group composition and functioning and conflicts of interest', *Implementation science*, 7:60.

Eccles, M.P., Mittman, B.S. (2006). 'Welcome to implementation science', *Implementation Science*, 1:pp.1.

Edwards, R. (1998). 'A critical examination of the use of interpreters in the qualitative research process', *Journal of Ethnic and Migration Studies*, 24: pp.197-208.

Eide, P.J. (2008). Recruiting participants, in Given, L.M. (ed) *The Sage Encyclopedia of Qualitative Research Methods*. Los Angeles, California: Sage Publications, pp.743-745.

El Hussein, M., Jakubec, S.L., Osuji, J. (2015). 'Assessing the FACTS: A Mnemonic for Teaching and Learning the Rapid Assessment of Rigor in Qualitative Research Studies', *The Qualitative Report,* 20(8): pp.1182-1184.

Evans, D. (1999). *Conducting a Systematic Review*. Adelaide, Australia: The Joanna Briggs Institute for Evidence Based Nursing and Midwifery.

Ezzy, D. (2002). *Qualitative Analysis Practice and Innovation*. London: Routledge.

Fàbregues, S., Molina-Azorin, J.F. (2017). 'Addressing quality in mixed methods research: a review and recommendations for a future agenda', *Quality & Quantity*, 51 (6): pp.2847-2863.

Faderl, S., Talpaz, M., Estrov, Z., O'Brien, S., Kurzrock, R., Kantarjian, H.M. (1999). 'The biology of chronic myeloid leukemia', *New England Journal of Medicine*, 341: pp.164-172.

Faller, H., Koch, U., Brähler, E., Härter, M., Keller, M., Schulz, H., Wegscheider, K., Weis, J., Boehncke, A., Hund, B., Reuter, K., Richard, M., Sehner, S., Szalai, C., Wittchen, H.U., Mehnert, A. (2016). 'Satisfaction with information and unmet information needs in men and women with cancer', *Journal of Cancer Survivorship*, 10(1): pp.62-70.

Ferlay, J., Soerjomataram, I., Ervik, M., Dikshit, R., Eser, S., Mathers, C., Rebelo, M., Parkin, D.M., Forman, D., Bray, F. (2013). *GLOBOCAN 2012 v1.0, Cancer Incidence*

and Mortality Worldwide: IARC CancerBase No. 11, [Online]. Available at: http://globocan.iarc.fr (Accessed: 24 October 2017).. Lyon, France: International Agency for Research on Cancer.

Ferré F, de Belvis AG, Valerio L, Longhi S, Lazzari A, Fattore G, Ricciardi W, Maresso A. Italy: Health System Review. *Health Systems in Transition*, 2014, 16(4):1–168.

Fink, A., Kosecoff, J., Chassin, M., Brook, R.H. (1984). 'Consensus methods: characteristics and guidelines for use', *American Journal of Public Health*, 74(9): pp.979-83.

Fitch, K., Bernstein, S.J., Aguilar, M.D., Burnand, B., LaCalle, J.R., Lazaro, P., van het Loo, M., McDonnell, J., Vader, J., Kahan, J.P. (2001). *The RAND/UCLA appropriateness method user's manual*. Santa Monica, CA: RAND Corporation.

Franco, B.B., Dharmakulaseelan, L., McAndrew, A., Bae, S., Cheung, M.C., Singh, S. (2016). 'The experiences of cancer survivors while transitioning from tertiary to primary care', *Current Oncology*, 23(6): pp.378-385.

Freeman, T. (2006). ''Best practice' in focus group research: making sense of different views', *Journal of Advanced Nursing*, 56(5): pp.491–497.

Fugmann, R. (1993). *Subject analysis and indexing. Theoretical foundation and practical advice.* Frankfurt/Main: Index Verlag.

Furzer, B.J., Ackland, T.R., Wallman, K.E., Petterson, A.S., Gordon, S.M., Wright, K.E., Joske, D.J. (2016). 'A randomised controlled trial comparing the effects of a 12-week supervised exercise versus usual care on outcomes in haematological cancer patients', *Supportive Care in Cancer*, 24(4): pp.1697-1707.

Gagliese, L., Jovellanos, M., Zimmermann, C., Shobbrook, C., Warr, D., Rodin, G. (2009). 'Age relater patterns in adaptation to cancer pain; a mixed methods study', *Pain Medicine*, 10: pp.1050-1961.

Gale, N.K., Heath, G., Cameron, E., Rashid, S., Redwood, S. (2013). 'Using the framework method for the analysis of qualitative data in multi-disciplinary health research' *BMC Medical Research Methodology*, 13:117. [Online]. Available at: http://www.biomedcentral.com/1471-2288/13/117 (Accessed: 24 May 2016).

Gansler, T., Kepner, J., Willacy, E., Soloe, C., Rupert, D., Jarblum, M., Driscoll, D., Orr, A., Fitzgerald, T., Esparza, A. (2010). 'Evolving information priorities of hematologic cancer survivors, caregivers, and other relatives', *Journal of Cancer Education*, 25: pp.302–311.

Ganzel, C., Rowe, J.M. (2012). 'Total ambulatory hemato-oncological care: a myth or reality?', *Leukemia & Lymphoma*, 53(12): pp.2335–2336.

Garrett, K., Okuyama, S., Jones, W., Barnes, D., Tran, Z., Spencer, L., Lewis, K., Maroni, P., Chesney, M., Marcus, A. (2013). 'Bridging the transition from cancer patient to

survivor: pilot study results of the Cancer Survivor Telephone Education and Personal Support (C-STEPS) program', *Patient Education and Counselling*, 92(2): pp.266-272.

Gee, J.P. (2014). *An Introduction to Discourse Analysis: Theory and Method*. 4th edn. London: Routledge, Taylor & Francis.

George, A., Boehme, A., Siegler, J., Moniezun, D., Fowler, B., Shaban, A., Albright, K., Beasley, T., Martin-Schild, S. (2013). 'Hospital-acquired infection underlies poor functional outcome in patients with prolonged length of stay', *Stroke*. [Preprint]. Available at: http://dx.doi: 10.1155/2013/312348. (Accessed: 12 July 2017).

Gill, P., Stewart, K., Treasure, E., Chadwick, B. (2008). 'Methods of data collection in qualitative research: interviews and focus groups', *British Dental Journal*, 204: pp.291-295.

Giorgi, A. (2009). *The descriptive phenomenological method in psychology: A modified Husserlian approach*. Pittsburgh, PA: Duquesne University Press.

Given, L.M. (ed) (2008). *The Sage Encyclopaedia of Qualitative Research Methods*. Los Angeles, California: Sage Publications.

Glaser, B.G. (1965). 'The constant comparative method of qualitative analysis', *Social Problems*, 12(4): pp.436-445.

Glaser, B.G. (1978). *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*. Mill Valley, CA: Sociology Press.

Glasgow, R.E., Vogt, T.M., Boles, S.M. (1999). Evaluating the public health impact of health promotion interventions: The RE-AIM Framework, *American Journal of Public Health*, 89: pp.1322–1327.

Gonella, S., Di Giulio, P. (2015). 'Delayed chemotherapy-induced nausea and vomiting in the hematology population: a review of the literature', *Clinical Journal of Oncology Nursing* 19(4): pp.438-443.

Gordon, L.G., Patrao, T., Kulartna, S., Hawkes, A.L. (2015). 'A telephone-delivered multiple health behaviour change intervention for colorectal cancer survivors: making the case for cost-effective healthcare', *European Journal of Cancer Care*, 24: pp.854–861.

Gough, B. (2003), Deconstructing reflexivity, in Finlay, L., Gough, B. (eds) *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences*. Oxford: Blackwell Science Ltd, pp.21-35.

Grade Working Group. (2004). 'Grading quality of evidence and strength of recommendations', *British Medical Journal*, 328: pp.1490.

Grant, M.J., Booth, A. (2009). 'A typology of reviews: an analysis of 14 review types and associated methodologies', *Health Informatics and Libraries Journal*, 26: pp.91–108.

Green, S., Higgins, J.P.T., Alderson, P., Clarke, M., Mulrow, C.D., Oxman, A.D. (2011) Introduction, in Higgins, J.P.T., Green, S. (eds). *Cochrane Handbook for Systematic Reviews of Interventions. Version 5.1.0.* The Cochrane Collaboration. [Online]. Available at: http://handbook-5-1.cochrane.org (Accessed: 5 May 2013).

Greenhalgh, T., Taylor, R. (1997). 'How to read a paper: Papers that go beyond numbers (qualitative research)', *British Medical Journal*, 315: p.740.

Grossman, P., Zwahlen, D., Halter, J., Passweg, J., Steiner, C., Kiss, A. (2015). 'A mindfulness-based program for improving quality of life among hematopoietic stem cell transplantation survivors: feasibility and preliminary findings', *Supportive Care in Cancer*, 23(4): pp.1105-1112.

Grundy, G., Ghazi, F. (2009). 'Research priorities in haemato-oncology nursing: results of a literature review and a Delphi study', *European Journal of Oncology Nursing*, 13(4): pp.235-249.

Guest, G., Bunce, A., Johnson, L. (2006). 'How many interviews are enough?: An experiment with data saturation and variability', *Field Methods*, 18: pp.59–82.

Hafiji, J., Salmon, P., Hussain, W. (2012). 'Patient satisfaction with post-operative telephone calls after Mohs micrographic surgery: a New Zealand and U.K. experience', *British Journal of Dermatology,* 167(3): pp.570-574.

Hagopian, G., Rubenstein, J.H. (1990). 'Effects of telephone call interventions on patients' well-being in a radiation therapy department', *Cancer Nursing,* 13(6): pp.339-344.

Haidich, B. (2010). 'Meta-analysis in medical research', *Hippokratia*, 14(Suppl 1): pp.29-37.

Halcomb, E., Davidson, P., Hardaker, L. (2008). 'Using the consensus development conference method in healthcare research', *Nurse Researcher*, 16(1): pp.56-71.

Hall, A., D'Este, C., Tzelepis, F., Sanson-Fisher, R., Lynagh, M. (2014). 'The survivor unmet needs survey (SUNS) for haematological cancer survivors: a cross-sectional study assessing the relevance and psychometric properties', *BMC Health Services Research*. 14: 211.

Hall, A., Lynagh, M., Bryant, J., Sanson-Fisher, R. (2013). 'Supportive care needs of haematological cancer survivors A critical review of the literature', *Critical Reviews in Oncology/Hematology*, 88(1): pp.102-116.

Hall, A., Sanson-Fisher, R., Lynagh, M., Tzelepis, F., D'Este, C. (2015). 'What do haematological cancer survivors want help with? A cross-sectional investigation of unmet supportive care needs', *BMC Research Notes*, 8: pp.221.

Hannes, K. (2011). Chapter 4: Critical appraisal of qualitative research, in Noyes, J., Booth, A,. Hannes, K., Harden, A., Harris, J., Lewin, S., Lockwood, C. (eds). *Supplementary Guidance for Inclusion of Qualitative Research in Cochrane Systematic Reviews of Interventions.* Collaboration Qualitative Methods Group. [Online]. Available

at: http://cqrmg.cochrane.org/supplemental-handbook-guidance (Accessed: 5 May 2013).

Hannes, K., Lockwood, C., Pearson, A. (2010). 'A comparative analysis of three online appraisal instruments' ability to assess validity in qualitative research', *Qualitative Health Research*, 20: pp.1736.

Harden, A., Thomas, J. (2005). 'Methodological issues in combining diverse study types in systematic reviews', *International Journal of Social Research Methodology*, 8(3): pp. 257-271.

Harden, J.K., Northouse, L.L., Mood, D.W. (2006). 'Qualitative analysis of couples' experience with prostate cancer by age cohort', *Cancer Nursing*, 29: pp.367–377.

Hart, S. (1971). 'Axiology - Theory of values', *Philosophy and Phenomenological Research*, (32)1: pp.29-41.

Health Care Practice Research & Development Unit. (2009). *Evaluation tool for qualitative research*. [Online]. Available at: http://www.fhsc.salford.ac.uk/hcprdu/qualitative.htm (Accessed: 5 June 2014).

Hegel, M.T., Lyons, K.D., Hull, J.G., Kaufman, P., Urquhart, L., Li, Z., Ahles, T.A. (2011). 'Feasibility study of a randomized controlled trial of a telephone-delivered problem-solving-occupational therapy intervention to reduce participation restrictions in rural breast cancer survivors undergoing chemotherapy,' *Psycho-Oncology*, 20(10): pp.1092-1101.

Heidrich, S.M., Brown, R.L., Egan, J.J., Perez, O.A., Phelan, C.H., Yeom, H., Ward, S.E. (2009). 'An individualized representational intervention to improve symptom management (IRIS) in older breast cancer survivors: three pilot studies', *Oncology Nursing Forum*, 36(3): E133-43.

Hekman, S.J. (1983). 'From epistemology to ontology: Gadamer's hermeneutics and Wittgensternian social Science', *Human Studies*, 6: pp.205-224.

Hennink, M., Hutter, I., Bailey, A. (2011). *Qualitative Research Methods*. London: Sage Publications.

Henselmans, I., Jacobs, M., van Berge Henegouwen, M.I., de Haes, H.C., Sprangers, M.A., Smets, E. (2012). 'Postoperative information needs and communication barriers of esophageal cancer patients', *Patient Education and Counseling*, 88: pp.138–146.

Heritage, J. (1984). *Garfinkel and Ethnomethodology*. Cambridge: Polity Press.

Hewitt, M., Greenfield, S., Stovall, E. (eds) (2006). *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press.
Heyvaert, M., Hannes, K., Maes, B., Onghena, P. (2013). Critical Appraisal of Mixed Methods Studies. *Journal of Mixed Methods Research.* [Online]. Available at: http://mmr.sagepub.com/content/early/2013/03/03/1558689813479449 (Accessed: 4 March 2013).

Higgins, J.P.T., Altman, D.G., Sterne, J.A.C. (2011) Chapter 8: Assessing risk of bias in included studies, in Higgins, J.P.T., Green, S. (eds). *Cochrane Handbook for Systematic Reviews of Interventions. Version 5.1.0.* The Cochrane Collaboration. [Online]. Available at: http://handbook-5-1.cochrane.org (Accessed: 5 May 2013).

Higgins, J.P.T., Deeks, J.J. (2011). Chapter 7: Selecting studies and collecting data, in Higgins, J.P.T., Green, S. (eds). *Cochrane Handbook for Systematic Reviews of Interventions. Version 5.1.0.* The Cochrane Collaboration. [Online]. Available at: http://handbook-5-1.cochrane.org (Accessed: 5 May 2013).

Higgins, J.P.T., Green, S. (eds). (2011) *Cochrane Handbook for Systematic Reviews of Interventions. Version 5.1.0.* The Cochrane Collaboration. [Online]. Available at: http://handbook-5-1.cochrane.org (Accessed: 5 May 2013).

Hintistan, S., Nural, N., Cilingir, D., Gursoy, A. (2017). 'Therapeutic effects of nurse led telephone follow-up for lung cancer patients in Turkey', *Cancer Nursing*, 40(6): pp. 508-516.

Hoepfl, M.C. (1997). 'Choosing qualitative research: a primer for technology education researchers', *Journal of Technology and Education*, 9(1): pp.47-63.

Hoffman, K.E., McCarthy, E.P., Recklitis, C.J., Ng, A.K. (2009). 'Psychological distress in long-term survivors of adult-onset cancer: results from a national survey', *Archives of Internal Medicine*, 169(14): pp.1274-1281.

Hoffmann, T., Glasziou, P., Boutron, I., Milne, R., Perera, R., Moher, D., Altman, D., Barbour, V., Macdonald, H., Johnston, M., Lamb, S., Dixon-Woods, M., McCulloch, P., Wyatt, J., Chan, A.W., Michie, S. (2014). 'Better reporting of interventions: template for intervention description and replication (TIDieR) checklist and guide', *British Medical Journal*, 348:g1687.

Högberg, K., Sandman, L., Nyström, M., Stockelberg, D., Broström, A. (2013). 'Prerequisites required for the provision and use of web-based communication for psychosocial support in haematologic care', *European Journal of Oncology Nursing*, 17: pp.596-602.

Holloway, D.I., Wheeler, S. (2015). *Qualitative Research in Nursing and Healthcare*. 3rd edn. Oxford: Wiley-Blackwell.

Howell, D., Hack, T.F., Oliver, T.K., Chulak, T., Mayo, S., Aubin, M., Chasen, M., Earle, C.C., Friedman, A.J., Green, E., Jones, G.W., Jones, J.M., Parkinson, M., Payeur, N., Sabiston, C.M., Sinclair, S. (2012). 'Models of care for post-treatment follow-up of adult cancer survivors: a systematic review and quality appraisal of the evidence', *Journal of Cancer Survivorship*, 6: pp.359–371.

Hudson, L., Ozanne, J. (1988). 'Alternative ways of seeking knowledge in consumer research', *Journal of Consumer Research*, 14(4): pp.508–521.

Hughes, R. (2008) Telephone interviews, in Given, L.M. (ed) (2008). *The Sage Encyclopedia of Qualitative Research Methods*. Los Angeles, California: Sage Publications, pp.862-863.

Hui, D. (2013). 'Definition of supportive care: does the semantic really matter?', *Current Opinion in Oncology*, 26: pp.372-379.

Humphrey-Murto, S., Varpio, L., Wood, T.J., Gonsalves, C., Ufholz, L.A., Mascioli, K., Wang, C., Foth, T. (2017). 'The use of the delphi and other consensus group methods in medical education research: a review', *Academic Medicine*, 92(10): pp.1491-1498.

Husson, O., Thong, M., Mols, F., Oerlemans, S., Kaptein, A.A., van de Poll-Franse, L. (2013). 'Illness perceptions in cancer survivors: what is the role of information provision?', *Psycho-Oncology*, 22: pp.490–498

Hutchings, A., Raine, R. (2006). 'A systematic review of factors affecting the judgments produced by formal consensus development methods in health care', *Journal of Health Services Research and Policy*, 11(3): pp.172-179.

Inman, D.M., Maxson, P.M., Johnson, K.M., Myers, R.P., Holland, D.E. (2011). 'The impact of follow-up educational telephone calls on patients after radical prostatectomy', *Urologic Nursing*, 31(2): pp.83-91.

Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington D.C: National Academies Press.

Institute of Medicine. (2008). *Cancer care for the whole patient: Meeting psychococial health needs*. Washington D.C: National Academies Press.

Irvine, A., Drew, P., Sainsbury, R. (2012). ''Am I not answering your questions properly?' Clarification, adequacy and responsiveness in semi-structured telephone and face-to-face interviews', *Qualitative Research*, 13(1): pp.87–106.

Jabbour, E., Faderl, S., Kantarjian, H. (2005). 'Adult acute lymphoblastic leukemia', *Mayo Clinic Proceedings*, 80: pp.1517-1527.

Jacobsen, P.B., Bovbjerg, D.H., Redd, W.H. (1993). 'Anticipatory anxiety in women receiving chemotherapy for breast cancer', *Health Psychology*, 12(6): p469.

Janesick, V..J. (2000). The choreography of qualitative research design, in Denzin, N.K., Lincoln, Y.S. *Handbook of Qualitative Research.* Thousand Oaks, CA: Sage, pp.379–399.

Jefford, M., Lotfi-Jam, K., Baravelli, C., Grogan, S., Rogers, M., Krishnasamy, M., Pezaro, C., Milne, D., Aranda, S., King, D., Shaw, B., Schofield, P. (2011). 'Development and pilot testing of a nurse-led posttreatment support package for bowel cancer survivors', *Cancer Nursing*, 34(3): E1-10.

Jensen, B.T., Kristensen, S., Christensen, S., Borre, M. (2011). 'Efficacy of tele-nursing consultations in rehabilitation after radical prostatectomy: a randomised controlled trial study', *Urological Nursing*, 5(3): pp.123-130.

Johnson, R.B., Onwuegbuzie, A.J., Turner, L.A. (2007). 'Toward a definition of mixed methods research', *Journal of Mixed Methods Research,* 1: pp.112–133.

Jones, J., Hunter, D. (1995). 'Consensus methods for medical and health services research', *British Medical Journal,* 311(7001): pp.376-80.

Jones, W., Parry, C., Devine, S., Main, D., Okuyamam S., Tran, Z. (2015a). 'Prevalence and predictors of distress in posttreatment adult leukemia and lymphoma survivors', *Journal of Psychosocial Oncology*, 33(2): pp.124-141.

Jones, W.C., Parry, C., Devine, S., Main, D.S., Okuyama, S. (2015b). 'Understanding distress in posttreatment adult leukemia and lymphoma survivors: a lifespan perspective', *Journal of Psychosocial Oncology*, 33(2): pp.142-162.

Joshi, S.T., Schultz, D.E. (2001). *An H. P. Lovecraft Encyclopedia*. Westport, CT: Greenwood Press.

Kea, B., Sun, C. (2015). 'Consensus development for healthcare professionals', *Internal and Emergeny Medicine,* 10(3): pp.373-383.

Kelly, A.P. (2011). *Social Research Methods*. London: University of London.

Kelly, D. (1999). 'Ovarian Cancer Treatment: the Benefit of Patient Telephone Follow-up Post Chemotherapy', *Canadian Oncology Nursing Journal,* 9(4): pp.175-178.

Kenyon, M., Young, F., Mufti, G.J., Pagliuca, A., Lim, Z., Ream, E. (2015). 'Life coaching following haematopoietic stem cell transplantation: a mixed-method investigation of feasibility and acceptability', *European Journal of Cancer Care (Engl)*, 24(4): pp.531-541.

Kessels, R.P. (2003). 'Patients' memory for medical information', *Journal of the Royal Society of Medicine,* 96(5): pp.219–222.

Kilbourn, K.M., Anderson, D., Costenaro, A., Lusczakoski, K., Borrayo, E., Raben, D. (2013). 'Feasibility of EASE: a psychosocial program to improve symptom management in head and neck cancer patients', *Supportive Care in Cancer,* 21(1): pp.191-200.

Kim, S.H., Shin, M.S., Lee, H.S., Lee, E.S., Ro, J.S., Kang, H.S., Kim, S.W., Lee, W.H., Kim, H.S., Kim, C.J., Kim, J., Yun, Y.H. (2011). 'Randomized pilot test of a simultaneous stage-matched exercise and diet intervention for breast cancer survivors', *Oncology Nursing Forum,* 38(2): E97-106.

Kimman, M.L., Bloebaum, M.M., Dirksen, C.D., Houben, R.M., Lambin, P., Boersma, L.J. (2010b). 'Patient satisfaction with nurse-led telephone follow-up after curative treatment for breast cancer', *BMC Cancer,* 10: 174.

Kimman, M.L., Dellaert, B.G.C., Boersma, L.J., Lambin, P., Dirksen, C.D. (2010a). 'Follow-up after treatment for breast cancer: One strategy fits all? An investigation of patient preferences using a discrete choice experiment', *Acta Oncologica,* 429: pp.328-337.

Kirkevold, M. (1997). 'Integrative nursing research – an important strategy to further the development of nursing science and practice', *Journal of Advanced Nursing*, 25: pp.977-984.

Kitson, A., Marshall, A., Bassett, K., Zeitz, K. (2013). 'What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing', *Journal of Advanced Nursing*, 69(1): pp.4-15.

Kitto, S.C., Chesters, J., Grbich, C. (2008). 'Quality in qualitative research', *Medical Journal of Australia*, 188: pp.243-246.

Kleiboer, A., Gowing, K., Holm Hansen, C., Hibberd, C., Hodges, L., Walker, J., Sharpe, M. (2010). 'Monitoring symptoms at home: What methods would cancer patients be comfortable using?', *Quality of Life Research*, 19(7): pp.965–968.

Kornblith, A.B., Herndon, J.E., Zuckerman, E., Viscoli, C.M., Horwitz, R.I., Cooper, M.R., Harris, L., Tkaczuk, K.H., Perry, M.C., Budman, D., Norton, L.C., Holland, J. Cancer and Leukemia Group B. (2001). 'Social support as a buffer to the psychological impact of stressful life events in women with breast cancer', *Cancer*. 91: pp.443–454.

Krueger, R.A. (2006). 'Is it a focus group? Tips on how to tell', *Journal of Wound Ostomy & Continence Nursing*, 33(4): pp.363–366.

Krumholz, H. M., Amatruda, J., Smith, G. L., Mattera, J. A., Roumanis, S. A., Radford, M. J., Crombie, P., Vaccarino, V. (2002). 'Randomized trial of an education and support intervention to prevent readmission of patients with heart failure', *Journal of the American College of Cardiology*, 39(1): pp.83–89.

Kvale, S. (1996). *InterViews: An Introduction to Qualitative Research Interviewing*. Thousand Oaks: Sage.

Larkin, P.J., Dierckx de Casterle, B., Schotsmans, P. (2007). 'Multilingual translation issues in qualitative research: reflections on a metaphorical process', *Qualitative Health Research*, 17: pp.468–476.

Laugsand, E.A., Sprangers, M.A.G., Bjordal, K., Skorpen, F., Kaasa, S., Klepstad, P. (2010). 'Health care providers underestimate symptom intensities of cancer patients: A multicenter European study', *Health and Quality of Life Outcomes*, 8:104.

Leahy, M., Krishnasamy, M., Herschtal, A., Bressel, M., Dryden, T., Tai, K.H., Foroudi, F. (2013). 'Satisfaction with nurse-led telephone follow up for low to intermediate risk prostate cancer patients treated with radical radiotherapy. A comparative study', *European Journal of Oncology Nursing*, 17(2): pp.162-169.

Lefebvre, C., Manheimer, E., Glanville, J. (2011). Chapter 6: Searching for studies, in Higgins, J.P.T., Green, S. (eds). *Cochrane Handbook for Systematic Reviews of Interventions. Version 5.1.0.* The Cochrane Collaboration. [Online]. Available at: http://handbook-5-1.cochrane.org (Accessed: 5 May 2013).

Lincoln, Y.S., Guba, E.G. (1985). *Naturalistic Inquiry*. Newbury Park, CA: Sage Publications.

Lincoln, Y.S., Lynham, S.A., Guba, E.G. (2011). Paradigmatic controversies, contradictions, and emerging confluences, revisited, in Denzin, N.K., Lincoln, Y.S. (eds.) *The Sage Handbook of Qualitative Research*. London: Sage Publications, pp. 97-128.

Linden, W., Vodermaier, A., Mackenzie, R., Greig, D. (2012). 'Anxiety and depression after cancer diagnosis: prevalence rates by cancer type, gender and age', *Journal of Affective Disorders*, 141(23): pp.343-351.

Liptrott, S., Bee, P., Lovell, K. (2017). 'Acceptability of telephone support as perceived by patients with cancer: A systematic review', *European Journal of Cancer Care, 2017:* e12643.

Livingston, P.M., Craike, M.J., White, V.M., Hordern, A.J., Jefford, M., Botti, M.A., Lethborg, C., Oldroyd, J.C. (2010). 'A nurse-assisted screening and referral program for depression among survivors of colorectal cancer: feasibility study', *Medical Journal of Australia*, 193(5 Suppl): S83-87.

Lobb, E.A., Joske, D., Butow P, Kristjanson, L.J., Cannell, P., Cull, G., Augustson, B. (2009). 'When the safety net of treatment has been removed: Patients' unmet needs at the completion of treatment for haematological malignancies', *Patient Education and Counseling*, 77: pp.103-108.

Loerzel, V.W., Dow, K.H. (2003) 'Cardiac toxicity related to cancer treatment', *Clinical Journal of Oncology Nursing*, 7(5): pp.557-562.

Loffe, H., Yardley, L. (2004). Content and thematic analysis, in Marks, D.F., Yardley, L. (eds.) *Research Methods for Clinical and Health Psychology*. London: Sage Publications, pp.56–69.

Lovell, K., Bower, P., Richards, D., Barkham, M., Sibbald, B., Roberts, C., Davies, L., Rogers, A., Gellatly, J., Hennessy, S. (2008). 'Developing guided self-help for depression using the Medical Research Council complex interventions framework: a description of the modelling phase and results of an exploratory randomized controlled trial', *BMC Psychiatry*, 8: 91. [Online]. Available at: http://www.biomedcentral.com/1471-244X/8/91 (Accessed: 25 October 2015).

Malmstrom, M., Ivarsson, B., Klefsgård, R., Persson, K., Jakobsson, U., Johansson, J. (2016). 'The effect of a nurse led telephone supportive care programme on patients' quality of life, received information and health care contacts after oesophageal cancer surgery – A six month RCT follow-up study', *International Journal of Nursing Studies*, 64: pp.86-95.

Mank. A., van der Lelie, J., de Vos, R., Kersten, M.J. (2011). 'Safe early discharge for patients undergoing high dose chemotherapy with or without stem cell transplantation: a prospective analysis of clinical variables predictive for complications after treatment', *Journal of Clinical Nursing*, 20(3-4): pp.388-395.

Marcus, A.C., Cella, D., Sedlacek, S., Crawford, D., Crane, L., Garrett, K., Quigel, C., Gonin, R. (1993). 'Psychosocial Counseling of Cancer Patients By Telephone: A Brief Note on Patient Acceptance of an Outcall Strategy', *Psycho-Oncology*, 2: pp.209-214.

Marcus, A C., Garrett, K.M., Cella, D., Wenzel, L., Brady, M.J., Fairclough, D., Pate-Willig, M., Barnes, D., Emsbo, S.P., Kluhsman, B.C., Crane, L., Sedlacek, S., Flynn, P. J. (2010). 'Can telephone counseling post-treatment improve psychosocial outcomes among early stage breast cancer survivors?', *Psycho-Oncology*, 19(9): pp. 923–932.

Martin, E.C., Basen-Engquist, K., Cox, M.G., Lyons, E.J., Carmack, C.L., Blalock, J.A., Demark-Wahnefried, W. (2016). 'Interest in health behavior intervention delivery modalities among cancer survivors: a cross-sectional study', *Journal of Medical Internet Research Cancer*, 2(1): e1.

Martin, L.A., Nelson, E.C., Lloyd, R.C., Nolan, T.W. (2007). *Whole System Measures [IHI innovation Series White Paper]*. Cambridge, MA, Institute for Healthcare Improvement. [online]. Available at: http://IHI.org (Accessed: 5 May 2013).

Martinella, V. (2016). 'Tumori, ogni anno 800mila italiani cambiano regione per curarsi'. Interview with Vera Martinella. Interview for the *Corriere della Sera*, 25 November [Online]. Available at: http://www.aiom.it/professionisti/aiom-notiziario/tumori-ogni-anno-800mila-italiani-cambiano-regione-per-curarsi/1,3015,1 (Accessed: 18 June 2017].

Mays, N., Pope, C., Popay, J. (2005). 'Systematically reviewing qualitative and quantitative evidence to inform management and policy-making in the health field', *Journal of Health Service Research and Policy*, 10(Suppl.1): pp.6–20.

McGrath, P. (2000). 'Post-treatment support for patients with haematological malignancies: findings from regional, rural and remote Queensland', *Australian Health Review*, 23(4): pp.142-150.

McGrath, P. (2001). '"It's horrendous—but really, what can you do?" Preliminary findings on the financial impact of relocation for specialist treatment', *Australian Health Review*, 23(3): pp.94–103.

McGrath, P. (2013). '"Receptivity": an important factor affecting supportive care provision', *Journal of Psychosocial Oncology*, 31(1): pp.30-50.

McGrath, P. (2015). 'Patient perspectives on the usefulness of routine telephone follow-up as psychosocial support for hematologic malignancies: Australian findings', *Oncology Nursing Forum*, 41(1): pp.40-44.

McGrath, P., Hartigan, B., Holewa, H., & Skarparis, M. (2012). 'Returning to work after treatment for haematological cancer: Findings from Australia', *Supportive Care in Cancer*, 20: pp.1957–1964.

McKeganey, N.P., Bloor, M.J. (1981). 'On the retrieval of sociological descriptions: respondent validation and the critical case of ethnomethodology', *International Journal of Sociology and Social Policy*, 1: pp.58–69.

Meade, M.O., Richardson, W.S. (1997). 'Selecting and appraising studies for a systematic review', *Annals of Internal Medicine,* 127: pp.531-537.

Medical Research Council. (2006). *Developing and evaluating complex interventions: new guidance*. London: MRC. [Online]. Available at: https://www.mrc.ac.uk/documents/pdf/complex-interventions-guidance/ (Accessed: 25 October 2014).

Mehta, A., Cohen, R., Chan, L. (2009). 'Palliative care: A need for a family systems approach', *Palliative and Supportive Care*, 7: pp.235–243.

Merckaert, I., Libert, Y., Messin, S., Milani, M., Slachmuylder, J., Razavi, D. (2010). 'Cancer patients' desire for psychological support: prevalence and implications for screening patients' psychological needs', *Psycho-Oncology*, 19: pp.141-149.

Meyrick, J. (2006). 'What is good qualitative research? A first step towards a comprehensive approach to judging rigour/quality', *Journal of Health Psychology*, 11: pp.799-808.

Miladinia, M., Baraz, S., Shariati, A., Malehi, A.S. (2017). 'Effects of slow-stroke back massage on symptom cluster in adult patients with acute leukaemia', *Supportive Care in Cancer Nursing*. 40(1): pp.31-38.

Mistiaen, P., Poot, E. (2006). 'Telephone follow-up, initiated by a hospital-based health professional for postdischarge problems in patients discharged from hospital to home'. *Cochrane Database Systematic Review*, Oct 18(4), CD004510.

Mohr, D.C., Hart, S.L., Howard, I., Julian, L., Vella, L., Catledge, C., Feldman, M.D. (2006). 'Barriers to psychotherapy among depressed and non depressed primary care patients', *Annals of Behavioural Medicine,* 32(3): pp.254-258.

Moore, G.F., Audrey, S., Barker, M. Bond, L., Bonell, C., Hardeman, W., Moore, L., O'Cathain, A., Tinati, T., Wight, D., Baird, J. (2014). *Process evaluation of complex interventions: Medical Research Council guidance*. London: MRC Population Health Science Research Network.

Moore, G.F., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., Moore, L., O'Cathain, A., Tinati, T., Wight, D., Baird, J. (2015). 'Process evaluation of complex interventions: Medical Research Council guidance', *British Medical Journal*, 350:h1258.

Moore, P.M. Rivera Mercado, S., Grez Artigues, M., Lawrie, T.A. (2013). 'Communication skills training for healthcare professionals working with people who have cancer', *Cochrane Database of Systematic Reviews*, 28(3): CD003751.

Moran, D. (2002). Editor's introduction, in Moran, D., Mooney, T. (eds.) *The Phenomenology Reader*. London: Routledge.

Mordenti, P., Capuano, D.L., Zanlari, L., Achilli, R., Galli, M.L., Marazzi, E., Gandolfi, S., Granelli, B., Terzoni, D., Civardi, G., Cavanna, L. (2013). 'Reduction of fear and acute toxicity from chemotherapy with a telephone call after the first cycle', *Journal of Pain and Symptom Management*, 46(2): e6-9.

Morgan, D.L. (1998). *The Focus Group Guide Book*. London: Sage Publications.

MORI. (2005). *Joined up texting: the role of mobile phones In young people's lives. Nestle Social Research Programme.* London: MORI. [Online]. Available at: http://www.mori.com/polls/2004/nestlesrp3.shtml (Accessed: 6 November 2014).

Morse, J.M. (2003). Principles of mixed methods and multimethod research design, in, Tashakkori, A., Teddie, C. (eds.) *Foundation of Mixed Methods Research: Integrating Quantitative and Qualitative Techniques in the Social and Behavioral Sciences*. Thousand Oaks, CA: Sage, pp.189–203.

Mosher, C.E., Winger, J.G., Given, B.A., Shahda, S., Helft, P.R. (2017). 'A systematic review of psychosocial interventions for colorectal cancer patients', *Supportive Care in Cancer,* 25(7): pp. 2349-2362.

Munro, A.J, Shaw, T., Clarke, L., Becker, L., Greenwood, S. (1994) 'A Randomized Study of Telephone Contact Following Completion of Radiotherapy', *Clinical Oncology,* 6: pp.242-244.

Murphy, M.K., Black, N.A., Lamping, D.L., McKee, C.M., Sanderson, C.F., Askham, J., Martineau, T. (1998). 'Consensus development methods and their use in clinical guidelines development', *Health Technology Assessment,* 2(3): pp.1-88.

Murray, B.L. (2003), 'Qualitative research interviews: therapeutic benefits for the participants', *Journal of Psychiatric and Mental Health Nursing* 10(2): pp.233-236.

Murray, E., Treweek, S., Pope, C., MacFarlane, A., Ballini, L., Dowrick, C., Finch, T., Kennedy, A., Mair, F., O'Donnell, C., Ong, B.E., Rapley, T., Rogers, A., May, C. (2010). 'Normalisation process theory: a framework for developing, evaluating and implementing complex interventions', *BMC Medicine*, 8:63.

Namey, E., Guest, G., Thairu, L., Johnson, L. (2008). Data reduction techniques for large qualitative data sets, in Guest, G., MacQueen, K.M. (eds) *Handbook for Team based Qualitative Research*. Plymoth, UK: AltaMira Press.

National Breast Cancer and National Cancer Control Initiative. (2003). *Clinical practice guidelines for the psychosocial care of adults with cancer*. Camperdown, NSW: National Breast Cancer Centre.

National Cancer Institute. (2017). *NCI Dictionary of Cancer Terms: haematological cancer* [Online]. Available at: https://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=45708 (Accessed: 24 October 2017).

National Institute for Clinical Excellence. (2004). *Guidance on Cancer Services: Improving Supportive and Palliative care for Adults with Cancer. The Manual*. London: NICE.

National Institute for Clinical Excellence. (2016). *Haematological cancers: Improving outcomes*. London: NICE. [Online]. Available at

https://www.nice.org.uk/guidance/ng47/resources/haematological-cancers-improving-outcomes-pdf-1837457868229 (Accessed: 2 December 2017].

National Institute for Clinical Excellence. (2017). *Haematological cancers*. London: NICE. [Online]. Available at: https://www.nice.org.uk/guidance/qs150/resources/haematological-cancers-pdf-75545533256389 (Accessed: 2 December 2017).

Naughton, M.J., Weaver, K.E. (2014). 'Physical and mental health among cancer survivors: considerations for long-term care and quality of life', *North Carolina Medical Journal*, 75(4): pp.283–286.

NCCN Guidelines (2017a). *Version 1.2017 Hodgkin Lymphoma.* Available at: https://www.nccn.org/professionals/physician_gls/pdf/hodgkins.pdf (Accessed: 25 October 2017).

NCCN Guidelines (2017b). *Version 5.2017 B-cell Lymphomas.* Available at: https://www.nccn.org/professionals/physician_gls/pdf/b-cell.pdf (Accessed: 25 October 2017).

NCCN Guidelines (2017c). *Version 2.2017 T-cell Lymphomas*. Available at: https://www.nccn.org/professionals/physician_gls/pdf/t-cell.pdf (Accessed: 25 October 2017).

NCCN Guidelines (2017d). *Acute Lymphoblastic Leukemia Version 4.2017*. Available at: https://www.nccn.org/professionals/physician_gls/pdf/all.pdf (Accessed: 25 October 2017).

NCCN Guidelines (2017e). *Acute Myeloid Leukemia Version 3.2017*. Available at: https://www.nccn.org/professionals/physician_gls/pdf/aml.pdf (Accessed: 25 October 2017).

NCCN Guidelines (2017f). *Chronic Lymphocytic Leukemia/ Small Lymphocytic Lymphoma Version 2.2018*. Available at: https://www.nccn.org/professionals/physician_gls/pdf/cll.pdf (Accessed: 25 October 2017).

NCCN Guidelines (2017g). *Chronic Myeloid Leukaemia Version 2.2018*. Available at: https://www.nccn.org/professionals/physician_gls/pdf/cml.pdf (Accessed: 25 October 2017).

NCCN Guidelines (2017h). *Multiple Myeloma Version 2.2018.* Available at: https://www.nccn.org/professionals/physician_gls/pdf/myeloma.pdf (Accessed: 25 October 2017).

Nekhlyudov, L., O'Malley, D., Hudson, S. (2017). 'Integrating primary care providers in the care of cancer survivors: gaps in evidence and future opportunities', *The Lancet Oncology*, 18(1): e30-e38.

Neuman, W. (2014). *Social research Methods: Qualitative and Quantitative Approaches*. 7th edn.. Essex: Pearson Education Limited.

Newman, I. (1998). *Qualitative-quantitative research methodology: exploring the interactive continuum*. Carbondale: Southern Illinois University Press.

Nissen, T., Wynn, R. (2014). 'The clinical case report: a review of its merits and limitations', *BMC Research Notes*, 7: pp.264.

Norton, T.R., Manne, S.L., Rubin, S., Carlson ,J., Hernandez, E., Edelson, M.I., Bergman, C. (2004). 'Prevalence and predictors of psychological distress among women with ovarian cancer', *Journal of Clinical Oncology*, 22(5): pp.919.

Noyes, J., Popay, J., Pearson, A., Hannes, K., Booth, A. (2011). Chapter 20: Qualitative research and Cochrane reviews, in Higgins, J.P.T., Green, S. (eds). *Cochrane Handbook for Systematic Reviews of Interventions. Version 5.1.0.* The Cochrane Collaboration. [Online]. Available at: http://handbook-5-1.cochrane.org (Accessed: 5 May 2013).

O'Connor, M., Payne, S. (2006). 'Discourse analysis: examining the potential for research in palliative care', *Palliative Medicine*, 20: pp.829-834.

Okuyama, S., Jones, W., Ricklefs, C., Tran, Z.V. (2015). 'Psychosocial telephone interventions for patients with cancer and survivors: a systematic review', *Psycho-Oncology*, 24(8): pp.857–870.

Okuyama, T., Endo, C., Seto, T., Kato, M., Seki, N., Akechi, T., Furukawa, T.A., Eguchi, K., Hosaka, T. (2008). 'Cancer patients' reluctance to disclose their emotional distress to their physicians: a study of Japanese patients with lung cancer', *Psycho-Oncology*. 17: pp.460–465.

Oltman, S.M. (2016). 'Qualitative interviews: a methodological discussion of the interviewer and respondent contexts', *Forum Qualitative Sozialforschung / Forum: Qualitative Social Research*, 17(2): Art 15.

Ostlund, U., Kidd, L., Wengstrom, Y., Rowa-Dewar, N. (2011). 'Combining qualitative and quantitative research within mixed method research designs: a methodological review', *International Journal of Nursing Studies*, 48(3): pp.369-383.

O'Toole, G., (2012). *Communication: Core Interpersonal Skills for Health Professionals.* 2nd edn. Chatswood, Australia: Elsevier.

Oxford English Dictionary Online, (2013a). *Oxford English Dictionary* [Online]. Available at: http://www.oed.com/view/Entry/1008?redirectedFrom=acceptable#eid (Accessed: 5 May 2013).

Oxford English Dictionary Online, (2013b). *Oxford English Dictionary* [Online]. Available at: http://www.oed.com/view/Entry/171223?redirectedFrom=satisfaction#eid (Accessed: 5 May 2013).

Oxford English Dictionary Online. (2013c). *Oxford English Dictionary* [Online]. Available at: http://www.oed.com/view/Entry/98431?redirectedFrom=intervention (Accessed: 5 May 2013).

Oxford English Dictionary Online, (2013d). *Oxford English Dictionary* [Online]. Avaliable at: http://www.oed.com/view/Entry/68797?redirectedFrom=feasibility#eid (Accessed: 5 May 2013).

Oxford English Dictionary Online, (2013e). *Oxford English Dictionary* [Online]. Available at: http://www.oed.com/viewdictionaryentry/Entry/149997 (Accessed: 5 May 2013).

Oxman, A.D., Guyatt, G.H. (1993). 'The science of reviewing research', *Annals of the New York Academy of Sciences,* 703: pp.125-133.

Pare, G., Mirou, J., Sicotte, C. (2007). 'Systematic review of home telemonitoring for chronic diseases. The evidence base', *Journal of the America Medical Informatics Association,* 14: pp.269-277.

Parikh, C.R., Sandmaier, B.M., Storb, R.F., Blume, K.G., Sahebi, F., Maloney, D.G., Maris, M.B., Nieto, Y., Edelstein, C.L., Schrier, R.W., McSweeney, P. (2004). 'Acute renal failure after nonmyeloablative hematopoietic cell transplantation', *Journal of the American Society of Nephrology,* 15(7): pp. 1868-1876.

Parker, P.A., Baile, W.F., de Moor, C., Cohen, L. (2003). 'Psychological and demographic predictors of quality of life in a large sample of cancer patients', *Psycho-Oncology,* 12: pp.183–193.

Parkinson, S., Eatough, V., Holmes, J., Stapley, E., Midgley, N. (2016). 'Framework analysis: a worked example of a study exploring young people's experiences of depression', *Qualitative Research in Psychology,* 13(2): pp.109-129.

Parry, C., Lomax, J.B., Morningstar, E.A., Fairclough, D.L. (2012). 'Identification and correlates of unmet service needs in adult leukemia and lymphoma survivors after treatment', *Journal of Oncology Practice,* 8(5): e135-141.

Parry, C., Morningstar, E., Kendall, J., Coleman, E. (2011). 'Working without a net: leukemia and lymphoma survivors' perspectives on care delivery at end-of treatment and beyond', *Journal of Psychosocial Oncology,* 29 (2): pp.175-198.

Patton, M.Q. (1990). *Qualitative evaluation and research methods*. 2nd edn. Newbury Park, CA: Sage.

Patton, M.Q. (2001). *Qualitative Research and Evaluation Methods*. 3rd edn. Saint Paul, MN: Sage Publications.

Pawson, R., Greenhalgh, T., Harvey, G., Walshe, K. (2005). 'Realist review–a new method of systematic review designed for complex policy interventions', *Journal of Health Services Research and Policy,* 10(Suppl 1): pp.21–34.

Petersen, M.A., Larsen, H., Pedersen, L., Sonne, N., Groenvold, M. (2006). 'Assessing health-related quality of life in palliative care: Comparing patient and physician assessments', *European Journal of Cancer,* 42: pp.1159-1166.

Plummer-D'Amato, P. (2008). '*Focus group methodology part 1: considerations for design, International Journal of Therapy and Rehabilitation*, 15(2): pp.69–73.

Polgar, S., Thomas, S. (2008). *Introduction to Research in the Health Sciences*. 5th edn. Philadelphia: Elsevier.

Polit, D., Beck, C. (2010). 'Generalization in quantitative and qualitative research: Myths and strategies', *International Journal of Nursing Studies*, 47: pp.1451–1458.

Polkinghorne, D.E. (2005). 'Language and meaning: Data collection in qualitative research', *Journal of Counseling Psychology*, 52(2): pp.137-145.

Polovich, M., White, J., Kelleher, L. (2005). *Chemotherapy and Biotherapy Guidelines and Recommendations for Practice*. 2nd edn. Pittsburgh, PA: Oncology Nursing Society.

Raine, R., Sanderson, C., Hutchings, A., Carter, S., Larkin, K., Black, N. (2004). 'An experimental study of determinants of group judgments in clinical guideline development', *Lancet*, 364(9432): pp429-437.

Redmond, R.A., Curtis, E.A. (2009). 'Focus groups: principles and process', *Nursing Research*, 16(3): pp.57–69.

Reese, J.B., Porter, L.S., Regan, K.R., Keefe, F.J., Azad, N.S., Diaz, L.A. Herman, J.M., Haythornthwaite, J.A. (2014). 'A randomized pilot trial of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer', *Psycho-Oncology*, 23(9): pp.1005-1013.

Reese, J.B., Porter, L.S., Somers, T.J., Keefe, F.J. (2012). 'Pilot feasibility study of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer*', Journal of Sex and Marital Therapy*, 38(5): pp.402-417.

Reid, R., Baran, A., Friedberg, J., Phillips, G. 2nd, Liesveld, J., Becker, M., Wedlow, L., Barr, P., Milner, L (2016). 'Outpatient administration of BEAM conditioning prior to autologous stem cell transplantation for lymphoma is safe, feasible, and cost-effective', *Cancer Medicine*, 5(11): pp.3059–67

Richards, H.M., Emslie, C. (2000). 'The 'doctor' or the 'girl from the University'? Considering the influence of professional roles on qualitative interviewing', *Family Practitioner*, 17: pp.71–75.

Rimkus, C. (2009) 'Acute complications of stem cell transplantation', *Seminars in Oncology Nursing*, 25(2): pp.129-138.
Ritchie, J. (2003). The applications of Qualitative methods to social research, in Ritchie, J., Lewis, J. *Qualitative Research Practice: a Guide for Social Science Students and Researchers*. London: Sage Publications, pp. 24-45.

Ritchie, J., Lewis, J. (2003). *Qualitative Research Practice: a Guide for Social Science Students and Researchers*. London: Sage Publications.

Ritchie, J., Lewis, J., Elam, G. (2003). Designing and Selecting Samples, in Ritchie, J.,

Lewis, J. *Qualitative Research Practice: a Guide for Social Science Students and Researchers*. London: Sage Publications, pp. 77-108.

Ritchie, J., Ormston, R. (2014). The applications of qualitative methods to social research, in Ritchie, J., Lewis, J., Mcnaughton Nicholls, C., Ormston, R. (eds.) *Qualitative Research Practice*. London: Sage Publications, pp.27-46.

Ritchie J, Spencer L. (1994). Qualitative Data Analysis for Applied Policy Research, in Ritchie, J., Spencer, E., Bryman, A., Burgess, R.G. (eds) *Analyzing Qualitative Data.* London: Sage Publications, pp.173-194.

Robson, C. (2002). *Real World Research*. 2nd edn. Oxford: Blackwell Publishers Ltd.

Romney, A.K., Weller, S.C., Batchelder, W.C. (1986). 'Culture as consensus: a theory of culture and informant accuracy', *American Anthropologist* 88(2): pp.313–338.

Rood, J., Eeltink, C., van Zuuren, F., Verdonck-de Leeuw, I., Huijgens, P. (2014). 'Perceived need for information of patients with haematological malignancies: A literature review', *Journal of Clinical Nursing*, 24: pp.353–369.

Rossman, G.B., Wilson, B.L. (1985). 'Numbers and words: Combining quantitative and qualitative methods in a single large-scale evaluation study', *Evaluation Review*, 9: pp.627-643.

Rueda, J.R., Solà, I., Pascual, A., Subirana Casacuberta, M. (2011). Non-invasive interventions for improving well-being and quality of life in patients with lung cancer, *Cochrane Database of Systematic Review*, 9: CD004282.

Ryan, R. (2013). *Cochrane Consumers and Communication Review Group: data synthesis and analysis*. [Online]. Available at: http://cccrg.cochrane.org (Accessed: 4 July 2017).

Sackett, D.L., Rosenberg, W.M.C., Gray, J.A.M., Haynes, R.B., Richardson, W.S. (1996). 'Evidence based medicine: what it is and what it isn't', *British Medical Journal*, 312: 71.

Saldaña, J. (2003). *Longitudinal qualitative research: Analyzing change through time*. New York: AltaMira Press.

Saldaña, J. (2009). *The coding manual for qualitative researchers*. London: Sage Publications.

Salonen, P., Tarkka, M., Pellokumpu-Lehtinen, P.L., Astedt-Kurki, P., Luukkaala, P., Kaunonen, M. (2009). 'Telephone intervention and quality of life in patients with breast cancer', *Cancer Nursing*, 32(3): pp.177–190.

Sandelowski, M. (1995). Sample size in qualitative research, *Research in Nursing and Health*, 18: pp.179-183.

Sandelowski, M., Docherty, S., Emden, C. (1997). Focus on qualitative methods. Qualitative metasynthesis: issues and techniques, *Research in Nursing and Health*, 20(4): pp.365-371.

Sandelowski, M., Voils, C.I., Barroso, J. (2006). 'Defining and designing mixed research synthesis studies', *Research in the Schools*, 13(1): pp29.

Sandgren, A.K., McCaul, K.D., King, B., O'Donnell, S., Foreman, G. (2000). 'Telephone therapy for patients with breast cancer', *Oncology Nursing Forum*, 27(4): pp.683-688.

Sardell, S., Sharpe, G., Ashley, S., Guerrero, D., Brada, M. (2000). 'Evaluation of a nurse-led telephone clinic in the follow-up of patients with malignant glioma', *Clinical Oncology*, 12(1): pp.36-41.

Saumure, K., Given, L.M. (2008). Rigour in qualitative research, in Given, L.M. (ed) (2008). *The Sage Encyclopedia of Qualitative Research Methods*. Los Angeles, California: Sage Publications, pp. 795-796.

Schreiber, J.B. (2008). Data, in Given, L.M. (ed) (2008). *The Sage Encyclopedia of Qualitative Research Methods*. Los Angeles, California: Sage Publications, pp. 185-186.

Schutt, R. (2009). *Investigating the Social World: the Process and Practice of Research*. 6th edn. Thousand Oaks, CA: Pine Forge Press/Sage.

Schutt, R. (2011). Quantitative Methods, in Ritzer, G. (ed) *The Wiley-Blackwell Companion to Sociology*. Oxford: John Wiley & Sons, Ltd, pp.55-72.

Schwandt, T.A. (2001). *Dictionary of Qualitative Inquiry*. Thousand Oaks, CA: Sage Publications.

Scott, D.A., Mills, M., Black, A., Cantwell, M., Campbell, A., Cardwell, C.R., Porter, S., Donnolley, M. (2013). 'Multidimensional rehabilitation programmes for adult cancer survivors', *Cochrane Database of Systematic Reviews*, 3: CD007730.

Seidman, I.E. (1991). *Interviewing as Qualitative Research*. New York: Teachers College Press.

Sekhon, M., Cartwright, M., Francis, J.J. (2017). 'Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework', *BMC Health Services Research*, 17(1): 88.
Sharp, L., O'Leary, E., Kinnear, H., Gavin, A., Drummond, F. (2015). 'Cancer-related symptoms predict psychological wellbeing among prostate cancer survivors: results from the PiCTure study', *Psycho-Oncology*, 25(3): pp.282-91.

Silverman, D. (2001). *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction*, 2nd edn. London: Sage Publications.

Sipe, L. Ghiso, M.P. (2004). 'Developing conceptual categories in classroom descriptive research: some problems and possibilities', *Anthropology & Education Quarterly*. 35(4): pp.472-485.

Sive, J., Ardeshna, K., Cheesman, S., Le Grange, F., Morris, S., Nicholas, C., Peggs, K., Statham, P., Goldstone, A. (2012). 'Hotel-based ambulatory care for complex cancer

patients: a review of the University College London Hospital experience', *Leukemia and Lymphoma*, 53(12): pp.2397–404.

Skarstein, J., Aass, N., Fosså, S.D., Skovlund, E., Dahl, A.A. (2000). 'Anxiety and depression in cancer patients: relation between the Hospital Anxiety and Depression Scale and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire', *Journal of Psychosomatic Research*, 49(1): pp.27–34.

Slavin, R. (1995). 'Best evidence synthesis: an intelligent alternative to met-analysis,' *Journal of Clinical Epidemiology*, 48(1): pp.9-18.

Smeenk, F., van Haastregt, J., Gubbels, E., de Witte, L., Crebolder, H. (1998). 'Care process and satisfaction analysis of a transmural home care program', *International Journal of Nursing Studies*, 35(3): pp.146-54.

Smith, A., Howell, D., Patmore, R., Jack, A., Roman, E. (2011) 'Incidence of haematological malignancy by sub-type: a report from the Haematological Malignancy Research Network', *British Journal of Cancer*, 105(11): pp.1684–1692.

Smith, B., Woodruff Smith, D. (1995). Introduction, in Smith, B., Woodruff Smith, D. (eds.) *The Cambridge Companion to Husserl*. pp. 1-44. [Online]. Available at: http://dx.doi.org/10.1017/CCOL0521430232.001 (Accessed 30 July 2016).

Smithies, M., Bettger-Hahn, M., Forchuk, C., Brackstone, M. (2009). 'Telephone contact intervention in women undergoing treatment for breast cancer', *Canadian Oncology Nursing Journal*, 19(3): pp.122-128.

Soumerai, S.B., Starr, D., Majumdar, S.R. (2015). 'How do you know which health care effectiveness research you can trust? a guide to study design for the perplexed', *Preventing Chronic Disease*, 12:150187.

Spiteri, L. (1998). 'A simplified model for facet analysis: Ranganathan 101', *Canadian Journal of Information and Library Science*, 23(1/2): pp.1–30. [Online]. Available at: http://iainstitute.org/en/learn/research/a_simplified_model_for_facet_analysis (Accessed: 23 October 2015).

Statista. (2017). Mobile phone users worldwide. *Statista: The Statistics Portal.* Available at: https://www.statista.com/statistics/274774/forecast-of-mobile-phone-users-worldwide/ (Accessed: 25 October 2017).

Steginga, S.K., Ferguson, M., Clutton, S., Gardiner, R.A., Nicol, D. (2008). 'Early decision and psychosocial support intervention for men with localised prostate cancer: an integrated approach', *Supportive Care in Cancer*, 16(7): pp.821-829.

Steinke, E.E. (2004). 'Research ethics, informed consent, and participant recruitment', *Clinical Nurse Specialist*, 18(2): pp.88-95.

Stephens, M. (2004). 'The lived experience post-autologous haematopoietic stem cell transplant (HSCT): a phenomenological study', *European Journal of Oncology Nursing*, 9(3): pp.204-215.

Stern, P N., Harris, C.C. (1985). ‘Women’s health and the self-care paradox: A model to guide self-care readiness’, *Health Care for Women International*, 6: pp.151–163.

Stewart, D.W., Shamdasani, P.M. (1990): *Focus groups. Theory and practice*. London: Sage Publications.

Stewart, D.W., Shamdasani, P.N., Rook, D.W. (2007). *Focus Groups: Theory and Practice*. 2nd edn. Thousand Oaks, CA: Sage Publications.

Strauss, A. Corbin, J.M. (1998). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory*. Thousand Oaks, CA: Sage Publications.

Suh, S.R., Lee, M.K. (2017). ‘Effects of nurse-led telephone-based supportive interventions for patients with cancer: a meta-analysis’, *Oncology Nursing Forum*, 44(4): e168-e184.

Sundberg, K., Wengström, Y., Blomberg, K., Hälleberg-Nyman, M., Frank, C., Langius-Eklöf, A. (2017). ‘Early detection and management of symptoms using an interactive smartphone application (Interaktor) during radiotherapy for prostate cancer’, *Supportive Care in Cancer*, 25(7): pp.2195-2204.

Swallow, V., Lambert, H., Santacrose, S., Macfadyen, A. (2011). ‘Father and mothers developing skills in managing children’s longterm medical conditions: how do their qualitative accounts compare?’, *Child: Care, Health and Development*, 37(4): pp.512–523.

Swash, B., Bramwell, R., Hulbert-Williams, N.J. (2017). ‘Unmet psychosocial supportive care needs and psychological distress in haematological cancer survivors: The moderating role of psychological flexibility’, *Journal of Contextual Behavioral Science*, 6: pp.187–194.

Swash, B., Hulbert-Williams, N. J., Bramwell, R. (2014). ‘Unmet psychosocial need in haematological cancer: A systematic review’, *Supportive Care in Cancer*, 22(4): pp.1131–1141.

Tammela, O. (2013). ‘Applications of consensus methods in the improvement of care of paediatric patients: a step forward from a 'good guess'’, *Acta Paediatrica*, 102(2): pp.111-115.

Tashakkori, A., Teddlie, C. (2003). *Handbook of Mixed Methods in Social and Behavioural Research*. London: Cassell.

Taylor, M.E., Ketels, M.M., Delbaere, K., Lord, S.R., Mikolaizak, A.S., Close, J.C. (2012). ‘Gait impairment and falls in cognitively impaired older adults: an explanatory model of sensorimotor and neuropsychological mediators’, *Age and Ageing*, 41(5): pp.665–669.

Taylor, S., Harley, C., Campbell, L.J., Bingham, L., Podmore, E.J., Newsham, A.C., Shelby, P.J., Brown, J.M., Velikova, G. (2011). ‘Discussion of emotional and social impact of cancer during outpatient oncology consultations’, *Psycho-Oncology*, 20: pp.242–251.

Temple, B. (2002). 'Crossed wires: interpreters, translators, and bilingual workers in cross-language research', *Qualitative Health Research,* 12: pp.844–854.

Temple, B., Edwards, R., Alexander, C.. (2006). 'Grasping at context: Cross language qualitative research as secondary qualitative data analysis', *Qualitative Social Research,* 7(4). [Online]. Available at: http://www.qualitative-research.net/index.php/fqs/article/view/176/393 (Accessed: 10 December 2015).

Temple, B., Young, A. (2004). 'Qualitative research and translation dilemmas', *Qualitative Research,* 4(2): pp.161-178.

Thomas, J., Harden, A. (2008). 'Methods for the thematic synthesis of qualitative research in systematic reviews', *BMC Medical Research Methodology*, 8: 45.

Thompson, C., Yang, H. (2009). 'Nurses' decisions, irreducible uncertainty and maximizing nurses' contribution to patient safety', *Healthcare Quarterly,* 12: e178-e185.

Thompson, P. (2000). *The Voice of the Past: Oral History*. 2nd edn. Oxford: Oxford University Press.

Tobin, G.A., Begley, C.M. (2004). 'Methodological rigour within a qualitative framework', *Journal of Advanced Nursing,* 48(4): pp.388–396.

Tonkin, J. (2007). 'Developing a telephone follow-up service for myeloproliferative disorders', *British Journal of Nursing,* 16(17): pp.1090–1094.

Traeger, L., McDonnell, T.M., McCarty, C.E., Greer, J.A., El-Jawahri, A., Temel, J.S. (2015). 'Nursing intervention to enhance outpatient chemotherapy symptom management: patient-reported outcomes of a randomized controlled trial', *Cancer,* 121(21): pp.3905-3913.

Trochim, W.M.K. (2006). Sampling Terminology. [Online]. Available at: http://www.socialresearchmethods.net/kb/sampterm.php (Accessed: 25 October 2015).

Trotter, R. (2012). 'Qualitative research sample design and sample size: Resolving and unresolved issues and inferential imperatives', *Preventive Medicine,* 55: pp. 398–400.

Twinn, S. (1997). 'An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research', *Journal of Advanced Nursing,* 26: pp.418–423.

Vakil, N. (2011). 'Consensus guidelines: method or madness?', *The American Journal of Gastroenterology,* 106(2): pp.225-227.

Vaona, A., Pappas, Y., Grewal, R.S., Ajaz, M., Majeed, A., Car, J. (2017). 'Training interventions for improving telephone consultation skills in clinicians', *Cochrane Database of Systematic Reviews*, Issue 1. Art. No.: CD010034.

van der Bij, A.K., Laurant, M.G., Wensing, M. (2002). 'Effectiveness of physical activity interventions for older adults: a review', *American Journal of Preventative Medicine,* 22(2): pp.120–133.

Van Tiel, F.H., Harbers, M.M., Kessels, A.G. Schouten, H.C. (2005). 'Home care versus hospital care of patients with hematological malignancies and chemotherapy-induced cytopenia', *Annals of Oncology,*16: pp.195–205.

Vickers A., Rees, R. (1995). 'Literature searching in complementary medicine research', *Complementary Therapies in Nursing and Midwifery,* 1(6): pp.175-177.

Walsh, D., Downe, S. (2005). 'Meta-synthesis method for qualitative research: a literature review', *Journal of Advanced Nursing,* 50(2): pp.204-11.

Ward, D.J., Furber, C., Tierney, S., Swallow, V. (2013). 'Using Framework Analysis in nursing research: a worked example', *Journal of Advanced Nursing,* 69(11): pp.2423–2431.

Wenzel, L., Osann, K., Hsieh, S., Tucker, J.A., Monk, B.J., Nelson, E.L. (2015). 'Psychosocial telephone counseling for survivors of cervical cancer: results of a randomized biobehavioral trial', *Journal of Clinical Oncology,* 33: pp.1171-1179.

Wilmoth, M.C., Tulman, L., Coleman, E.A., Stewart, C.B., Samarel, N. (2006). 'Women's perceptions of the effectiveness of telephone support and education on their adjustment to breast cancer during the year following diagnosis', *Oncology Nursing Forum;* 33(1): pp.138-44.

Wright, M., Leahey, M. (2005). *Nurses and Families. A Guide to Family Assessment and Intervention*. 4th edn. Philadelphia: F.A. Davis

Young, J.M., Butow, P.N., Walsh, J., Durcinoska, I., Dobbins, T.A., Rodwell, L., Harrison, J.D., White, K., Gilmore, A., Hodge, B., Hicks, H., Smith, S., O'Connor, G., Byrne, C.M., Meagher, A.P., Jancewicz, S., Sutherland, A., Ctercteko, G., PathmaNathan, N., Curtin, A., Townend, D., Abraham, N.S., Longfield, G., Rangiah, D., Young, C.J., Eyers, A., Lee, P., Fisher, D., Solomon, M.J. (2013). 'Multicenter randomized trial of centralized nurse-led telephone-based care coordination to improve outcomes after surgical resection for colorectal cancer: the CONNECT intervention', *Journal of Clinical Oncology,* 31(28):pp.3585-3591.

Young, J.M., Harrison, J., Solomon, M., Butow, P., Dennis, R., Robson, D., Auld, S. (2010). 'Development and feasibility assessment of telephone-delivered supportive care to improve outcomes for patients with colorectal cancer: pilot study of the CONNECT intervention', *Supportive Care in Cancer,* 18(4): pp.461-70.

Yuan, S., Hussain, S.A., Hales, K.D., Cotton, S.R.. (2016). 'What do they like? Communication preferences and patterns of older adults in the United States: The role of technology', *Educational Gerontology,* 42(3): pp.163-174.

Zaman, A.G.N.M., Tytgat, K.M.A.J., van Hezel, S., Klinkenbijl, J.H.G., de Boer, A.G.E.M., Frings-Dresen, M.H.W. (2017). 'Development of a tailored work-related support intervention for gastro-intestinal cancer patients', *European Journal of Cancer*

Care (Engl), [Preprint]. Available at: http://dx.doi:10.1111/ecc.12782 (Accessed: 01 November 2017).

Zhang, J.E., Wong, F.K., You, L.M., Zheng, M.C., Li, Q., Zhang, B.Y., Huang, M.R., Ye, X.M., Liang, M.J., Liu, J.L. (2013). 'Effects of enterostomal nurse telephone follow-up on postoperative adjustment of discharged colostomy patients', *Cancer Nursing*, 36(6): pp.419-428.

Zheng, M.C., Zhang, J.E., Qin, H.Y., Fang, Y.J., Wu, X.J. (2013). 'Telephone follow-up for patients returning home with colostomies: views and experiences of patients and enterostomal nurses', *European Journal of Oncology Nursing*, 17(2): pp.184-189.

Appendices

Appendix 1 - Published article

Liptrott S, Bee P, Lovell K. (2017). Acceptability of telephone support as perceived by patients with cancer: A systematic review. *European Journal of Cancer Care*. e12643

Accepted: 5 December 2016
DOI: 10.1111/ecc.12643

FEATURE AND REVIEW PAPER

WILEY European Journal of Cancer Care

Acceptability of telephone support as perceived by patients with cancer: A systematic review

S. Liptrott MSc, Clinical Research Nurse[1] | P. Bee PhD, Senior Lecturer[2] | K. Lovell PhD, Professor[2]

[1]European Institute of Oncology, Milan, Italy
[2]School of Nursing, Midwifery and Social Work, University of Manchester, Manchester, UK

Correspondence
Sarah Liptrott, European Institute of Oncology, Milan, Italy.
Email: sarah.liptrott@ieo.it

Funding information
Fondazione IEO

Telephone-based interventions can increase accessibility to healthcare and are increasingly used as a convenient method of providing support. We conducted a systematic review of published literature reporting adult patients' perceptions of the acceptability of, and satisfaction with, telephone-based interventions during or post-treatment for cancer. Systematic searches identified 4,855 articles. Forty-eight articles describing 50 studies were included in the review. Three intervention categories were identified post hoc: (1) telephone follow-up in lieu of routine hospital follow-up, (2) telephone interventions for treatment side-effect monitoring and toxicity management supplementary to usual care, and (3) supplementary psycho-educational telephone interventions. Across studies, some consistent findings emerged. Positive perceptions emphasised the convenience of telephone interventions and increased accessibility to care. Conflicting perceptions of the quality of the support received, the impact of telecare on the patient–healthcare professional relationship and the need for such interventions emerged. In conclusion, the evidence base relating to patients' perceptions of telephone-based interventions is increasing. Interpretation of findings is currently limited by methodological limitations in the primary research. The instruments chosen to assess patient satisfaction quantitatively do not always reflect the patient-centred priorities that emerge from qualitative data. Subsequent research would benefit from well-designed qualitative studies and patient-centred outcome measures to ensure that the individuality of participants' positive and negative experiences is captured.

KEYWORDS
acceptability, cancer, satisfaction, support, systematic review, telephone

1 | BACKGROUND

Approximately 14.1 million people worldwide are diagnosed with cancer per year (Cancer Research UK, 2014) and with ongoing treatment development, long-term prognosis is improving. Treatment for cancer is increasingly outpatient based and patients are often discharged early to reduce hospital stays (van Tiel, Harbers, Kessels, & Schouten, 2005). Potential or ongoing side effects are managed at home. Inadequate management of symptoms such as fatigue and pain can impact on patient mood and psychological well-being with subsequent implications for functional status (Dodd, Miaskowski, & Paul, 2001). The need for optimal monitoring of side-effect evolution and management and support for patients continuing complex therapies in the community is clear.

Support for patients dealing with cancer and its treatments is available and largely evidence-based, with systematic reviews evaluating a variety of psychological (Mustafa, Carson-Stevens, Gillespie, & Edwards, 2013; Parahoo et al., 2013) and symptom management (Cramp & Byron-Daniel, 2012; Rueda, Solà, Pascual, & Subirana Casacuberta, 2011) interventions. Such services, however, must be provided within the context of increasing patient numbers and finite

 © 2017 John Wiley & Sons Ltd

healthcare resources. Efforts to maximise service efficiency are, therefore, high on research and practice agendas.

Economic evaluations of telemedicine for the delivery of healthcare interventions suggest that remote interventions can increase cost-effectiveness (Davalos, French, Burdick, & Simmons, 2009), prevent re-hospitalisation (Krumholz et al., 2002), facilitate time-savings (Pare, Mirou, & Sicotte, 2007) and enhance service quality and accessibility (Car & Sheik, 2003). Telephone-delivered support, in particular, is an expanding field, used across a variety of clinical settings and patient populations (Mistiaen & Poot, 2006), including surgery, mental health, cardiac and diabetes care. It is increasingly being used in cancer care (Macartney, Stacey, Carley, & Harrison, 2012; Stacey, Bakker, Green, Zanchetta, & Conlon, 2012) and in the delivery of symptom management interventions (Badger et al., 2005; Barsevick et al., 2004). However, patient and professional preferences for face-to-face support (Kimman, Dellaert, Boersma, Lambin, & Dirksen, 2010) and resistance to adopt remote communication technologies (i.e. e-mail, mobile phone text message and computer-generated calls) (Kleiboer et al., 2010) highlight potential conflict regarding the best method of providing support for patients.

Under the philosophy of patient-centred care, a focus on patients' needs, perspectives and experiences (Epstein et al., 2005) is crucial. Patient satisfaction with care and services is central to evaluating service quality (Martin, Nelson, Lloyd, & Nolan, 2007). Demonstrating satisfaction, however, is not straightforward. Systematic reviews of interventions for cancer patients tend to focus wholly or predominantly on intervention efficacy (Rueda et al., 2011; Scott et al., 2013). A recent systematic review (Dickinson, Hall, Sinclair, Bond, & Murchie, 2014) examining patient satisfaction with technology use for cancer follow-up reports only quantitative data. In-depth qualitative syntheses of patient perspectives are lacking. Where patient perspectives on acceptability have been considered, the term has often been inter-mixed with concepts of "utility" (Clark, Inglis, McAlister, Cleland, & Stewart, 2007), "benefit" or "feasibility" (Campbell et al., 2007) and "value" (Castro, Mitchell, Rowe, & Jacobs, 2007). Working definitions of these different constructs are rarely stated, highlighting a blurring of the terms used to elicit patient experiences, and variability in their application as both concepts and outcomes to be measured.

The literature lacks a comprehensive synthesis of patient's perceptions of telephone as a method of providing support for cancer patients both during and after treatment and of the different research strategies that have been used to measure this concept.

2 | AIMS

The aim of this review was to systematically identify and synthesise published literature reporting on patient satisfaction and acceptability of support delivered by telephone for cancer during or post-therapy.

The objectives for the study were to (1) identify the size and nature of the international evidence base, (2) assess its methodological quality and (3) synthesise the availability to generate a preliminary framework of patients perceptions of satisfaction and acceptability with telephone-based interventions.

3 | METHODS

3.1 | Inclusion criteria

Studies were included in the review if they described:

1. Data relating to cancer patients perceptions of the acceptability of, or satisfaction with, a healthcare professional (HCP)-initiated telephone intervention. Acceptability and satisfaction were defined as opinions, beliefs, views, attitudes, impressions, experience or perceptions. It is recognised that these are individual but related concepts and all articles with such terms were screened for inclusion in the review in order to capture pertinent literature.
2. ≥75% of patients were over 18 years of age,
3. Receiving the intervention during or after treatment for cancer and
4. The study was published in English language.

As the overall aim of the systematic review was to look at acceptability of telephone support as perceived by patients, traditional hierarchies of evidence for intervention effectiveness did not apply. As such, a wide variety of sources were included in the search. This included randomised controlled trials (RCTs), controlled and uncontrolled studies, qualitative studies and theses. Due to concerns regarding study generalisability, individual case studies and conference proceedings were excluded. Study inclusion and exclusion criteria are summarised in Table 1.

3.2 | Search strategy

A systematic search of 13 electronic databases was performed (Table 2) in March 2013 and updated on 17 September 2014. The search strategy used key words (Table 3) and identified from a prior scoping exercise and via discussion within the clinical academic and research team. A condensed list of generic search terms (Table 4) were used for searches performed in the UKCRN Clinical Trials Portfolio and NIH Clinical Trials Databases. Reference lists of articles were also checked for potentially eligible studies.

3.3 | Selection of studies

Following the search, a title and abstract screening was performed. All articles were screened for inclusion by one reviewer (S.L.). An attempt to contact study authors was made where it was unclear whether the study met the inclusion criteria. Reasons for study exclusion are summarised in Table 5. Articles identified as eligible for inclusion by one reviewer were independently reviewed by all other researchers to verify eligibility. The study selection process is shown in Figure 1.

3.4 | Data extraction

A study-specific a priori data extraction template was created in order to extrapolate key data of interest. This pro-forma covered (1) study type, (2) data source, (3) study quality indicators, (4) study population

TABLE 1 Study inclusion/exclusion criteria

Inclusion criteria		Exclusion criteria
Participant related	≥75% of patients (any gender) aged ≥18 years old (no upper age limit) Clinical diagnosis of cancer (any type)	Support not instigated by the service provider, i.e. where participants call in to a helpline
Treatment related	Cancer treatment is defined as surgery, chemotherapy, radiotherapy, immunotherapy or biological therapies, hormonal therapies, radio-immunotherapy, stem cell transplant, bone marrow transplant, photodynamic therapy or radiofrequency ablation Studies evaluating telephone interventions during or post-cancer treatment only	Telephone intervention not related to cancer treatment (i.e. smoking cessation) Use of automated voice response systems (not personal interactions)
Intervention related	Telephone intervention providing support for physical or psychosocial issues related to cancer or cancer treatment. For the purpose of this review, support is defined as psychological, social, emotional, information support or monitoring Delivered by any qualified healthcare professional At least one telephone call initiated by a healthcare professional who is specified to be individually involved in the treatment/care of the patient	Studies not in English language (due to time and resource constraints) Proxy reports of patient satisfaction (i.e. healthcare professionals or carers reporting satisfaction)
Type of study	Published studies providing data relating to any of the outcome concepts will be included (including RCTs, controlled and uncontrolled studies, qualitative studies, theses, but not conference proceedings or individual case studies)	
Type of outcomes	Perceptions of patients as service users Reporting acceptability of telephone as a means of support/intervention delivery in any part of the document. For the purpose of this review, acceptability is defined as acceptance, acceptability, satisfaction with, opinions, beliefs, views, attitudes, impressions, experience or perceptions of patients having participated in a telephone intervention	

TABLE 2 Databases searched

Database
PUBMED
EMBASE (1974 to present)
PsychINFO (1989 to present)
MEDLINE (1948 to present)
CINAHL (1981 to present)
British Nursing Index (1985 to present)
Cochrane Library
Web of Knowledge
ASSIA (Applied Social Sciences Index and Abstracts)
AMED (Allied and Complementary Medicine Database—includes palliative care)
TRIP (Turning Research into Practice) Database
UKCRN clinical trials portfolio
NIH Clinical trials database

(recruitment context, methods, study inclusion and exclusion criteria, number receiving the intervention, number asked about acceptability and providing data), (5) participant characteristics (diagnosis, sex, age, cancer treatment received), (6) intervention description, (7) quantitative acceptability outcome measures and (8) qualitative acceptability data. Qualitative data were extracted at the level of themes identified and reported within the text of the primary paper. All studies were subject to double-blind extraction to ensure accuracy; discrepancies were resolved via team discussion and return to the original paper when required.

3.5 | Quality assessment

Acceptability and satisfaction are two related constructs that can be both quantitatively and qualitatively explored. In this review, the gold standard for research was set as a qualitative investigation or an open-ended question schedule that allowed for patient opinions to be expressed in depth and without limitation, either as a stand-alone study or nested within another study design. Studies using closed-question or a priori designed questionnaires were deemed to be of lower quality due to the potential lack of opportunity for patient-centred perceptions to spontaneously emerge. Each study was initially assessed on the basis of whether (1) qualitative data/open-ended questions were used and (2) sufficient data were provided to support the findings. Items were scored "yes" or "no" on each criterion and studies were provisionally considered as high quality if they fulfilled both these criteria. Within the higher quality category (i.e. traditional qualitative studies), critical appraisal of individual study quality was then performed (Table 6).

Randomised controlled trials reporting patient satisfaction outcomes in both intervention and comparison arms were assessed against the Cochrane Collaboration Risk of Bias Assessment Tool for RCTs (Higgins & Green, 2011). Non-RCT (nRCT), single-group designs were assessed against the relevant Cochrane guidance (Higgins & Green, 2011). RCTs or nRCTs providing intervention group only

TABLE 3 Search terms for the systematic review

Search words	Search term	Terms covered
Diagnostic terms		
Cancer	cancer*	Cancer/cancerous/cancers
	neoplasm*	Neoplasm/neoplasms
	carcinoma*	Carcinoma/carcinomas
	tumour*	Tumour/tumours
	adenocarcinoma*	Adenocarcinoma/adenocarcinomas
	tumor*	Tumor/tumors
	malignan*	Malignant/malignancy
	oncolog*	Oncology/oncological
Treatment terms		
Treatment	surg*	Surgery/surgical
	*ectomy	Lumpectomy/prostatectomy....
	chemotherap*	Chemotherapy/chemotherapies/chemotherapeutic
	radiotherap*	Radiotherapy/radiotherapies
	immunotherap*	Immunotherapy/immunotherapies
	biological AND therap*	biological therapy/therapies
	hormon* AND therap*	hormone/hormonal AND therapy/therapies
	radioimmuno* AND therap*	radioimmunotherapy radioimmunotherapies
	stem AND cell AND transplant*	stem cell transplant/stem cell transplantation
	bone AND marrow AND transplant*	bone marrow transplant/bone marrow transplantation
	hematopoietic AND stem AND cell AND transplant	hematopoietic stem cell transplant/haematopoietic stem cell transplantation
	photodynamic AND therap*	photodynamic therapy/therapies
	radiofrequency AND ablation	radiofrequency ablation
	treatment	treatment
Intervention terms		
Intervention	phone/telephone/mobile phone/mobile telephone remote/non-face-to-face/distance	
Support terms		
Support	monitor*	Monitor/monitored/monitoring
	follow-up follow AND up	
	information* AND support	Information
	social AND support	
	psych* AND support	Psychological/psychosocial
	emotion* AND support	Emotion/emotions/emotional
Acceptability terms		
Acceptability/ satisfaction	accepta*	Acceptable/acceptability/acceptance
	adequa*	Adequate/adequacy/adequateness
	satisf*	satisfaction/satisfy/satisfied/satisfactory
	opinion*	opinion/opinions
	belief*	belief/beliefs
	view*	view/views
	attitude*	attitude/attitudes
	impression*	impression/impressions
	experience*	experience/experiences
	perception*	perception/perceptions
	uptake	uptake
	barrier*	barrier/barriers
	valu*	value/values

TABLE 4 Search terms used for specific databases

Database	Search words
TRIP terms	phone OR telephone OR mobile OR remote OR distance AND Cancer
UKCRN clinical trials portfolio	Type: cancer Any of the following: phone OR telephone OR mobile OR remote OR non-face-to-face OR distance
NIH Clinical trials database	Cancer AND Phone OR telephone OR mobile AND Adult or senior

data were treated as single-group designs and appraised accordingly. Qualitative studies were assessed using the Critical Appraisal Skills Programme (2013) tool.

3.6 | Methods of data synthesis

The articles included in the review were synthesised according to the nature of the acceptability data they provided. Themes identified and reported within the text of qualitative studies were summarised, following the principles of thematic synthesis. Heterogeneity in the populations and measurements used to elicit quantitative data meant that it was not possible to perform a meta-analysis. A narrative synthesis of quantitative data was performed. Some studies provided both forms of data and contributed to both types of synthesis. The data in each section were different and not double counted.

4 | RESULTS

A total of 4,855 records were identified after duplicate removal (total hits n = 10,423, duplicates n = 5,568). Based on title and abstract screening, 4,611 were rejected. Seventy-eight articles were identified following hand search and reference review. A total of 267 full-text articles were reviewed with a further 219 rejected and 48 articles eligible for inclusion (Figure 1). One article described three studies of different patient populations (Heidrich et al., 2009), and for the purpose of this review, the three studies reported are treated separately. Two articles reported on the same intervention with an overlapping time frame of recruitment, and authors confirmed that some patients had been included in both studies. The two articles (Zhang et al., 2013; Zheng, Zhang, Qin, Fang, & Wu, 2013) provided different and complementary forms of data (qualitative and quantitative), and thus, both were included in the review.

4.1 | Study characteristics

The main characteristics of the 50 studies (from 48 articles) are described in Table 7. All studies were conducted in developed countries, predominantly the United States and Canada, the United Kingdom and Australia. Thirty-nine studies reported quantitative data (n = 39). Twenty-four studies provided qualitative data.

Quantitative data were most frequently reported as part of a RCT (n = 17) or single-group designs (n = 16). Qualitative data were collected mainly from stand-alone, single-group designs (n = 11) and nested process evaluations (n = 4).

4.2 | Quality appraisal

The review included both qualitative and quantitative data with qualitative data being seen as superior quality.

4.2.1 | Qualitative data

Of the 24 studies providing qualitative data, six were judged to be of high methodological quality (Archer, Montague, & Bali, 2014; Beaver, Williamson, & Chalmers, 2010; Campbell et al., 2007; Donnelly et al., 2013; Wilmoth, Tulman, Coleman, Stewart, & Samarel, 2006; Zheng et al., 2013), with data collected via well-conducted interviews, open-ended questions or focus groups (Table 6). Three additional studies reported interview but insufficient details regarding study methods or data completeness were provided; these studies were judged lower,

TABLE 5 Summary of excluded articles

Reason for rejection	Number of articles from 1st search	Number of articles from 2nd search
Lack of information to confirm inclusion, e.g. conference proceedings, no further information/data available from authors	12	2
Failed to meet participant criteria, e.g. <75% receiving treatment, no cancer diagnosis, participants not patients	14	8
Failed to meet intervention criteria, e.g. patient initiated calls, not HCP delivered, no telephone intervention, videophone, telemedicine, telephone for data collection not intervention	44	19
Failed to meet outcome criteria, e.g. not patient perceptions, not satisfaction data, no results	54	27
Other, e.g. not primary research studies, data in another article	34	5
Total number of articles rejected	158	61

HCP, healthcare professional.

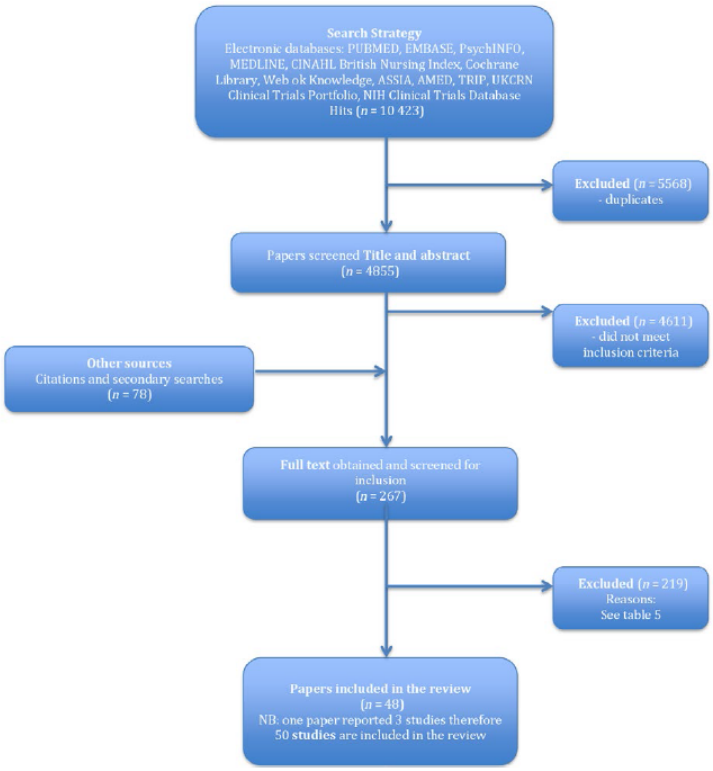


FIGURE 1 Study selection process

or at best unclear, quality (Kilbourn et al., 2013; Livingston et al., 2010; Young et al., 2013).

The remaining studies providing qualitative data (n = 15) included the use of open-ended questions that focused on only one pre-defined aspect of the intervention (Badger, Segrin, Pasvogel, & Lopez, 2013), and/or data collection methods relying on written questionnaires, feedback or comments where there was insufficient evidence to confirm completeness of data reporting. These studies were also judged to be of lower quality data (Alter et al., 1996; Badger et al., 2013; Booker et al., 2004; Cimprich et al., 2005; Cox et al., 2008; Dixon, 2010; Hafiji, Salmon, & Hussain, 2012; Hagopian & Rubenstein, 1990; Inman, Maxson, Johnson, Myers, & Holland, 2011; Kelly, Faught & Holmes, 1999; Smithies, Bettger-Hahn, Forchuk, & Brackstone, 2009; Steginga, Ferguson, Clutton, Gardiner, & Nicol, 2008; Young et al., 2010).

4.2.2 | Quantitative data

Quantitative data was provided in 39 studies of which only two studies used validated measures—the Ware's Patient Satisfaction Questionnaire III (Kimman, Bloebaum, et al., 2010) and the Satisfaction and Experience of Care Questionnaire (Cox et al., 2008). All other quantitative studies (n = 37) used adapted scales or (Beaver et al., 2012; Cox, Wilson, Arthur, Elkan, & Armstrong, 2005; Leahy et al., 2013; Salonen et al., 2009) or unvalidated tools specifically designed for the study (n = 34, 87%). Likert scales were used in 21/39 studies (54%), with patients responding to set statements on ordinal scales of agreement or disagreement. The number of items used to assess satisfaction was reported in 24/39 studies (62%), with a median of four items per outcome measure (range 1–42). The majority of studies provided details of the questions asked (11/39, 28%) or some information about which topics were covered (24/39, 62%); these were determined a priori by research teams with no evidence of bottom-up, patient-led development. A summary of acceptability and satisfaction data quality is provided in Table 8.

4.3 | Sample sizes

The RE_AIM framework (Glasgow, Vogt, & Boles, 1999) identifies the reach of health behaviour interventions as an important factor influencing the implementation of research findings into practice. Reach is defined as the number, proportion and representativeness of individuals who are willing to participate in any given intervention. As such, it represents a partial assessment of intervention acceptability and an indicator of potential selection bias in study samples.

Study participation rates and sample representativeness were inconsistently reported. Sample size was variously defined, and

TABLE 6 Overall study quality. (A) Tabulated data from study quality assessment of bias in RCTs and non-RCTs providing quantitative acceptability/satisfaction data from all cohorts (based on Cochrane Collaboration Risk Bias of Assessment Tool for RCTs and for nRCTs, Higgins & Green, 2011). (B) Tabulated data from study quality assessment of bias in RCTs, non-RCTs and single-group studies providing quantitative acceptability/satisfaction data from the intervention group only (based on Cochrane Collaboration Risk Bias of Assessment Tool for nRCTs, Higgins & Green, 2011). (C) Tabulated data from study quality bias assessment of studies providing high-quality qualitative data (Critical Appraisal Skills Programme (CASP) tool, Critical Appraisal Skills Programme, 2013)

(A)

First author/date	Sequence generation	Random allocation	Selection bias (nRCTs)	Performance bias (intervention)	Attrition reporting	Outcome reporting	Completeness of data reporting	Overall study quality
RCTs								
Badger et al. (2013)	H	H	N/A	L	H	H	H	L
Beaver et al. (2009)	L	L	N/A	L	L	L	L	H
Beaver et al. (2012)	L	L	N/A	H	L	H	L	M
Hegel et al. (2011)	H	H	N/A	L	L	H	H	M
Heidrich et al. (2009) Pilot Study 1	H	H	N/A	L	L	H	U	M
Heidrich et al. (2009) Pilot Study 2	H	H	N/A	L	L	H	U	M
Kimman, Bloebaum, et al. (2010), Kimman, Dellaert, et al. (2010)	L	L	N/A	L	H	L	L	H
Munro et al. (1994)	U	U	N/A	L	L	L	L	M
Non-RCTs								
Hafiji et al. (2012)	N/A	N/A	H	L	U	U	U	L
Leahy et al. (2013)	N/A	N/A	U	L	H	L	H	M

(B)

First author/date	Selection bias	Performance bias (intervention)	Attrition reporting	Outcome reporting	Completeness of data	Overall study quality
Anderson (2010)	H	L	L	H	H	M
Barsevick et al. (2002)	H	L	U	H	H	L
Booker et al. (2004)	H	U	L	U	U	L
Cimprich et al. (2005)	L	L	L	U	U	M
Cirillo et al. (2014)	U	U	U	H	H	L
Cox et al. (2005)	H	L	U	H	H	L
Cox et al. (2008)	H	L	U	L	L	M
Craven et al. (2013)	H	L	L	U	U	L
Delaney et al. (2009)	H	L	L	H	L	M
Garrett et al. (2013)	H	U	H	U	U	L
Hagopian and Rubenstein (1990)	H	L	U	H	H	L

Continues

TABLE 6 (Continued)

(B)

First author/date	Selection bias	Performance bias (intervention)	Attrition reporting	Outcome reporting	Completeness of data	Overall study quality
Heidrich et al. (2009) Pilot Study 3	H	L	U	H	H	L
Inman et al. (2011)	U	L	L	U	L	M
Jensen et al. (2011)	U	U	L	L	L	M
Kelly et al. (1999)	H	L	H	H	H	L
Kilbourn et al. (2013)	H	L	U	L	L	M
Kim et al. (2011)	L	L	L	H	L	M
Livingston et al. (2010)	H	L	L	L	U	M
Marcus et al. (1993)	H	H	L	U	U	L
Marcus et al. (2010)	H	L	U	L	L	M
Mordenti et al. (2013)	H	H	U	L	L	L
Reese et al. (2012)	H	L	L	L	L	M
Reese et al. (2014)	U	L	L	H	H	M
Salonen et al. (2009)	H	H	L	U	L	M
Sandgren et al. (2000)	U	L	U	L	L	M
Sardell et al. (2000)	H	L	L	U	H	M
Smithies et al. (2009)	H	L	L	U	H	M
Steginga et al. (2008)	H	L	L	H	H	M
Young et al. (2010)	H	L	L	H	H	M
Young et al. (2013)	L	L	L	U	U	L
Zhang et al. (2013)	L	L	U	L	L	H

(C)

Author/date	Appropriate methodology	Appropriate design	Data collection methods	Data saturation	Researcher role in question formulation	Researcher role in data collection	Analysis	Rigour	Sufficient data	Clear findings	Findings discussed in relation to the original research question	Overall study quality
Archer et al. (2014)	L	L	L	H	H	L	L	H	L	L	L	M
Beaver et al. (2010)	L	L	L	U	U	U	L	L	L	L	L	H
Campbell et al. (2007)	L	H	L	H	H	H	L	L	L	L	L	H
Donnelly et al. (2013)	L	L	L	H	L	L	L	L	L	L	L	H
Wilmoth et al. (2006)	L	L	L	H	L	H	L	L	L	L	L	H
Zheng et al. (2013)	L	L	L	L	H	H	L	L	L	L	L	H

N/A, not applicable; H, high; L, low; M, medium; U, unclear.

TABLE 7 Patient and study characteristics

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Alter et al. (1996), USA *Medium*	Colorectal cancer patients receiving CT *N* = 8 Range 59–79 years (TSS only) 63% male Recruited via oncologist NOS	Quasi-experimental: single group Interpersonal counselling 4 sessions biweekly over 8 weeks Semi-structured technique Nurse led	Feasibility Discussion of intervention: NOS	6 weeks after end of study AD: *N* = 7 (88%)	Qual (low)
Anderson (2010), UK *Medium*	Prostate cancer patients receiving various treatments *N* = 67 Range 67–97 years (TSS only) 100% male Recruited via OP oncology clinic	Non-experimental: single group Telephone FU for symptom and PSA monitoring 3, 6 or 12 monthly Intervention followed specific guideline Nurse led	Satisfaction Likert scale–12 q's (provided) Not validated	Patients still receiving intervention AD: *N* = 43 (64%)	Quant (low)
Archer et al. (2014), UK *Medium*	Gynaecological cancer patients post-surgery *N* = 34 Mean 66 years (range 53–80) 0% male Recruited via regional cancer centre	Non-experimental: single group Enhanced Recovery Team telephone call post–discharge: NOS Structure NR Enhanced Recovery Team: NOS	Experience Semi-structured interviews: NOS	Post-intervention NOS AD: *N* = 14 (41%)	Qual (high)
Badger et al. (2013), USA *Low*	Breast cancer patients receiving treatment: NOS *N* = 51 (TSS only) Mean (a) 52 years, *SD* 14, (b) 58 years, *SD* 11, (c) 47 years, *SD* 12 (TSS only) 0% male Recruited via local cancer centre, oncologists offices, support groups, self-referral	RCT-3 groups (patient and dyad) (a) Telephone Health Education (*n* = 18) (b) Telephone Interpersonal Counselling (*n* = 20) (c) Video Interpersonal Counselling (*n* = 13) 8 weekly sessions for patients (4 biweekly sessions for dyads) Protocol for counselling stated to be the same (a) Information specialist, (b) & (c) Social Worker	Satisfaction Open-ended questions (topic provided): NOS	End of intervention period AD: (a) THE *N* = 9 (50%) (b) TIC *N* = 18 (90%) (c) VIC *N* = 13 (100%)	Qual (low)
Barsevick et al. (2002), USA *Low*	Breast, lung, colon, prostate cancer patients receiving CT or RT (a) Intervention *N* = 80, (b) Ctrl *N* = 182 Age NR/ Gender NR Recruitment NR	nRCT: 2 groups (a) Energy conservation and activity management for patients developing fatigue 3 sessions weekly (over 3 weeks in CT group and 5 weeks in RT group) Semi-structured technique Nurse led (b) Standard care	Acceptability/helpfulness Interview with 10 closed q's (topics provided) Not validated	End of study (NOS) AD: Intervention group only *N* = 64 (80%)	Quant (low)

Beaver et al. (2009), UK
High
	Breast cancer patients post-surgery/receiving RT/CT
	(a) Intervention *N* = 191, (b) Ctrl *N* = 183
	Mean 63 years, *SD* 10.1 (TSS only)/
	0% male
	Recruited via DGH or Breast Cancer Unit
		RCT: 2 groups
		(a) Telephone FU: general and symptom monitoring, support, long-term issues
		Timing in line with standard FU
		Structured intervention
		Nurse
		(b) Standard hospital FU
			Satisfaction
			Questionnaire designed and piloted: NOS
			Not validated
				Start, mid and end of study
				AD: (a) Intervention
				mid trial *N* = 138 (72%);
				end trial *N* = 154 (81%)
				(b) Ctrl
				mid trial *N* = 121 (66%);
				end trial *N* = 145 (79%)
					Quant (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Beaver et al. (2010), UK *High*	Breast cancer patients receiving surgery, RT or CT *N* = 28 Mean 61 years (range 48–80) (TSS only)/0% male Computer selected random sample of patients receiving a telephone intervention	Nested: single group Telephone FU: general and symptom monitoring, support, long-term issues Timing in line with standard FU Structured intervention Nurse led	Explore and describe views Semi-structured interviews (topics provided)	Timing of assessment not reported AD: *N* = 28 (100%)	Qual (high)
Beaver et al. (2012, UK *Medium*	Colorectal cancer patients receiving RT, CT or surgery (a) Intervention *N* = 31, (b) Ctrl *N* = 31 Mean (a) Intervention 73.6 years, *SD* 7.6; (b) Ctrl 72.4 years, *SD* 8.2 (a) Intervention 64% male, (b) Ctrl 52% male Recruited via hospital OP department	RCT: 2 groups (a) Telephone FU: general and symptom monitoring, support, long-term issues Timing in line with standard FU Structured intervention Nurse led (b) Standard hospital FU	Satisfaction Adapted Likert scale (topics provided) Not validated Likert scale: overall satisfaction Not validated	Baseline and one additional time point (chosen to maximise number of sessions received) AD: (a) Intervention *N* = 25 (80%) (b) Ctrl *N* = 25 (80%)	Quant (low)
Booker et al. (2004), UK *Low*	Prostate cancer patients post-RT *N* = 36 Age NR 100% male Recruited via tertiary referral centre (convenience sample)	Non-experimental: single group Telephone FU: symptom monitoring, addressing concerns, information provision Timing/duration NR Structured interview and pro forma Nurse led	Acceptability Closed q's (topics provided) Not validated Comments (qual data)	After telephone FU call AD: *N* = 36 (100%)	Quant (low) Qual (low)
Campbell et al. (2007), USA *High*	Prostate cancer patients (and partner) post-prostatectomy or receiving HT or WW (a) Intervention *N* = 15, (b) Ctrl *N* = 18 Mean 59.8 years, *SD* 8 100% male Recruited via urology clinic or self-referral from community	RCT: 2 groups (a) Coping skills training: education, training, information, problem solving, motivation and coping skills 6 sessions weekly (over 6 weeks) Structured intervention with outline for each session Psychologist led (b) Standard care	Experience 1 open-ended question (provided)	After final session Intervention only AD: Intervention group only *N* = 15 (100%)	Qual (high)
Cimprich et al. (2005), USA *Medium*	Breast cancer patients receiving surgery, RT or CT combinations (a) Intervention *N* = 25, (b) Ctrl *N* = 24 Mean 48 years, *SD* 8 0% male Recruited via cancer centre or oncology clinic	RCT: 2 groups (a) Self-management and survivorship programme teaching skills, addressing concerns, providing information 4 sessions biweekly over 8 weeks (2 group sessions, 2 telephone sessions) Structured intervention with manual Nurse + health educator led (b) Standard care	Usefulness Likert scale 1 q (topic provided) Not validated 2 open-ended q's (topic provided) & comments	At end of 4th (final) session AD: Intervention group only *N* = 22 (88%)	Quant (low) Qual (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Cirillo et al. (2014), Italy *Low*	Variety cancer patients receiving CT or targeted agents *N* = 81 Mean 68 years (range 33–91) (TSS only) 46% male (TSS only) Recruited via medical oncology department	Quasi-experimental: Single group Patient monitoring service: information and support for side-effect management Phone calls at days 7 and 14 after 1st treatment, then at day 14 of 2nd treatment (additional 2 face-to-face clinic visits) Patient self-reported questionnaire as basis Nurse led	Usefulness Rating scale: NOS Not validated	Timing of assessment NR AD: *N* = 63 (78%)	Quant (low)
Cox et al. (2005), UK *Low*	Variety cancer patients having received anticancer therapy: NOS (a) Intervention *N* = 47, (b) Ctrl *N* = 58 Mean 59.8 years, *SD* 11.6 (TSS only) 53% male Recruited via 2 cancer centres	RCT: 2 groups (a) Trial exit intervention: information provision and emotional support 2 sessions, 2 weeks apart (one session face-to-face) Structured intervention following trial feedback sheet Research Nurse led (b) Standard care	Satisfaction Adapted MISS (26 items) Not validated	7–10 days post-trial AD: Intervention group only *N* = 44 (93%)	Quant (low)
Cox et al. (2008), UK *Medium*	Ovarian cancer patients having completed initial cancer treatment: NOS *N* = 52 Mean 62 years, *SD* 10.89 0% male Recruitment NR	Quasi-experimental: Single group Telephone FU post-treatment: monitoring, information provision, support, practical advice, coping strategies 3 sessions, once every 3 months over 10 months Structured intervention with checklist Nurse led	Satisfaction Likert scale (4 domains provided) Validated in other studies Open section on general views of care experienced: NOS	End of 10-month period AD: *N* = 46 (100%)	Quant (low) Qual (low)
Craven et al. (2013), UK *Low*	Colorectal cancer patients receiving targeted agents *N* = 30 (random sample of 298 receiving intervention) Mean 67.3 years, *SD* 11.3 (TSS only) 54% male (TSS only) Recruited via large cancer centre	Non-experimental audit: single group Telephone FU: monitoring, toxicity management, evaluation, support Phone calls at days 3 and 10 after 1st treatment, then at day 10 of 2nd treatment Protocol to be followed Colorectal cancer nurse specialist led	Satisfaction/Use/ Helpfulness Questionnaire (topics provided) Not validated	Nurse-led FU ongoing AD: *N* = 30 (*n* = 298 already receiving intervention)	Quant (low)
Delaney et al. (2009), Canada *Medium*	Neurological cancer patients post-RT/CT *N* = 13 Median 66 years (range 45–67) (TSS only) 77% male (TSS only) Recruited via neuro-oncology OP clinic	Quasi-experimental: Single group Education and support in CT administration, side-effect management, supportive therapy, medication interactions and questions 3 sessions; 1 hospital visit and calls at 1 and 5 days later (one session face-to-face) Standardised counselling Pharmacist led	Feasibility/Usefulness Likert scale 2 q's (provided) Not validated	End of study: NOS AD: *N* = 11 (85%)	Quant (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Dixon (2010), Canada *Low*	Variety cancer patients post-RT *N* = 53 Mean 69 years (TSS only) 63% male (TSS only) Recruitment NR	Quasi-experimental audit: Single group Telephone FU post–RT: monitoring of side effects/ information provision 2 sessions 1 and 4 weeks post-RT Structured intervention (ESAS) Radiation therapist led	Feedback/satisfaction Comments during telephone calls	During intervention: NOS AD: *N* = 38 (72%)	Qual (low)
Donnelly et al. (2013), UK *High*	Gynaecological cancer patients having completed or receiving treatment: NOS (patients having participated in RCT) *N* = 31 Mean 55 years (range 38–78) 0% male Recruited following invitation to all patients involved in RCT	Nested: sample from 2 groups (a) Telephone contact: symptom checklist (b) Telephone contact + physical activity programme: levels of activity, barriers, goals, symptom checklist Weekly telephone calls: NOS: over 12 weeks NR: Telephone component Physiotherapist: Activity Programme	Experiences Focus groups: open-ended questions (topics provided)	Timing of assessment NR AD: *N* = 16 (52%)	Qual (high)
Garrett et al. (2013), USA *Low*	Variety cancer patients receiving surgery, CT or RT *N* = 66 Range 20–69 years 48% male Recruited via oncology clinics and rural community cancer centre	Quasi-experimental: single group Cancer Survivor Telephone Education and Personal Support Programme (C-STEPS): Choice to participate in either/both modules: Uncertainty and Stress Management/Healthy Diet & Physical Exercise 6 weekly sessions Semi-structured intervention following worksheet Occupational therapist led	Satisfaction/Helpfulness Likert scale questionnaire (topics provided) Not validated	After completion of programme: NOS AD: *N* = 46 (70%)	Quant (low)
Hafiji et al. (2012), New Zealand (NZ) & UK *Low*	Non-melanoma skin cancer patients post-surgery (a) Intervention *N* = 187, (b) Ctrl *N* = 54 Mean (a) Intervention 64.5 years (range 21–91) NZ, mean 64.8 years (range 20–90) UK, (b) Ctrl mean 64.5 years (range 34–87) (a) Intervention 57% male, (b) Ctrl 56% male Recruited via 2 regional MMS centres	nRCT: 2 groups (a) Telephone call: monitoring, information provision 1 call: the evening post-surgery Semi-structured: specific and open q's Surgeon led (b) Standard care	Satisfaction/perception Likert scale: NOS Not validated Comments/feedback from patients	5–7 days after phone call AD: Intervention *N* = 187 (% unclear) Ctrl *N* = 54 (% unclear)	Quant (low) Qual (low)
Hagopian and Rubenstein (1990), USA *Low*	Variety cancer patients receiving RT (a) Intervention *N* = 27, (b) Ctrl *N* = 28 Mean 58 years (range 22–84) (TSS only) 33% male (TSS only) Recruited via hospital RT Department	RCT: 2 groups (a) Telephone FU during RT: side-effect monitoring, information, anticipatory guidance, coping strategies, address concerns Weekly, continuing 4–6 weeks post-RT Semi-structured, standardised set of topics Nurse led (b) Standard care	Satisfaction/Helpfulness Questionnaire: NOS Not validated Comments from patients	Timing assessment NR AD: Intervention group only *N* = 18 (55%)	Quant (low) Qual (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Hegel et al. (2011), USA *Medium*	Breast cancer patients receiving CT (a) Intervention *N* = 14, (b) Ctrl *N* = 15 Mean 52.6 years, *SD* 9.4 0% male Recruited via cancer centre OP clinic	RCT: 2 groups (a) Problem-solving information provision, motivating, goal setting, support and problem solving 6 weekly sessions Semi-structured intervention following work sheet Occupational therapist led (b) Standard care	Acceptability/ Satisfaction Likert scale 2 q's (topics provided) Not validated	6 weeks after the end of the intervention AD: Intervention *N* = 9 (64%) Ctrl *N* = 15 (100%)	Quant (low)
Heidrich et al. (2009), USA *Medium* *Medium* *Low*	Breast cancer patients receiving surgery, CT, RT, HT combinations (a) Intervention *N* = 20, (b) Ctrl *N* = 21 Mean 72.5 years (range 68–86) 0% male Recruited via cancer centre OP clinic + community advertising	Pilot Study 1: RCT: 2 groups (a) Individualised Representational Intervention to Improve Symptom Management: support, symptom monitoring, management plan and strategies, information provision 5 sessions (baseline, 2, 4, 6 and 8 weeks later) (Baseline session face to face) Protocol-driven intervention Nurse led (b) Standard care	Acceptability/ Satisfaction 8 q's (topics provided) Not validated	At 6 and 10 weeks post-intervention AD: Intervention *N* = 20 (100%) Ctrl *N* = 21 (100%)	Quant (low)
	Breast cancer patients receiving surgery, CT, RT, HT combinations (a) Intervention *N* = 9, (b) Ctrl *N* = 11 Mean 69.7 years (range 65–82) 0% male Recruited via cancer centre OP clinic + community advertising	Pilot Study 2: RCT: 2 groups (a) Individualised Representational Intervention to Improve Symptom Management: support, symptom monitoring, management plan and strategies, information provision 5 sessions (baseline, 2, 4, 6 and 8 weeks later) (Baseline session face to face) Protocol-driven intervention Nurse led (b) Standard care	Acceptability/ Satisfaction 8 q's (topics provided) Not validated	At 2, 4, 6, 8 and 16 weeks AD: Intervention *N* = 9 (100%) Ctrl *N* = 11 (100%)	Quant (low)
	Breast cancer patients receiving surgery, CT, RT, HT combinations *N* = 20 Mean 67.9 years (range 65–73) 0% male Recruited via cancer centre OP clinic + community advertising	Pilot Study 3: Single group Individualised Representational Intervention to Improve Symptom Management: support, symptom monitoring, management plan and strategies, information provision 5 sessions (baseline, 2, 4, 6 and 8 weeks later) (Baseline session face to face) Protocol-driven intervention Nurse led	Acceptability/ Satisfaction 8 q's (topics provided) Not validated	At 2, 4, 6, 8 and 16 weeks AD: *N* = 20 (100%)	Quant (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Inman et al. (2011), USA *Medium*	Prostate cancer patients post-surgery (a) Intervention *N* = 30, (b) Ctrl *N* = 30 Mean 60.2 years, *SD* 6.99 100% male Recruited via academic centre	RCT: 2 groups (a) Educational Intervention: monitoring, education, information provision 1 session, 3–5 days post-discharge Intervention algorithm for educational reinforcement Nurse led (b) Standard care	Satisfaction/Helpfulness 1 closed q (provided) Not validated Comments from patients during calls	30 days after discharge AD: Intervention group only *N* = 30 (100%)	Quant (low) Qual (low)
Jefford et al. (2011), Australia *Medium*	Colorectal cancer patients receiving surgery, CT, RT, combinations *N* = 10 Mean 55 years (range 35–71) (TSS only) 50% male (TSS only) Recruited via cancer centre	Quasi-experimental: single group Post-treatment support package: education, information provision, monitoring, support, coaching, health promotion 4 sessions (1st at end of treatment, then 1, 3 and 7 weeks later) (one session face-to-face: package included DVD and written information) Semi-structured intervention: manual for 1st session Nurse	Satisfaction Interview: NOS	After 3rd pone call (NOS) AD: *N* = 8 (80%)	Qual (low)
Jensen et al. (2011), Denmark *Medium*	Prostate cancer patients following prostatectomy (a) Intervention *N* = 46, (b) Ctrl *N* = 49 Mean (a) Intervention 64.1 years (95% CI 62.5–65.8), (b) Ctrl 62. 5 years (95% CI 60.9–64. 2) 100% male Recruited via urology centre	RCT: 2 groups (a) Telephone FU: NOS 1 session 3 days after discharge Semi-structured intervention: manual for interview Nurse led (b) Standard care	Satisfaction Likert questionnaire (topic provided): NOS Not validated	2 weeks post-operative AD: Intervention only *N* = 46 (100%)	Quant (low)
Kelly et al. (1999), Canada *Low*	Ovarian cancer patients receiving CT *N* = 50 Age NR 0% male Recruited via OP CT clinic	Non-experimental: single group Telephone FU: symptom monitoring, information provision, support Calls 5–7 days post-CT and once every 3–4 weeks during CT: NOS Semi-structured intervention—assessment tool to follow Nurse led	Benefit/Acceptability/ Helpfulness 4 closed q's (topics provided) Not validated 2 open q's (topics provided) Not validated	Evaluation time point NR AD: *N* = 31 (62%)	Quant (low) Qual (low)
Kilbourn et al. (2013), USA *Low*	Head & neck cancer patients receiving RT *N* = 16 Mean 59.66 years, *SD* 9.78 (TSS only) 76.2% male (TSS only) Recruited via radiation oncology clinic (convenience sample)	Quasi-experimental: single group Easing + Alleviating Symptoms during treatment: stress management, coping skills training, psycho-education to increase understanding of treatment related side effects 2–10 sessions (50% received 4–6 sessions) Structure NR Psychologist led	Satisfaction Likert scale 2 q's (topics provided) Not validated Exit interviews: NOS	Evaluation time point NR AD: Process evaluation *N* = 11 (69%) Qualitative interviews *N* = 8 (50%)	Quant (low) Qual (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Kim et al. (2011), South Korea *Medium*	Breast cancer patients receiving surgery, RT, CT or HT (a) Intervention *N* = 23, (b) Ctrl *N* = 22) Mean (a) Intervention 44.6 years (range 26–69), (b) Ctrl NR (TSS only) 0% male Recruited via cancer centre	RCT: 2 groups (a) Individualised diet and exercise counselling: monitoring, motivation, support, information provision 12 weekly sessions Semi-structured: use of telephone counselling protocol Nurse led (b) Standard care	Feasibility/Helpfulness Likert scale (topics provided) Not validated	Baseline and 12 weeks after intervention AD: Intervention group only *N* = 14 (61%)	Quant (low)
Kimman, Bloebaum, et al. (2010), Kimman, Dellaert, et al. (2010), The Netherlands *High*	Breast cancer patients receiving surgery, RT, CT or HT Study compared hospital FU groups (Ctrl a) + (c) vs. telephone FU groups (Intervention b) + (d) b + d) Intervention *N* = 120, a + c) Ctrl *N* = 149 Mean b+d) Intervention 55 years, *SD* 9, (TSS only) a + c) Ctrl 56 years, *SD* 10.7 0% male Recruited via 7 hospitals + 2 RT clinics	RCT: 4 groups a) Standard hospital FU: 4 sessions, 3monthly b) Telephone FU: 4 sessions, 3 monthly c) Hospital FU + Educational Group Programme 2 EGP sessions within 3 months after treatment d) Telephone FU + Educational Group Programme 4 sessions, 3 monthly and 2 EGP sessions within 3 months after treatment (Telephone FU: symptom monitoring, treatment side-effect management, drug compliance) (Educational Group Programme: education, information coping strategies, group discussion) (Groups c) + d) received 2 group sessions) Structured educational group sessions Nurse-delivered telephone FU Nurse + psychologist-delivered EGP	Satisfaction PSQIII Validated	Baseline, 3, 6 and 12 months post-treatment AD: Intervention *N* = 120 (100%) Ctrl *N* = 149 (100%)	Quant (low)
Leahy et al. (2013), Australia *Medium*	Prostate cancer patients receiving HT, RT, brachytherapy, prostatectomy or WW (a) Intervention *N* = 86, (b) Ctrl *N* = 83 Mean (a) Intervention 68.4 years (range 49–80), (b) Ctrl 70.2 years (range 55–82) 100% male Recruited via cancer centre OP clinics	nRCT: 2 groups (a) Telephone FU: general and symptom monitoring, PSA level review, information provision Once every 6 months: NOS Structured intervention following evidence-based algorithms Nurse led (b) Standard care	Satisfaction Adapted Satisfaction with Consultation Scale Not re-validated	1 week after intervention AD: Intervention *N* = 86 (100%) Ctrl *N* = 83 (100%)	Quant (low)
Livingston et al. (2010), Australia *Medium*	Colorectal cancer patients post-CT *N* = 59 Range 30–79 years 63% male Recruited via 6 public + private health services	Quasi-experimental: Single group Screening for depression post-CT: DIT completion, information provision, support, referral to psycho-oncologist 2 sessions (1st 7–10 days post-recruitment, 2nd 4 weeks later) Intervention based on clinical practice guidelines Nurse led	Experience/Perception/ Satisfaction Likert scale questionnaire (topics provided) Not validated Telephone interview with open questions: NOS	1 month after last call AD: *N* = 45 (100%) NR	Quant (low) Qual (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Marcus et al. (1993), USA *Low*	Breast cancer patients post-adjuvant treatment *N* = 30 Mean 49.9 years (range 40–70) 0% male Recruited via 4 hospitals + 1 cancer clinic	Quasi-experimental: single group Telephone counselling: interviews assessing physical and psychosocial concerns: NOS Timing NR Structure NR Counsellor led	Feasibility 1 evaluation indicator (provided) Not validated	Evaluation timing NR AD: *N* = 30 (100%)	Quant (low)
Marcus et al. (2010), USA *Medium*	Breast cancer patients post-treatment (a) Intervention *N* = 152, (b) Ctrl *N* = 152 "About half the sample was 50 years of age or less" (a) Intervention (range <40 to 70+), (b) Ctrl (range <40 to 70+) 0% male Recruited in 21 hospitals and medical centres nationwide	RCT: 2 groups (a) Booklet provided listing psychosocial + rehabilitation services in their community + telephone counselling over 12 months—6 modules: living with uncertainty, physical change, self-change, sexuality, relationships, economic change 16 sessions: 9 sessions at biweekly intervals, 7 sessions monthly Structured: thematic modules, guides, worksheets (prioritised by participant) Psycho-oncology counsellors (b) Booklet provided listing psychosocial + rehabilitation services in their community	Helpfulness Questionnaire on component of intervention which was most helpful (provided) Not validated	End of intervention AD: Intervention group only *N* = 129 (85%)	Quant (low)
Mordenti et al. (2013), Italy *Low*	Patients receiving CT: NOS *N* = 170 Age NR Gender NR Recruitment: consecutive patients invited: NOS	Quasi-experimental: single group Telephone support post-CT: monitoring, education and support One call the 1st day after 1st cycle of CT Structured (3q's) Nurse led	Usefulness Survey (topics provided) Not validated	At the following visit AD: *N* = 170 (100%)	Quant (low)
Munro et al. (1994), UK *Medium*	Variety cancer patients receiving RT (a) Intervention *N* = 49, (b) Ctrl *N* = 51 Mean (a) Intervention 63 years (range 30–87), (b) Ctrl 65 years (range 37–88) Recruited via RT department	RCT: 2 groups (a) Telephone intervention between clinic visits: general, side effect and symptom monitoring, information provision 4 sessions on days 4, 8, 14 and 18 post-RT Semi-structured calls with open-ended q's Radiographer, nurse or doctor led (b) Standard care	Helpfulness Likert scale 1 q (provided) Not validated	4 weeks after RT AD: Intervention *N* = 49 (100%) Ctrl *N* = 51 (100%)	Quant (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Reese et al. (2012), USA *Medium*	Colorectal cancer patients post-surgery, RT/CT combinations (and partners) *N* = 9 Mean 61.6 years, *SD* 14.5 56% male Recruited via cancer centre registry, medical record screening, GI cancer clinic, self- referral	Quasi-experimental: single group Intimacy enhancement programme: education, behavioural skills for coping, improving sexual intimacy, intimacy building activities Weekly sessions over mean 5.1 weeks (*SD* 1.1) Manual provided Agent NR	Acceptability/Ease of participation/Helpfulness Likert scale 4q's (topics provided) Not validated	Evaluation timing NR AD: *N* = 9 (and 9 partners) (100%)	Quant (low)
Reese et al. (2014), USA *Medium*	Colorectal cancer patients post-surgery/on treatment (and partners) (a) Intervention *N* = 10, (b) Ctrl *N* = 8 Mean (a) Intervention 48.7 years, *SD* 11, (b) Ctrl 57.4 years, *SD* 8.4 (a) Intervention 60% male, (b) Ctrl 60% male Recruited via cancer centre registry, medical record screening, GI cancer clinic, self- referral	RCT: 2 groups (a) Intimacy enhancement programme: education, behavioural skills for coping, improving sexual intimacy, intimacy building activities Weekly sessions over mean 4.8 weeks (*SD* 2.5) Manual provided Psychologist led (b) Standard care	Acceptability/Ease of participation/ Helpfulness Likert scale 3q's (topics provided) Not validated	Evaluation timing NR AD: Intervention group only *N* = 10 (and 10 partners) (100%)	Quant (low)
Salonen et al. (2009), Finland *Medium*	Breast cancer patients post-surgery (a) Intervention *N* = 120, (b) Ctrl *N* = 108 Mean (a) Intervention 57 years (range 31–75), (b) Ctrl 56 years (range 24–75) 0% male Recruited via departments of oncology and surgery	nRCT: 2 groups a) Social support: education, information provision, instructions for exercise, support, health education 1 session 1 week post-surgery Semi-structured interview manual Physiotherapist led (b) Standard care	Perception Revised Likert scale [80] Validated 1 open-ended q (topic provided)	Within 2 weeks after discharge AD: Intervention group only *N*=unclear (unclear %)	Quant (low) Qual (low)
Sandgren et al. (2000), USA *Medium*	Breast cancer patients receiving surgery, RT, CT or HT combinations (a) Intervention *N* = 24, (b) Ctrl *N* = 29 Mean (a) Intervention 51.23 years, *SD* 12.5, (b) Ctrl age NR (TSS only) 0% male Recruited via hospital: NOS	RCT: 2 groups a) Cognitive Behavioural Therapy: support, teaching coping skills, managing anxiety and stress, problem solving 10 sessions (weekly for 4 weeks then biweekly) Structure NR Clinical Psychology Masters Candidate led b) Standard care	Value Likert scale 4q's (provided) Not validated	4- and 10-month FU intervals AD: Intervention group only *N* = 24 (100%)	Quant (low)
Sardell et al. (2000), UK *Medium*	Neurological cancer patients receiving surgery or RT *N* = 45 Median 50 years (range 23–69) (TSS only) 67% male (TSS only) Recruited via hospital: NOS	nRCT: 2 groups (a) Telephone FU: general and symptom monitoring, medication issues, support, information, ADL assessment 3 sessions (monthly over 3 months) Semi-structured questionnaire Nurse led (b) Standard care	Satisfaction Satisfaction questionnaire (topics provided) Not validated	Unclear: patients still receiving telephone FU AD: Intervention group only *N* = 22 (49%)	Quant (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Smithies et al. (2009), Canada *Medium*	Breast cancer patients receiving CT *N* = 20 Mean 54 years, *SD* 8.2 0% male Recruited via hospital cancer centre	Quasi-experimental: single group Telephone support post-1st chemotherapy: symptom monitoring, provision of information, support 1 session (average 3 days post-CT, range 1–5) Checklist questionnaire Member of research team, nurse or doctor	Value/Utility Likert scale 1 q (topic provided) Not validated Method NR	Post-consultation: NOS AD: *N* = 20 (100%)	Quant (low) Qual (low)
Steginga et al. (2008), Australia *Medium*	Prostate cancer patients receiving RT, brachytherapy, prostatectomy combinations or WW *N* = 20 Mean 63 years, *SD* 6.7 100% male Recruited via hospital from treating urologist	Quasi-experimental: single group Telephone counselling: decision support, stress management, preparation for treatment, adjustment to cancer, problem solving, coping strategies 4 sessions (2 pre-treatment and at 4 and 7 weeks post) Nurse led Structured counselling protocols	Acceptability Likert scale 1 q (topic provided) Not validated Verbatim responses (topics provided)	2 months post-treatment AD: *N* = 20 (100%)	Quant (low) Qual (low)
Wilmoth et al. (2006), USA *High*	Breast cancer patients receiving surgery, CT, RT, HT or no treatment (a) Intervention *N* = 35, (b) Ctrl *N* = 42 Mean (a) Intervention 57 years, (b) Ctrl 59 years 0% male Sample of patients participating in an RCT with a telephone intervention vs. standard care Recruited via hospital and community: NOS	Nested: subjects from 2 groups (a) Educational materials and telephone social support: information provision Unclear number of telephone sessions (initially weekly, then biweekly, then monthly up to 13 months post-surgery) Semi-structured intervention with manual supporting educational materials Nurse led (b) Standard care + educational materials	Comments about the project Interview with schedule (topics provided)	End of study (13 months) AD: Intervention group only *N* = 35 (100%)	Qual (high)
Young et al. (2010), Australia *Medium*	Colorectal cancer patients post-surgery/receiving adjuvant therapy (a) Intervention *N* = 20, (b) Ctrl *N* = 21 Mean (a) Intervention 66.9 years, (b) Ctrl 64.5 years (TSS only) (a) Intervention 60% male, (b) Ctrl 50% male (TSS only) Recruited via hospital	nRCT: 2 groups (a) Telephone support: general and side-effect monitoring, information provision, emotional support, advice 5 sessions (days 3 and 10, 1, 3 and 6 months post-discharge) Standardised checklist screening for patients needs Nurse led (b) Standard care	Views of content and timing Questionnaire: NOS Not validated	6 months after hospital discharge AD: Intervention group only *N* = 13 (65%)	Quant (low) Qual (low)

(Continues)

TABLE 7 (Continued)

First author/ date/ country/ study quality	Study population *N*/age/% male Recruitment	Study design Intervention intensity/duration/other components/ structure Delivery agent Comparison group(s)	Outcome type Method/instrument	Timing of assessment Acceptability data (AD): *N* providing data (% of total receiving intervention)	Outcome data type (quality)
Young et al. (2013), Australia *Low*	Colorectal cancer patients post-surgery (a) Intervention *N* = 387, (b)Ctrl *N* = 369 Mean (a) Intervention 68.6 years, *SD* 12.2, (b) Ctrl 67.0 years, *SD* 12.1 (a) Intervention 56.8% male, (b) Ctrl 54.2% male Recruitment NR	RCT: 2 groups (a) Telephone support: general and side-effect monitoring, information provision, emotional support, advice 5 sessions (days 3 and 10, 1, 3 and 6 months post-discharge) Standardised checklist screening for patients needs Nurse led (b) Standard care	Views of intervention Likert scale 13 state-ments (provided) Not validated Semi-structured interviews: NOS	Questionnaire at 6 months Every 3 months semi-structured interviews AD: Intervention group only Quantitative *N* = 350 (90%) Qualitative *n* = 29 (7%)	Quant (low) Qual (low)
Zhang et al. (2013), China *High*	Rectal cancer patients post-surgery (a) Intervention *N* = 59, (b) Ctrl *N* = 60 Mean (a) Intervention 52.9 years, *SD* 13.3, (b) Ctrl 55.3 years, *SD* 13.7 (a) Intervention 59.6% male, (b) Ctrl 70.6% male Recruited via regional hospitals	RCT: 2 groups (a) Telephone FU for post-operative adjustment: monitoring, motivation, information provision 1st call 3–7 days post-discharge, 2nd call on days 14–20, 3rd call on days 23–27 Structured programme Nurse led (b) Standard care	Satisfaction Likert scale 1 q (topic provided) Not validated	At 1 and 3 months after discharge AD: Intervention group only *N* = 52 (88%)	Quant (low)
Zheng et al. (2013), China *High*	Colorectal cancer patients post-surgery Random sample of patients receiving telephone intervention (*N* = 59, main study) [31] Recruitment NR	Nested: single group Telephone FU for post-operative adjustment: monitoring, motivation, information provision 1st call 3–7 days post-discharge, 2nd call on days 14–20, 3rd call on days 23–27 Structured programme Nurse	Explore perceptions of telephone FU Semi-structured interviews (topics provided)	Evaluation timing NR AD: *N* = 11 (NR)	Qual (high)

AD, acceptability data; CI, confidence interval; CT, chemotherapy; DGH, District General Hospital; ESAS, Edmonton Symptom Assessment Score; FU, follow-up; HT, hormone therapy; MISS, Medical Interview Satisfaction Scale; MMS, Mohs micrographic surgery; NOS, not otherwise specified; NR, not reported; nRCT, non-randomised controlled trial; OP, outpatient; PSQ III, Ware's Patient Satisfaction Questionnaire III; Qual, Qualitative data; Quant, quantitative data; q's, questions; RCT, randomised controlled trial; RT, radiotherapy; *SD*, standard deviation; THE, telephone health education; TIC, telephone interpersonal counselling; TSS, total sample size; VIC, videophone interpersonal counselling; WW, watch & wait.

TABLE 8 Acceptability/satisfaction data quality: (A) Qualitative data; (B) quantitative data

(A)

First author/date	Qualitative/ open-ended questioning	Sufficient data to support findings	Outcome descriptor	Acceptability data quality
Alter et al. (1996)	Y	N	Discussion of intervention: NOS	Low
Archer et al. (2014)	Y	Y	Semi-structured interviews: NOS	High
Badger et al. (2013)	N	N	Open-ended q's (topic provided)	Low
Beaver et al. (2010)	Y	Y	Semi-structured interviews (topics provided)	High
Booker et al. (2004)	Y	N	Comments	Low
Campbell et al. (2007)	Y	Y	1 q—what was it like to undergo CST by telephone?	High
Cimprich et al. (2005)	Y	U	2 open-ended q's (topics provided)	Low
Cox et al. (2008)	Y	U	Open section on general views of care experienced: NOS	Low
Dixon (2010)	U	U	Comments during telephone calls	Low
Donnelly et al. (2013)	Y	Y	Focus groups with open-ended q's (topics provided)	High
Hafiji et al. (2012)	Y	U	Comments/feedback	Low
Hagopian and Rubenstein (1990)	U	U	Comments	Low
Inman et al. (2011)	Y	U	Comments from patients during calls	Low
Jefford et al. (2011)	Y	Y	Interview: NOS	High
Kelly et al. (1999)	Y	U	2 open q's (improvements/positive effects)	Low
Kilbourn et al. (2013)	U	U	Exit interviews: NOS	Low
Livingston et al. (2010)	Y	N	Telephone interview with open questions: NOS	Low
Salonen et al. (2009)	Y	N	1 open-ended q (most appropriate timing for call)	Low
Smithies et al. (2009)	U	U	Method NR	Low
Steginga et al. (2008)	Y	U	Verbatim responses (topics provided)	Low
Wilmoth et al. (2006)	Y	Y	Interviews with schedule (topics provided)	High
Young et al. (2013)	Y	U	Semi-structured interviews	Low
Zheng et al. (2013)	Y	Y	Semi-structured interviews (topics provided)	High

(B)

Author/date	Qualitative/ open-ended questioning	Sufficient data to support findings	Outcome descriptor	Acceptability data quality
Anderson (2010)	N	N	Likert scale—12 q's (provided): NV	Low
Barsevick et al. (2002)	N	N	Interview—10 closed q's (topics provided): NV	Low
Beaver et al. (2009)	N	U	Questionnaire designed and piloted—NOS: NV	Low
Beaver et al. (2012)	N	Y	Adapted Likert scale questionnaire (topics provided): NV	Low
			Likert scale—overall satisfaction: NV	
Booker et al. (2004)	N	Y	Closed q's (topics provided): NV	Low
Cimprich et al. (2005)	N	Y	Likert scale 1 closed q (provided): NV	Low
Cirillo et al. (2014)	N	U	Rating scale: NOS, NV	Low
Cox et al. (2005)	N	Y	Adapted MISS (26 items): NV	Low
Cox et al. (2008)	N	N	Likert scale questionnaire (4 domains provided): V	Low
Craven et al. (2013)	U	U	Questionnaire (topics provided): NV	Low
Delaney et al. (2009)	N	Y	Likert scale 2q's (provided): NV	Low
Garrett et al. (2013)	N	N	Likert scale questionnaire (topics provided): NV	Low
Hafiji et al. (2012)	N	N	Likert scale questionnaire: NOS, NV	Low
Hagopian and Rubenstein (1990)	U	U	Questionnaire: NOS, NV	Low

(Continues)

TABLE 8 (Continued)

(B)

Author/date	Qualitative/ open-ended questioning	Sufficient data to support findings	Outcome descriptor	Acceptability data quality
Hegel et al. (2011)	N	Y	Likert scale 2q's (topics provided): NV	Low
Heidrich et al. (2009) (Pilot Study 1)	N	U	8 q's (topics provided): NV	Low
Heidrich et al. (2009) (Pilot Study 2)	N	U	8 q's (topics provided): NV	Low
Heidrich et al., 2009 (Pilot Study 3)	N	U	8 q's (topics provided): NV	Low
Inman et al. (2011)	Y	U	1 closed q (provided)	Low
Jensen et al., 2011;	U	U	Likert questionnaire (topic provided): NOS, NV	Low
Kelly et al. (1999)	N	U	4 closed q's (topics provided): NV	Low
Kilbourn et al. (2013)	N	Y	Likert scale 2 closed q's (topics provided): NV	Low
Kim et al. (2011)	N	N	Likert scale questionnaire (topics provided): NV	Low
Kimman, Bloebaum, et al. (2010), Kimman, Dellaert, et al. (2010)	N	N	PSQIII: V	Low
Leahy et al. (2013)	N	N	Adapted Satisfaction with Consultation Scale: NV	Low
Livingston et al. (2010)	N	N	Likert scale questionnaire (topics provided): NV	Low
Marcus et al. (1993)	N	N	Single evaluation indicator (topic provided): NV	Low
Marcus et al. (2010)	N	Y	Questionnaire which component most helpful (provided): NV	Low
Mordenti et al. (2013)	N	U	Survey (topics provided): NV	Low
Munro et al. (1994)	N	N	Likert scale 1 q (provided): NV	Low
Reese et al. (2012)	N	Y	Likert scale 4 q's (topics provided): NV	Low
Reese et al. (2014)	N	Y	Likert scale 3 q's (topics provided): NV	Low
Salonen et al. (2009)	N	Y	Revised Likert scale questionnaire (Kaunonen, 2000): V	Low
Sandgren et al. (2000)	N	N	Likert scale 4 q's (provided): NV	Low
Sardell et al. (2000)	N	N	Satisfaction questionnaire (topics provided): NV	Low
Smithies et al. (2009)	N	Y	Likert scale 1 q (topic provided): NV	
Steginga et al. (2008)	N	Y	Likert scale 1 q (topic provided): NV	Low
Young et al. (2010)	U	U	Questionnaire: NOS, NV	Low
Young et al. (2013)	N	Y	Likert scale 13 statements (provided): NV	Low
Zhang et al. (2013)	N	Y	Likert scale 1 q (topic provided): NV	Low

CST, coping skills training; MISS, Medical Interview Satisfaction Scale; N, no; NOS, not otherwise specified; NR, not reported; NV, not validated; PSQ III, Patient Satisfaction Questionnaire III; q (q's), question (questions); U, unclear; V, validated; Y, yes.

it was often unclear whether participant numbers referred to the number of patients who were approached to participate or the number who consented, received the intervention or provided acceptability data.

Twenty-six of the 50 studies provided acceptability data for all participants receiving a telephone intervention. Ten studies (20%) provided acceptability data for less than 75% of their sample. Two were notable for providing data for under half of their participants (49%, Sardell, Sharpe, Ashley, Guerrero, & Brada, 2000 and 41% Archer et al., 2014), respectively. Many participants in the latter study expressed a wish not to take part in an acceptability evaluation.

In studies providing quantitative satisfaction data (n = 39), the number of participants receiving interventions and thus potentially providing satisfaction ratings ranged from 9 to 387 (median 38 participants). In studies providing qualitative acceptability data (n = 24), sample sizes ranged from 8 to 187, median 30.5 participants. The highest sample size in this category (n = 187) was achieved in a study reporting feedback and qualitative comments (Hafji et al., 2012); however, it is unclear from how many participants these were collected.

4.4 | Patient characteristics

Most studies (n = 43) tended to be focused on a single cancer type, specifically breast cancer (n = 16), colorectal cancer (n = 11) or prostate cancer (n = 7). Seven studies recruited mixed samples that included patients with different cancer diagnoses. Study participants had received or were still receiving a variety of treatments for their

TABLE 9 Summary of outcomes

Intervention category	TFU post-initial diagnosis and treatment				Side-effect monitoring during/post-treatment				Psycho-educational interventions			
Data type	Qualitative data		Quantitative data		Qualitative data		Quantitative data		Qualitative Data		Quantitative data	
Data quality	High	Low	High[a]	Low	High	Low	High[a]	Low	High	Low	High[a]	Low
Positive findings												
Convenience	√	√		√	√	√		√	√	√		√
Familiar environment/facilitating sensitive discussions	√	√							√	√		√
Positive personal experiences	√				√	√		√	√	√		√
Accessibility to HCP/continuity of care	√			√	√	√		√				
Support/reassurance					√	√		√	√	√		√
Positive aspects of intervention structure	√								√			
Positive patient–HCP relationship				√		√		√				√
Prefer telephone-based intervention						√				√		
Overall satisfaction				√				√		√		√
Negative findings												
Lack of contact–Peer/HCP	√											
Negative patient–HCP relationship	√							√		√		
Barrier to emotional discussions					√							
Not useful for all patients					√	√						√
Changes to intervention structure					√	√		√	√	√		√
Lack of choice–receiving calls/timing						√				√		
Preference for other intervention methods								√		√		√

HCP, healthcare professional, TC, telephone consultation; √, at least one reported finding.
[a]No high-quality data.

cancer, including surgery, CT, targeted agents, RT or hormone therapy. In a large proportion of studies (48%), gender and age demographics were only described in terms of the total sample size and not specific for those who provided data relating to acceptability of the intervention. Mean age across the 41 studies providing data was 60.2 years (*SD* 6.98). Potential for gender bias was observed; in studies targeting cancers that were not gender-specific, 60% of participants were male.

4.5 | Characteristics of the interventions

Intervention content and objectives varied greatly, as well as the timing, duration and format of their delivery. Three main categories of intervention emerged.

4.5.1 | Telephone follow-up interventions

Telephone follow-up (TFU) interventions involved general and cancer symptom monitoring as well as provision of information and support post diagnosis and treatment (n = 6). Intervention content and timing typically mirrored that of standard hospital follow-up, the only difference being a change in the mode of service delivery. Six studies described structured interventions of this type in patients with breast (Beaver et al., 2009, 2010), colorectal (Beaver et al., 2012) and prostate cancer (Anderson, 2010; Booker et al., 2004; Leahy et al., 2013). All of these interventions were nurse led.

4.5.2 | Treatment side effect/toxicity monitoring

The second (and largest) category described telephone interventions, which were delivered during and after cancer treatment and focused wholly or predominantly on side effect and toxicity monitoring (n = 23). Some also included side-effect management and coping strategies and/or education and information provision. Interventions were often nurse led and delivered to a variety of cancer patients receiving a variety of treatments. Intervention timing varied according to the specific treatment being received. The vast majority were presented as supplementary to standard care (Cirillo et al., 2014; Cox et al., 2008; Delaney et al., 2009; Dixon, 2010; Hagopian & Rubenstein, 1990; Heidrich et al., 2009; Inman et al., 2011; Jefford et al., 2011; Jensen, Kristensen, Christensen, & Borre, 2011; Mordenti et al., 2013; Munro, Shaw, Clarke, Becker, & Greenwood, 1994; Sardell et al., 2000; Smithies et al., 2009; Young et al., 2010, 2013; Zhang et al., 2013;

Zheng et al., 2013), although four were described as standard care interventions (Archer et al., 2014; Craven, Hughes, Burton, Saunders, & Molassiotis, 2013; Hafiji et al., 2012; Kelly et al., 1999).

4.5.3 | Psycho-educational interventions

The third category (n = 21) described a wide variety of psycho-educational telephone-based interventions. Almost half were nurse led, although psychologists, physiotherapists, social workers, counsellors and health educators also provided interventions. Thirteen studies reported psychological interventions involving an element of counselling (Alter et al., 1996; Badger et al., 2013; Barsevick, Whitmer, Sweeney, & Nail, 2002; Kim et al., 2011; Marcus et al., 1993, 2010), coping strategies and skills training (Campbell et al., 2007; Kilbourn et al., 2013), problem solving (Hegel et al., 2011; Steginga et al., 2008), self-management (Cimprich et al., 2005), cognitive behavioural skills training (Sandgren, McCaul, King, O'Donnell, & Foreman, 2000) or intimacy enhancement programmes (Reese, Porter, Somers, & Keefe, 2012; Reese et al., 2014). Seven studies described educational and supportive interventions, varying widely in timing and duration (Cox et al., 2005; Donnelly et al., 2013; Garrett et al., 2013; Kimman, Bloebaum, et al., 2010; Livingston et al., 2010; Salonen et al., 2009; Wilmoth et al., 2006).

4.6 | Acceptability outcome data

A summary of outcome data is provided in Table 9. This table is intended to demonstrate the breadth of factors potentially impacting on intervention acceptability, according to data type and quality. Scales and quantitative data tended to provide more generalised information focusing on positive aspects of interventions such as convenience, accessibility and relationship with the HCP, perceived support and overall satisfaction. Qualitative data presented further insight into opinions of intervention-specific components and perceived negative aspects of the interventions. Consistency of findings across studies is indicated.

4.6.1 | Findings across all intervention categories

High-quality evidence frequently endorsed that cancer patients valued telephone-based interventions for their convenience. Convenience was reported across intervention categories, in terms of facilitating personal organisation (Beaver et al., 2010), time and travel savings (Campbell et al., 2007; Jefford et al., 2011), and overcoming participation restrictions (Campbell et al., 2007). Similar findings were also reflected in a further seven studies providing lower quality data (Alter et al., 1996; Anderson, 2010; Booker et al., 2004; Cox et al., 2008; Hafiji et al., 2012; Hegel et al., 2011; Sardell et al., 2000).

Positive personal experiences of the intervention process were evident across the three different intervention categories and supported by both higher and lower quality evidence (Beaver et al., 2010; Donnelly et al., 2013; Jefford et al., 2011; Zheng et al., 2013). This included some evidence of patient acceptance (Zheng et al., 2013) and appreciation of calls (Donnelly et al., 2013). Nineteen studies providing lower quality evidence echoed these findings, reporting perceptions of intervention helpfulness or usefulness (Barsevick et al., 2002; Cimprich et al., 2005; Delaney et al., 2009; Garrett et al., 2013; Hafiji et al., 2012; Hagopian & Rubenstein, 1990; Heidrich et al., 2009; Inman et al., 2011; Kelly et al., 1999; Kim et al., 2011; Livingston et al., 2010; Marcus et al., 2010; Mordenti et al., 2013; Munro et al., 1994; Reese et al., 2012, 2014; Salonen et al., 2009; Steginga et al., 2008), ease of participation (Reese et al., 2012, 2014) and patient appreciation of the calls (Dixon, 2010).

High overall satisfaction was revealed from low-quality evidence across the three intervention categories (Alter et al., 1996; Anderson, 2010; Badger et al., 2013; Beaver et al., 2009; Booker et al., 2004; Cox et al., 2005; Craven et al., 2013; Garrett et al., 2013; Hafiji et al., 2012; Hagopian & Rubenstein, 1990; Hegel et al., 2011; Heidrich et al., 2009; Jensen et al., 2011; Kilbourn et al., 2013; Kimman, Bloebaum, et al., 2010; Leahy et al., 2013; Sardell et al., 2000; Steginga et al., 2008; Zhang et al., 2013). In three studies providing comparative control group analysis, statistically significant greater satisfaction with telephone-based intervention was reported compared with standard hospital care (Beaver et al., 2009; Jensen et al., 2011; Zhang et al., 2013).

4.6.2 | Telephone follow-up interventions

With regard to TFU in lieu of routine hospital follow-up, high-quality evidence suggested that it was important to have access to HCPs, in order to deal with concerns in a timely manner (Beaver et al., 2010). The "normality" of talking by telephone made this easier (Beaver et al., 2010), and a structured intervention helped to organise thoughts and revisit topics (Beaver et al., 2010). However, some participants missed contact with other patients and the reassurance of a physical examination, describing consultations as rushed and impersonal.

4.6.3 | Treatment side-effect/toxicity monitoring

In side-effect and post-treatment monitoring interventions, high-quality findings described the telephone-based approach as more comfortable (Jefford et al., 2011), providing prompt access to HCPs who could address concerns (Jefford et al., 2011). In particular, high-quality evidence from post-surgical monitoring interventions described continuity of care—facilitating the transition from hospital to home (Archer et al., 2014) and, during the return to a "normal life" (Zheng et al., 2013). While a single study described high-quality evidence of psychological support (Zheng et al., 2013), lower quality evidence captured concepts with more emotive terminology. This included the benefits of having someone to talk to (Smithies et al., 2009), feeling listened to (Dixon, 2010), cared for (Hafiji et al., 2012; Hagopian & Rubenstein, 1990), showing concern (Inman et al., 2011) and reducing isolation (Kelly et al., 1999), especially in interventions delivered over longer periods of time. The support that was provided was not always deemed necessary, however, especially where existing support systems were in place (Young et al., 2013).

Conflicting perceptions of the impact on the patient–HCP relationship were described. High-quality evidence highlighted difficulties in dealing with emotions by telephone (Jefford et al., 2011) and was matched by opinions from low-quality evidence, which suggested a lack of emotional support (Young et al., 2013), a lack of "enhanced care giving" (Mordenti et al., 2013) and generally poorer knowledge of a patient's case (Young et al., 2013). In direct contrast, other lower quality evidence described positive opinions of the patient–HCP relationship (Cirillo et al., 2014; Cox et al., 2008; Dixon, 2010; Sardell et al., 2000; Young et al., 2013).

Low-quality evidence alluded to potentially critical aspects of intervention structure, including the need to ensure appropriate call timing (Sardell et al., 2000; Young et al., 2010), frequency of calls (Hafiji et al., 2012; Kelly et al., 1999), patient choice in receiving calls (Hafiji et al., 2012), and consideration of and potential solutions for overcoming language difficulties in calls (Young et al., 2010).

4.6.4 | Psycho-educational interventions

High-quality evidence from psycho-educational interventions described a telephone-based approach as useful especially when dealing with sensitive subjects (Campbell et al., 2007), facilitating a sense of control (Wilmoth et al., 2006). Low-quality data findings positively described support (Cimprich et al., 2005), having someone to talk to (Salonen et al., 2009), giving reassurance (Livingston et al., 2010), and having a HCP that is responsive, understands and cares with high levels of participants reporting contact by telephone to be the most helpful component of the intervention (Marcus et al., 2010). One study revealed the impersonal nature of the telephone method (Kilbourn et al., 2013) being a barrier to discussions.

Intervention structure was a theme, with high-quality data eliciting the utility of a structured intervention as a memory aid (Wilmoth et al., 2006), promoting accountability and motivation in an exercise and diet programme (Donnelly et al., 2013). Lower quality evidence revealed call timing was appropriate for many (Cimprich et al., 2005; Donnelly et al., 2013; Kilbourn et al., 2013; Kim et al., 2011; Salonen et al., 2009; Sandgren et al., 2000), although a lack of control over call timing was described (Sandgren et al., 2000), as well as the influence of treatment side effects interfering with counselling calls (Kilbourn et al., 2013).

Lower quality evidence questioned the suitability of a telephone intervention for all patients on the basis that needs differed between individuals and over time (Zheng et al., 2013). Alternative methods such as group sessions (Cimprich et al., 2005) or face-to-face contact (Sandgren et al., 2000) were preferred by some participants, and in some cases, the intervention had not been useful, as patients already had support (Kilbourn et al., 2013). Despite this, positive perceptions of the patient–HCP relationship were cited in relation to good rapport (Reese et al., 2014). There was high satisfaction with technical competence (Kimman, Bloebaum, et al., 2010; Reese et al., 2014), with high levels of preference for telephone-based interventions (Kilbourn et al., 2013; Reese et al., 2012, 2014), although interestingly, two studies described this in terms of negatively worded indicators—with participants "not at all" worried about calls (Livingston et al., 2010), and 0% of patients "complained about the interview to the interviewer" (Marcus et al., 1993).

5 | DISCUSSION

We conducted a narrative systematic review of the acceptability of telephone-based interventions for adult cancer patients. The review identified 48 articles reporting on 50 studies. The overall quality of the existing evidence base was not high, as determined by appropriate and validated quality appraisal tools used.

The review included primary research with significant variation in sample size. Smaller samples were evident in "pilot" or "feasibility" studies and larger samples in service evaluations. Participants were often self-selected, raising the possibility of selection bias. In the majority of studies, difficulty in understanding actual numbers of patients approached to participate in studies and the proportion of those accepting to participate remains unclear. A clear understanding of participant characteristics was blurred by a lack of data relating to those participating in the evaluation and whether these were representative of a total group.

Methods to evaluate acceptability and satisfaction were predominantly short quantitative questionnaires, which were not standardised or validated, providing at best generalised, preliminary findings. Although it is recognised that quantitative outcome assessment can be patient-centred, especially when developed from rigorous qualitative insight, findings demonstrated that scales used did not always map directly and wholly on to patient identified concerns identified with more open-ended designs. This was especially in relation to issues that were intervention specific and negative opinions.

New, quantitative tools should be developed that enable respondents to be critical, as well as positive about their experience, with items that explore patient perceptions of intervention utility, timing, convenience, accessibility and communication preferences. Reliance on quantitative data in isolation may lead to unintentional bias in findings, as patients are known to tend towards positive responses on such instruments (Bradley, Plowright, Stewart, Valentine, & Witthaus, 2007). There is also potential for a ceiling effect, making differentiation of clustered upper end results challenging (Dell-Kuster et al., 2014). Employing a mixed methods or qualitative approach may, thus, be more appropriate.

Qualitative research offers an opportunity to explore patient perceptions in depth, with acceptability defined according to patient priorities and concerns. Qualitative studies, however, can be conducted for different reasons. While stand-alone studies may explore intervention acceptability from a neutral standpoint, nested process evaluations are often driven by the desire to understand positive or negative intervention effects. The specific objectives of a study may, thus, determine to some extent whether strengths or limitations of telephone interventions are reported. Rigorous development of evidence-based interventions demands that all potential viewpoints are considered. We, thus, included all eligible qualitative studies in our review, irrespective of their design or primary objective.

Despite heterogeneity in the intervention categories and the data collection methods, this review revealed some consistent and potentially important findings. The convenience of telephone-delivered interventions was evident across all interventions and data types (Alter et al., 1996; Anderson, 2010; Barsevick et al., 2002; Beaver et al., 2010; Booker et al., 2004; Campbell et al., 2007; Cox et al., 2008; Hafiji et al., 2012; Hegel et al., 2011; Jefford et al., 2011). Positive personal experiences were also reported across the different intervention types, although more so in side-effect/post-treatment monitoring and psycho-educational interventions, where the enhanced communication was viewed as additional component to usual care (Campbell et al., 2007; Sandgren et al., 2000). TFU in lieu of routine hospital follow-up received more negative feedback and left some patients feeling as though they lacked assurance (Beaver et al., 2010). These potential differences suggest that the nature and setting of the intervention is influential on perceptions of acceptability and satisfaction.

Accessibility to care was a recurrent theme in side-effect and post-treatment monitoring interventions. Telephone-based interventions were often a source of prompt reassurance, continuity of care and information provision to deal with practical issues. The provision of information is recognised as one of the most important factors of supportive cancer care across the trajectory (Husson et al., 2013). Some patients, however, reported difficulty receiving emotional support in these interventions (Jefford et al., 2011; Mordenti et al., 2013), which was perhaps reflective of a lack of discussion around psychosocial well-being issues (Taylor et al., 2011). More holistic and complex interventions with a psychosocial component may be required to address this practice gap.

The need for patient choice is noted throughout the review, in terms of satisfaction with the intervention content (Jefford et al., 2011), but more so in recurrent findings relating to a lack of choice over intervention delivery mode (Hafiji et al., 2012) and call timing (Hafiji et al., 2012; Jefford et al., 2011; Kelly et al., 1999; Kilbourn et al., 2013; Sandgren et al., 2000). Both higher and lower quality data suggests that the utility of telephone-delivered interventions may be enhanced when they are shaped by and respond to individual patient need (Hafiji et al., 2012; Kilbourn et al., 2013; Young et al., 2013; Zheng et al., 2013) rather than a global guideline. Patient participation and involvement in care planning is seen as a core element of patient-centred care (Kitson, Marshall, Bassett, & Zeitz, 2013), without which, services may be delivered and resources employed wastefully. Clearer identification of patients' needs at specific time points during the cancer journey and choice of access to services may aid in providing truly patient-centred care.

While the majority of studies indicated the potential positive effect of telephone-delivered interventions on patient–provider relationships and healthcare communication, a small number alluded to a negative impact (Beaver et al., 2010; Delaney et al., 2009; Mordenti et al., 2013; Young et al., 2013), and patient preferences for alternative methods of contact (Cimprich et al., 2005; Sandgren et al., 2000). These findings are evident in lower quality quantitative data and reflected in a few studies providing higher quality qualitative data. Nevertheless, the depth of understanding in relation to motivators for such responses is lacking. The impact of telephone delivery on professional–patient relationships is one area that may benefit from further qualitative investigation into different stakeholder perspectives.

High levels of overall satisfaction (Alter et al., 1996; Anderson, 2010; Badger et al., 2013; Beaver et al., 2009; Booker et al., 2004; , Cox et al., 2005; Craven et al., 2013; Garrett et al., 2013; Hafiji et al., 2012; Hagopian & Rubenstein, 1990; Hegel et al., 2011; Heidrich et al., 2009; Jensen et al., 2011; Kilbourn et al., 2013; Kimman, Bloebaum, et al., 2010; Leahy et al., 2013; Sardell et al., 2000; Steginga et al., 2008; Zhang et al., 2013) were reported; however, interpretation of these results should take into account the context of this assessment. Findings from low-quality data and in some cases feedback were provided during the delivery of a telephone intervention (Anderson, 2010; Booker et al., 2004; Craven et al., 2013; Kelly et al., 1999), with potential for respondent and social desirability biases. Despite being a "comforting" indicator, overall satisfaction as a measure does not provide sufficient detail to enable key features of intervention design to be identified and maximised.

To our knowledge, this is the first systematic review of patients' acceptability and satisfaction of telephone-delivered for cancer patients both during and after treatment. It incorporates data from a variety of research strategies. The methodological approach undertaken was comprehensive and transparent, with a search strategy that the authors believe enabled identification of the majority of articles meeting the inclusion criteria. The approach to include both qualitative (nested and non-nested) and quantitative designs maximises the likelihood that the full breadth of responses to telephone-based care is included in our synthesis. Similarities between the data reported by stand alone and nested process evaluations lend weight to the likely components determining acceptability in practice.

Several limitations to the review are to be acknowledged. Although the review included a variety of methodological approaches, only those with interventions delivered by HCPs were included in order to have a more homogenous level of educational training. This systematic review dealt only with data presented within the original research paper itself, and it is appreciated that word limits and space restrictions for publication may influence selective rather than complete reporting of findings. The review excluded studies that were not published in English, and although a detailed protocol was developed for the review, it is recognised that relevant studies may have been unintentionally missed.

6 | CONCLUSIONS

This systematic review reveals an insight into current published research pertaining to the acceptability and satisfaction of support delivered by telephone for cancer patients during or after therapy. Telephone-based interventions are a potential resource that can make healthcare initiatives accessible to a variety of patients, and as such merit further investigation. The growth in telephone-delivered interventions, especially in the form of smaller "pilot" or "feasibility" studies, is evident, but more often participants' perspectives are not

featured within the study aims and therefore are often not part of a rigorous study design, leading to several reports of low-quality qualitative data derived through post hoc comments or informal feedback. Subsequent research in this field should reflect the need to incorporate a high-quality qualitative component, in order to ensure that the individuality of participants and their experiences are represented.

The disease-specific nature of the majority of studies and differing nature of the interventions presents difficulty in generalising findings; however, the consistency data emerging from these studies allows a useful understanding of patients' perceptions. Current evidence relating to the acceptability and satisfaction of support delivered by telephone for cancer patients during or after therapy suggests it is convenient, provides positive personal experiences, enhances accessibility to HCPs and provides a familiar environment in which to facilitate potentially sensitive healthcare discussions. Data synthesis suggests a need for services (and individual, facilitating professionals) to have a clearer understanding of the needs of patients in order to develop truly patient-centred interventions that reflect individual's needs and choices.

ACKNOWLEDGEMENT

SL wishes to acknowledge and thank the Fondazione IEO for funding received to support her PhD.

REFERENCES

Alter, C. L., Fleishman, S. B., Kornblith, A. B., Holland, J. C., Biano, D., Levenson, R., …Rai, K. R. (1996). Supportive telephone intervention for patients receiving chemotherapy. A pilot study. *Psychosomatics*, *37*(5), 425–431.

Anderson, B. (2010). The benefits to nurse-led telephone follow-up for prostate cancer. *British Journal of Nursing*, *19*(17), 1085–1090.

Archer, S., Montague, J., & Bali, A. (2014). Exploring the experience of an enhanced recovery programme for gynaecological cancer patients: A qualitative study. *Perioperative Medicine (London)*, *3*(1), 2.

Badger, T., Segrin, C., Meek, P., Lopez, A., Bonham, E., & Sieger, B. (2005). Telephone interpersonal counselling for women with breast cancer: Symptom management and quality of life. *Oncology Nursing Forum*, *32*(2), 273–279.

Badger, T., Segrin, C., Pasvogel, A., & Lopez, A. M. (2013). The effect of psychosocial interventions delivered by telephone and videophone on quality of life in early-stage breast cancer survivors and their supportive partners. *Journal of Telemedicine and Telecare*, *19*(5), 260–265.

Barsevick, A., Dudley, W., Beck, S., Sweeney, C., Whitmer, K., & Nail, L. (2004). A randomised clinical trial of energy conservation for patients with cancer-related fatigue. *Cancer*, *100*(6), 1302–1310.

Barsevick, A. M., Whitmer, K., Sweeney, C., & Nail, L. M. (2002). A pilot study examining energy conservation for cancer treatment-related fatigue. *Cancer Nursing*, *25*(5), 333–341.

Beaver, K., Campbell, M., Williamson, S., Procter, D., Sheridan, J., Heath, J., & Susnerwala, S. (2012). An exploratory randomized controlled trial comparing telephone and hospital follow-up after treatment for colorectal cancer. *Colorectal Disease*, *14*(10), 1201–1209.

Beaver, K., Tysver-Robinson, D., Campbell, M., Twomey, M., Williamson, S., Hindley, A., … Luker, K. (2009). Comparing hospital and telephone follow-up after treatment for breast cancer: Randomised equivalence trial. *British Medical Journal*, *14*(338), a3147.

Beaver, K., Williamson, S., & Chalmers, K. (2010). Telephone follow-up after treatment for breast cancer: Views and experiences of patients and specialist breast care nurses. *Journal of Clinical Nursing*, *19*, 2916–2924.

Booker, J., Eardley, A., Cowan, R., Logue, J., Wylie, J., & Caress, A. L. (2004). Telephone first post-intervention follow-up for men who have had radical radiotherapy to the prostate: Evaluation of a novel service delivery approach. *European Journal of Oncology Nursing*, *8*(4), 325–333.

Bradley, C., Plowright, R., Stewart, J., Valentine, J., & Witthaus, E. (2007). The Diabetes Treatment Satisfaction Questionnaire change version (DTSQc) evaluated in insulin glargine trials shows greater responsiveness to improvements than the original DTSQ. *Health and Quality of Life Outcomes*, *5*, 57.

Campbell, L. C., Keefe, F. J., Scipio, C., McKee, D. C., Edwards, C. L., Herman, S. H., … Donatucci, C. (2007). Facilitating research participation and improving quality of life for African American prostate cancer survivors and their intimate partners: A pilot study of telephone-based coping skills training. *Cancer*, *109*(Suppl. 2), 414–424.

Cancer Research UK. Worldwide Cancer. Cancer Research UK (2014). [online] Available from: http://publications.cancerresearchuk.org/downloads/product/CS_KF_WORLDWIDE.pdf > [last accessed 13 March 2015].

Car, J., & Sheik, A. (2003). Telephone consultations. *British Medical Journal*, *2003*(326), 966–999.

Castro, K., Mitchell, S., Rowe, T., & Jacobs, M. (2007). A chronic graft-versus-host disease (cGVHD) telephone support group: Partnering with an advocacy organization to address an undeserved population of cancer survivors. *Oncology Nursing Forum*, *35*(3), 514.

Cimprich, B., Janz, N. K., Northouse, L., Wren, P. A., Given, B., & Given, C. W. (2005). Taking CHARGE: A self-management program for women following breast cancer treatment. *Psychooncology*, *14*(9), 704–717.

Cirillo, M., Lunardi, G., Coati, F., Ciccarelli, L., Alestra, S., Mariotto, M., … Venturini, M. (2014). Management of oral anticancer drugs: Feasibility and patient approval of a specific monitoring program. *Tumori*, *100*(3), 243–248.

Clark, R. A., Inglis, S. C., McAlister, F. A., Cleland, J. G. F., & Stewart, S. (2007). Telemonitoring or structured telephone support programmes for patients with chronic heart failure: Systematic review and meta-analysis. *British Medical Journal 334*(7600): 942.

Cox, A., Bull, E., Cockle-Hearne, J., Knibb, W., Potter, C., & Faithfull, S. (2008). Nurse led telephone follow up in ovarian cancer: A psychosocial perspective. *European Journal of Oncology Nursing*, *12*(5), 412–417.

Cox, K., Wilson, E., Arthur, A., Elkan, R., & Armstrong, S. (2005). A randomised controlled trial of nurse-managed trial conclusion following early phase cancer trial participation. *British Journal of Cancer*, *93*(1), 41–45.

Cramp, F., & Byron-Daniel, J. (2012). Exercise for the management of cancer-related fatigue in adults. *Cochrane Database of Systematic Reviews*, *11*, CD006145.

Craven, O., Hughes, C. A., Burton, A., Saunders, M. P., & Molassiotis, A. (2013). Is a nurse-led telephone intervention a viable alternative to nurse-led home care and standard care for patients receiving oral capecitabine? Results from a large prospective audit in patients with colorectal cancer. *European Journal of Cancer Care (England)*, *22*(3), 413–419.

Critical Appraisal Skills Programme (2013). Qualitative Research Checklist [online]. Available from: http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf [last accessed 5 June 2014].

Davalos, M. E., French, M. T., Burdick, A. E., & Simmons, S. C. (2009). Economic evaluation of telemedicine: Review of the literature and research guidelines for benefit-cost analysis. *Telemedicine Journal and e-Health*, *15*(10), 933–948.

Delaney, L., Chambers, C., Roldán, G., de Robles, P., Cairncross, G., Forsyth, P., & Easaw, J. (2009). A feasibility study to assess the integration of a pharmacist into neurooncology clinic. *Journal of Oncology Pharmacy Practice*, *15*(2), 79–85.

Dell-Kuster, S., Sanjuan, E., Todorov, A., Weber, H., Heberer, M., & Rosenthal, R. (2014). Designing questionnaires: Healthcare survey to compare two different response scales. *BMC Medical Research Methodology*, *14*, 96.

Dickinson, R., Hall, S., Sinclair, J., Bond, C., & Murchie, P. (2014). Using technology to deliver cancer follow-up: A systematic review. *BMC Cancer*, *14*, 311.

Dixon, W. (2010). The feasibility of telephone follow-up led by a radiation therapist: Experience in a multidisciplinary bone metastases clinic. *Journal of Medical Imaging and Radiation Sciences*, *41*(4), 175–179.

Dodd, M., Miaskowski, C., & Paul, S. (2001). Symptom clusters and their effect on the functional status of patients with cancer. *Oncology Nursing Forum*, *28*(3), 465–470.

Donnelly, C. M., Lowe-Strong, A., Rankin, J. P., Campbell, A., Blaney, J. M., & Gracey, J. H. (2013). A focus group study exploring gynecological cancer survivors' experiences and perceptions of participating in a RCT testing the efficacy of a home-based physical activity intervention. *Supportive Care in Cancer*, *21*(6), 1697–1708.

Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., & Duberstein, P. R. (2005). Measuring patient-centred communication in patient-physician consultations: Theoretical and practical issues. *Social Science and Medicine*, *61*(7), 1516–1528.

Garrett, K., Okuyama, S., Jones, W., Barnes, D., Tran, Z., Spencer, L., … Marcus, A. (2013). Bridging the transition from cancer patient to survivor: Pilot study results of the Cancer Survivor Telephone Education and Personal Support (C-STEPS) program. *Patient Education and Counselling*, *92*(2), 266–272.

Glasgow, R. E., Vogt, T. M., & Boles, S. M. (1999). Evaluating the public health impact of health promotion interventions: The RE-AIM Framework. *American Journal of Public Health*, *89*, 1322–1327.

Hafiji, J., Salmon, P., & Hussain, W. (2012). Patient satisfaction with postoperative telephone calls after Mohs micrographic surgery: A New Zealand and U.K. experience. *British Journal of Dermatology*, *167*(3), 570–574.

Hagopian, G., & Rubenstein, J. H. (1990). Effects of telephone call interventions on patients' well-being in a radiation therapy department. *Cancer Nursing*, *13*(6), 339–344.

Hegel, M. T., Lyons, K. D., Hull, J. G., Kaufman, P., Urquhart, L., Li, Z., & Ahles, T. A. (2011). Feasibility study of a randomized controlled trial of a telephone-delivered problem-solving-occupational therapy intervention to reduce participation restrictions in rural breast cancer survivors undergoing chemotherapy. *Psychooncology*, *20*(10), 1092–1101.

Heidrich, S. M., Brown, R. L., Egan, J. J., Perez, O. A., Phelan, C. H., Yeom, H., & Ward, S. E. (2009). An individualized representational intervention to improve symptom management (IRIS) in older breast cancer survivors: Three pilot studies. *Oncology Nursing Forum*, *36*(3), E133–E143.

Higgins, J. P. T. & Green, S. (Eds.) (2011). *Cochrane handbook for systematic reviews of interventions*. Version 5.1.0 [updated March 2011]. The Cochrane Collaboration. Available from: www.cochrane-handbook.org.

Husson, O., Thong, M., Mols, F., Oerlemans, S., Kaptein, A. A., & van de Poll-Franse, L. (2013). Illness perceptions in cancer survivors: What is the role of information provision? *Psycho-Oncology*, *22*, 490–498.

Inman, D. M., Maxson, P. M., Johnson, K. M., Myers, R. P., & Holland, D. E. (2011). The impact of follow-up educational telephone calls on patients after radical prostatectomy. *Urologic Nursing*, *31*(2), 83–91.

Jefford, M., Lotfi-Jam, K., Baravelli, C., Grogan, S., Rogers, M., Krishnasamy, M., … Schofield, P. (2011). Development and pilot testing of a nurse-led posttreatment support package for bowel cancer survivors. *Cancer Nursing*, *34*(3), E1–E10.

Jensen, B. T., Kristensen, S., Christensen, S., & Borre, M. (2011). Efficacy of tele-nursing consultations in rehabilitation after radical prostatectomy: A randomised controlled trial study. *Urological Nursing*, *5*(3), 123–130.

Kaunonen, M. (2000) Support for a family in grief. Acta Universitatis Tamperensis 731. Tampere, Finland: Tampere University.

Kelly, D., Faught, W., Holmes, L. (1999). Ovarian cancer treatment: The benefit of patient telephone follow-up post chemotherapy. *Canadian Oncology Nursing Journal*, *9*(4), 175–178.

Kilbourn, K. M., Anderson, D., Costenaro, A., Lusczakoski, K., Borrayo, E., & Raben, D. (2013). Feasibility of EASE: A psychosocial program to improve symptom management in head and neck cancer patients. *Supportive Care in Cancer*, *21*(1), 191–200.

Kim, S. H., Shin, M. S., Lee, H. S., Lee, E. S., Ro, J. S., Kang, H. S., … Yun, Y. H. (2011). Randomized pilot test of a simultaneous stage-matched exercise and diet intervention for breast cancer survivors. *Oncology Nursing Forum*, *38*(2), E97–E106.

Kimman, M. L., Bloebaum, M. M., Dirksen, C. D., Houben, R. M., Lambin, P., & Boersma, L. J. (2010). Patient satisfaction with nurse-led telephone follow-up after curative treatment for breast cancer. *BMC Cancer*, *10*, 174.

Kimman, M. L., Dellaert, B. G. C., Boersma, L. J., Lambin, P., & Dirksen, C. D. (2010). Follow-up after treatment for breast cancer: One strategy fits all? An investigation of patient preferences using a discrete choice experiment. *Acta Oncologica*, *429*, 328–337.

Kitson, A., Marshall, A., Bassett, K., & Zeitz, K. (2013). What are the core elements of patient-centred care? A narrative review and synthesis of the literature from health policy, medicine and nursing. *Journal of Advanced Nursing*, *69*(1), 4–15.

Kleiboer, A., Gowing, K., Holm Hansen, C., Hibberd, C., Hodges, L., Walker, J., … Sharpe, M. (2010). Monitoring symptoms at home: What methods would cancer patients be comfortable using? *Quality of Life Research*, *19*(7), 965–968.

Krumholz, H. M., Amatruda, J., Smith, G. L., Mattera, J. A., Roumanis, S. A., Radford, M. J., … Vaccarino, V. (2002). Randomized trial of an education and support intervention to prevent readmission of patients with heart failure. *Journal of the American College of Cardiology*, *39*(1), 83–89.

Leahy, M., Krishnasamy, M., Herschtal, A., Bressel, M., Dryden, T., Tai, K. H., & Foroudi, F. (2013). Satisfaction with nurse-led telephone follow up for low to intermediate risk prostate cancer patients treated with radical radiotherapy. A comparative study. *European Journal of Oncology Nursing*, *17*(2), 162–169.

Livingston, P. M., Craike, M. J., White, V. M., Hordern, A. J., Jefford, M., Botti, M. A., … Oldroyd, J. C. (2010). A nurse-assisted screening and referral program for depression among survivors of colorectal cancer: Feasibility study. *Medical Journal of Australia*, *193*(5 Suppl.), S83–S87.

Macartney, D., Stacey, M., Carley, M., & Harrison, M. B. (2012). Priorities, barriers and facilitators for remote telephone support of cancer symptoms: A survey of Canadian oncology nurses. *Canadian Oncology Journal*, *22*(4), 135–144.

Marcus, A. C., Cella, D., Sedlacek, S., Crawford, D., Crane, L., Garrett, K., … Gonin, R. (1993). Psychosocial counseling of cancer patients by telephone: A brief note on patient acceptance of an outcall strategy. *Psycho-oncology*, *2*, 209–214.

Marcus, A. C., Garrett, K. M., Cella, D., Wenzel, L., Brady, M. J., Fairclough, D., … Flynn, P. J. (2010). Can telephone counseling post-treatment improve psychosocial outcomes among early stage breast cancer survivors? *Psycho-oncology*, *19*(9), 923–932.

Martin, L. A., Nelson, E. C., Lloyd, R. C., & Nolan, T. W. (2007). *Whole system measures [IHI innovation series white paper]*. Cambridge, MA, Institute for Healthcare Improvement [online] Available from: http://IHI.org [last accessed 5 May 2013].

Mistiaen, P., & Poot, E. (2006). Telephone follow-up, initiated by a hospital-based health professional for postdischarge problems in patients discharged from hospital to home. *Cochrane Database of Systematic Reviews 18*(4): CD004510.

Mordenti, P., Capuano, D. L., Zanlari, L., Achilli, R., Galli, M. L., Marazzi, E., … Cavanna, L. (2013). Reduction of fear and acute toxicity from chemotherapy with a telephone call after the first cycle. *Journal of Pain and Symptom Management*, *46*(2), e6–e9.

Munro, A. J., Shaw, T., Clarke, L., Becker, L., & Greenwood, S. (1994). A randomized study of telephone contact following completion of radiotherapy. *Clinical Oncology*, *6*, 242–244.

Mustafa, M., Carson-Stevens, A., Gillespie, D., & Edwards, A.G. (2013). Psychological interventions for women with metastatic breast cancer. *Cochrane Database of Systematic Reviews 6*: CD004253.

Parahoo, K., McDonough, S., McCaughan, E., Noyes, J., Semple, C., Halstead, E.J., … Dahm, P. (2013). Psychosocial interventions for men with prostate cancer. *Cochrane Database of Systematic Reviews 12*: CD008529.

Pare, G., Mirou, J., & Sicotte, C. (2007). Systematic review of home telemonitoring for chronic diseases. The evidence base. *Journal of the America Medical Informatics Association*, *14*, 269–277.

Reese, J. B., Porter, L. S., Regan, K. R., Keefe, F. J., Azad, N. S., Diaz, L. A. Jr, … Haythornthwaite, J. A. (2014). A randomized pilot trial of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer. *Psychooncology*, *223*(9), 1005–1013.

Reese, J. B., Porter, L. S., Somers, T. J., & Keefe, F. J. (2012). Pilot feasibility study of a telephone-based couples intervention for physical intimacy and sexual concerns in colorectal cancer. *Journal of Sex and Marital Therapy*, *38*(5), 402–417.

Rueda, J.R., Solà, I., Pascual, A., & Subirana Casacuberta, M. (2011) Non-invasive interventions for improving well-being and quality of life in patients with lung cancer. *Cochrane Database of Systematic Reviews 9*: CD004282.

Salonen, P., Tarkka, M., Pellokumpu-Lehtinen, P. L., Astedt-Kurki, P., Luukkaala, P., & Kaunonen, M. (2009). Telephone intervention and quality of life in patients with breast cancer. *Cancer Nursing*, *32*(3), 177–190.

Sandgren, A. K., McCaul, K. D., King, B., O'Donnell, S., & Foreman, G. (2000). Telephone therapy for patients with breast cancer. *Oncology Nursing Forum*, *27*(4), 683–688.

Sardell, S., Sharpe, G., Ashley, S., Guerrero, D., & Brada, M. (2000). Evaluation of a nurse-led telephone clinic in the follow-up of patients with malignant glioma. *Clinical Oncology*, *12*(1), 36–41.

Scott, D. A., Mills, M., Black, A., Cantwell, M., Campbell, A., Cardwell, C. R., … Donnolley, M. (2013). Multidimensional rehabilitation programmes for adult cancer survivors. *Cochrane Database of Systematic Reviews 3*: CD007730.

Smithies, M., Bettger-Hahn, M., Forchuk, C., & Brackstone, M. (2009). Telephone contact intervention in women undergoing treatment for breast cancer. *Canadian Oncology Nursing Journal*, *19*(3), 122–128.

Stacey, D., Bakker, D., Green, E., Zanchetta, M., & Conlon, M. (2012). Ambulatory oncology nursing telephone services: A provincial survey. *Canadian Oncology Nursing Journal*, *17*, 1–5.

Steginga, S. K., Ferguson, M., Clutton, S., Gardiner, R. A., & Nicol, D. (2008). Early decision and psychosocial support intervention for men with localised prostate cancer: An integrated approach. *Supportive Care in Cancer*, *16*(7), 821–829.

Taylor, S., Harley, C., Campbell, L. J., Bingham, L., Podmore, E. J., Newsham, A. C., … Velikova, G. (2011). Discussion of emotional and social impact of cancer during outpatient oncology consultations. *Psycho-Oncology*, *20*, 242–251.

van Tiel, F., Harbers, M., Kessels, A., & Schouten, H. (2005). Home care versus hospital care of patients with haematological malignancies and chemotherapy-induced cytopenia. *Annals of Oncology*, *16*(2), 195–205.

Wilmoth, M. C., Tulman, L., Coleman, E. A., Stewart, C. B., & Samarel, N. (2006). Women's perceptions of the effectiveness of telephone support and education on their adjustment to breast cancer during the year following diagnosis. *Oncology Nursing Forum*, *33*(1), 138–144.

Young, J. M., Butow, P. N., Walsh, J., Durcinoska, I., Dobbins, T. A., Rodwell, L., … Solomon, M. J. (2013). Multicenter randomized trial of centralized nurse-led telephone-based care coordination to improve outcomes after surgical resection for colorectal cancer: The CONNECT intervention. *Journal of Clinical Oncology*, *31*(28), 3585–3591.

Young, J., Harrison, J., Solomon, M., Butow, P., Dennis, R., Robson, D., & Auld, S. (2010). Development and feasibility assessment of telephone-delivered supportive care to improve outcomes for patients with colorectal cancer: Pilot study of the CONNECT intervention. *Supportive Care in Cancer*, *18*(4), 461–470.

Zhang, J. E., Wong, F. K., You, L. M., Zheng, M. C., Li, Q., Zhang, B. Y., … Liu, J. L. (2013). Effects of enterostomal nurse telephone follow-up on postoperative adjustment of discharged colostomy patients. *Cancer Nursing*, *36*(6), 419–428.

Zheng, M. C., Zhang, J. E., Qin, H. Y., Fang, Y. J., & Wu, X. J. (2013). Telephone follow-up for patients returning home with colostomies: Views and experiences of patients and enterostomal nurses. *European Journal of Oncology Nursing*, *17*(2), 184–189.

How to cite this article: Liptrott S, Bee P, and Lovell K. Acceptability of telephone support as perceived by patients with cancer: A systematic review. *Eur J Cancer Care*. 2017;00: e12643. doi:10.1111/ecc.12643.

Appendix 2 - Protocol for Systematic Review of the Literature (Version 9 – 16th Oct 2014)

Research question

Is telephone intervention an acceptable method of providing support during or post treatment as perceived by patients with a cancer diagnosis?

Objectives

The objectives for the study were to:

- identify and quantify the type of studies available in this area,
- assess the methodological quality of the existing evidence,
- synthesise evidence of patients perceptions of acceptability and satisfaction with telephone interventions.

This review will be performed in 2 stages. Stage 1 - to perform a systematic review of quantitative literature looking at validated and non-validated measures of patient acceptability, attitudes to intervention and uptake. Stage 2 – to perform a systematic review of qualitative literature exploring patient perspectives of the intervention. A synthesis of the literature will be performed in these two stages.

Methods – inclusion and exclusion criteria for studies

Participants

Studies including ≥ 75% adults aged ≥ 18 years old with a clinical diagnosis of cancer. There will be no restriction to upper age limit, gender or type of cancer diagnosis. Studies included will evaluate telephone interventions delivered during or post- cancer treatment (in > 75% of participants). For the purpose of this review, cancer treatment is defined as surgery, chemotherapy, radiotherapy, immunotherapy or biological therapies, hormonal therapies, radio-immunotherapy, stem cell transplant, bone marrow transplant, photodynamic therapy (PDT) or radiofrequency ablation.

Types of interventions

The intervention will be delivered via telephone to provide support for any physical or psychological issues related to cancer or cancer treatment. For the purpose of this review, support is defined as social, emotional, information support or monitoring. The

telephone intervention will be delivered by any qualified healthcare professional and will include at least one telephone call from a healthcare professional who is specified to be individually involved in the treatment and care of the patient, however telephone calls by patients to a generic call centre will be excluded. Studies with or without comparison groups will be included. Where studies identify a comparison group, this may include standard care, no care, or interventions in the form of written support, face-to-face support, or support using other mediums (e.g. internet, web based, or DVD).

Types of outcomes

The following outcomes for the review are specified:

- To identify the quantity and type of studies available in this area.
- To explore the rating of satisfaction/ acceptability with the telephone intervention (also in terms of methods / tools used for evaluation)
- To identify the uptake by patients of the telephone support proposed or provided
- To describe attitudes towards telephone intervention
- To investigate barriers and facilitators to telephone interventions as perceived by patients.

Only studies where perceptions/ opinions of patients as service users are given, will be included in the study.

Only studies with at least 1 telephone call as an intervention will be eligible for inclusion.

For the purpose of this review, acceptability is defined as acceptance, acceptability, satisfaction with, opinions, beliefs, views, attitudes, impressions, experience or perceptions of patients having participated in a telephone intervention.

Types of studies

All studies published in English language providing data relating to any of the outcome concepts will be included, including RCT's, controlled and uncontrolled studies, qualitative studies, and theses. In cases where there is a comparison of telephone interventions with another group, this group may receive standard care or no care, or another form of intervention including alternative forms of telephone intervention. Due

to time and resource constraints, studies included will be limited to published work, and only English language.

Exclusion criteria

- Where studies include a mixed age group of paediatric and adult subjects, studies with ≤ 75% of participants ≥ 18 years old, will be excluded.
- Studies where the term 'telephone' and its derivatives are used within another context and not for the purpose of delivering an intervention will be excluded (i.e. invitation to participate in a study, telephone survey, telemedicine).
- Studies where participants do not have a cancer diagnosis will also be excluded (i.e. screening programmes).
- Where the term 'distance' is not used to refer to the telephone intervention (i.e. physical distance from treatment centre, distance related to tumour and treatment methods) studies will be excluded.
- Studies reporting support not instigated by the service provider will be excluded i.e. where participants call in to a designated helpline.
- Studies with a telephone intervention not related to cancer treatment (i.e. smoking cessation), or those failing to provide information regarding patient perceptions of an intervention will be excluded.
- Studies related to cancer and mobile phone use, will also be excluded.
- Studies involving an automated voice response system will be excluded.
- Where intervention delivery by telephone is less than 50% of the overall intervention delivery method, and only an overall rating for satisfaction with the intervention is provided (not just the telephone delivered intervention) studies will be excluded.

Search methods:

The following search strategy will be used for the review, using the keyword and MeSH terms in each database.

Terms to be searched:

Diagnostic terms - Cancer* , neoplasm*, carcinoma*, tumor*, tumour*, adenocarcinoma*, malignan*, oncolog*

Treatment terms	– surg*, *ectomy, chemotherap*, radiotherap*, immunotherap*, biological AND therap*, hormon* AND therap*, radioimmuno* AND therap*, stem AND cell AND transplant*, bone AND marrow AND transplant*, hematopoietic AND stem AND cell AND transplant*, photodynamic AND therap*, radiofrequency AND ablation, treatment
Intervention terms	– (phone, telephone, mobile phone, mobile telephone) OR (remote, non-face-to-face, distance)
Support terms	- monitor*, follow-up, follow AND up, information* AND support, social AND support, emotion* AND support, psych* AND support
Acceptability terms	– accepta*, adequa*, satisf*, opinion*, belief*, view*, attitude*, impression*, experience*, perception*, uptake, barrier*, valu*

The following databases will be searched:

PUBMED

MEDLINE (1948 to present)

EMBASE (1974 to present)

CINAHL (1981 to present)

British Nursing Index (1985 to present)

PsychINFO (1989 to present)

Cochrane Library

Web of Knowledge

ASSIA (Applied Social Sciences Index and Abstracts)

AMED (Allied and Complementary Medicine Database – includes palliative care)

TRIP (Turning Research into Practice) Database

UKCRN clinical trials portfolio

NIH Clinical trials database

As the search possibilities in the TRIP Database, UKCRN clinical trials portfolio and NIH Clinical trials database do not allow for the use of an advanced search, the following search terms will be used:

TRIP Database – (phone OR telephone OR mobile OR remote OR distance) AND cancer

UKCRN clinical trials portfolio - Type: Cancer, Any of the following – phone OR telephone OR mobile OR remote OR non face-to-face OR distance
NIH Clinical trials database: Cancer AND (phone OR telephone OR mobile) AND (adult or senior)

Searching other resources:

- Reference lists of articles will be checked for further studies. In cases where large cancer charities / organizations have published research, they will be contacted in order to evaluate the resources they have available. An attempt to contact study authors will be made where necessary, to find missing data and for clarity. Due to time and resource limitations of the review, conference proceedings, individual case studies, books and any unpublished abstracts will not be included.

Data collection:

Selection of studies

All studies where reference is made to telephone support and acceptability will be retrieved in full. Studies will be evaluated to decide on inclusion in this review. They must include at least one telephone call originating from a healthcare professional as an intervention of support for patients. The evaluation of inclusion or exclusion from the review will then be verified by two other researchers. In cases of doubt, resolution will be achieved by discussion between parties.

Appendix 3 – Systematic review search strategy

PUBMED

Searched - 18 March 2012
Updated - 2 October 2014

Search Terms
#1 (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
#2 (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
#3 (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
#4 (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
#5 (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)
#6 (#1 AND #2 AND#3 AND #4 AND #5)

MEDLINE (1948 to present)

Searched - 13 March 2012
Updated - 3 October 2014

Search Terms
1. (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
2. (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
3. (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
4. (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
5. (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)
6. (1 AND 2 AND 3 AND 4 AND 5)

EMBASE (1974 to present)

Searched - 18 March 2012
Updated - 3 October 2014

Search Terms
1. (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
2. (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
3. (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
4. (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
5. (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)

6. (1 AND 2 AND 3 AND 4 AND 5)

CINAHL Plus – Cumulative Index to Nursing and Allied Health Literature

Searched - 13 March 2012
Updated - 4 October 2014

Search Terms
S6 – S5 and S4 and S3 and S2 and S1
Search Modes: Boolean/phrase
Interface: EBCSOhost

S5 (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)
Search Modes: Boolean/phrase
Interface: EBCSOhost

S4 (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
Search Modes: Boolean/phrase
Interface: EBCSOhost

S3 (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
Search Modes: Boolean/phrase
Interface: EBCSOhost

S2 (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
Search Modes: Boolean/phrase
Interface: EBCSOhost

S1 (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
Search Modes: Boolean/phrase
Interface: EBCSOhost

British Nursing Index (1985 to present)

Searched - 18 March 2012
Updated - 3 October 2014

Search Terms
S6 – S5 and S4 and S3 and S2 and S1
Interface: ProQuest

S5 (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)
Interface: ProQuest

S4 (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
Interface: ProQuest

S3 (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
Search Modes: Boolean/phrase
Interface: EBCSOhost

S2 (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
Interface: ProQuest

S1 (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
Interface: ProQuest

PsychINFO (1989 to present)

Searched 18 March 2012
Updated - 3 October 2014

Search Terms
1. (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
2. (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
3. (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
4. (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
5. (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)
6. (1 AND 2 AND 3 AND 4 AND 5)

The Cochrane Library database

Searched – 24 March 2012
Updated - 17 September 2014

Search Terms
1. (phone OR telephone OR mobile OR remote OR distance) AND Cancer

Web of Science Core Collection (Web of Knowledge)

Searched - 13 March 2012
Updated - 4 October 2014

Search Terms
#1 (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
#2 (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
#3 (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
#4 (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
#5 (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)
#6 (#1 AND #2 AND#3 AND #4 AND #5)

ASSIA (Applied Social Sciences Index and Abstracts)

Searched - 13 March 2012
Updated - 3 October 2014

Search Terms

S6 – S5 and S4 and S3 and S2 and S1
Interface: ProQuest

S5 (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)
Interface: ProQuest

S4 (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
Interface: ProQuest

S3 (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
Search Modes: Boolean/phrase
Interface: EBCSOhost

S2 (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
Interface: ProQuest

S1 (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
Interface: ProQuest

AMED (Allied and Complementary Medicine Database – includes palliative care)

Searched - 18 March 2012
Updated - 3 October 2014

Search Terms
1. (cancer* OR neoplasm* OR carcinoma* OR tumour* OR adenocarcinoma* OR tumor* OR malignan* OR oncolog*)
2. (chemotherap* OR radiotherap* OR immunotherap* OR (biological AND therap*) OR (hormon* AND therap*) OR (radioimmuno* AND therap*) OR (stem AND cell AND transplant*) OR (bone AND marrow AND transplant*) OR (hematopoietic AND stem AND cell AND transplant) OR (photodynamic AND therap*) OR (radiofrequency AND ablation) OR treatment OR (surg* OR *ectomy))
3. (phone OR telephone OR mobile phone OR mobile telephone OR remote OR non face-to-face OR distance)
4. (monitor* OR follow-up OR (follow AND up) OR (information* AND support) OR (social AND support) OR (psych* AND support) OR (emotion* AND support))
5. (accepta* OR adequa* OR satisfaction OR opinion* OR belief* OR view* OR attitude* OR impression* OR experience* OR perception* OR uptake OR barrier* OR valu*)
6. (1 AND 2 AND 3 AND 4 AND 5)

TRIP (Turning Research into Practice) Database

Searched – 4 February 2012
Updated - 1 October 2014

Search Terms
1. (phone OR telephone OR mobile OR remote OR distance) AND Cancer

UKCRN clinical trials portfolio

Searched - 18 March 2012
Updated - 1 October 2014

Search Terms
Clinical Trial Type - Cancer
1. Any of the following - phone OR telephone OR mobile OR remote OR non face-to-face OR distance

NIH Clinical trials database

Searched - 17 March 2012
Updated - 1 October 2014

Search Terms
Condition/ Disease: Cancer
Other Terms: Phone OR telephone OR mobile
Eligibility criteria: Adult (18-65) OR Senior (66+)

Appendix 4 – Data extraction form for the systematic review of the literature

DATA EXTRACTION FORM (v7 – 16/10/13)

AUTHOR YYYY Name of reviewer:

Section 1: General information

Section 2: Population providing satisfaction /feasibility/acceptance data

Section 3: Patient Characteristics (providing satisfaction/ feasibility/ acceptance data)

Section 4: Intervention(s)
- **4.1: Control group**
- **4.2: Intervention 1 (please complete Section 4.2 for each intervention)**

Section 5: Objectives

Section 6: Outcomes related to satisfaction/ feasibility/ acceptance

Section 7: Study design and outcome reporting
- **7.1 Quantitative study design (satisfaction/ feasibility/ acceptability data only)**
- **7.2: Qualitative Study Design (satisfaction/ feasibility/ acceptability data only)**
- **7.3 Questionnaire feedback (satisfaction/ feasibility/ acceptability data only)**

Section 8: Ethics

Section 9: Data analysis
- **9.1 Quantitative Data Analysis (Satisfaction/ feasibility/ acceptance data)**
- **9.2. Qualitative Data analysis (satisfaction / acceptability /feasibility data**
- **9.3 Questionnaire data analysis (satisfaction/ feasibility/ acceptability data only)**

Section 10: Results
- **10.1: Results: Quantitative data (Satisfaction / feasibility/ acceptability data)**
- **10.2: Results: Qualitative data (Satisfaction / feasibility / acceptance data)**
- **10.3 Results: Questionnaire data (satisfaction/ feasibility/ acceptability data only)**

Section 11: Other

DATA EXTRACTION FORM

Section 1: General information

- Study ID (First author + Year)
- Report title
- Country where data collected
- Study design (please provide brief description e.g. qualitative / quantitative/ RCT, Controlled before/after, Uncontrolled)

Section 2: Population providing satisfaction /feasibility/acceptance data

- Target population
- Recruitment Context
- Recruitment method (how – description of actual recruitment procedure)
- Inclusion criteria
- Exclusion criteria
- Total number receiving intervention
- Total number that were asked about satisfaction / acceptance
- Total number providing data about satisfaction / acceptance
- Total number not providing data (e.g. didn't meet inclusion criteria / refused to participate / other reason……..)
- Are the reasons why decided not to participate discussed?

SECTION 3: Patient Characteristics (providing satisfaction/ feasibility/ acceptance data)

Where data are extracted for a quantitative study, please provide the characteristics of the different groups – extracting data of those giving satisfaction / adherence data

- Patients diagnosis (with % sample and/or n as appropriate)
- Duration of cancer (e.g. new diagnosis / in treatment phase/ post treatment (years/months))
- Patients baseline sex (Male / Female)
- Patients baseline age
- Treatment undergone / undergoing (e.g. chemotherapy, radiotherapy, immunotherapy or biological therapies, hormonal therapies, radio-immunotherapy, stem cell transplant, bone marrow transplant, photodynamic therapy (PDT) or radiofrequency ablation, surgery)
- Other

SECTION 4: Intervention(s)

Section 4.1: Control group

- Brief description of the control group (please enter a one sentence summary description e.g. no treatment, standard treatment)
- Please provide information regarding the content of the telephone contact (where applicable)

Section 4.2: Intervention 1 (please complete Section 11.2 for each intervention)

- Brief description of the intervention (please enter a one sentence description)
- Full description of intervention (include sufficient detail for replication, e.g. content, components, any underpinning theory)
- Total duration/time period over which the intervention was delivered (i.e 12 weeks)
- Who was involved in delivering the intervention? (e.g. professional background, experience)
- How (e.g. face to face, by telephone – provide %)?
- Was there any procedure for tailoring the intervention to individual participants?
- How were the interventions standardised? (e.g. what measures were in place / reported)?
- Number and timing of scheduled interventions (e.g. 6 bi-weekly sessions)?
- Length of each scheduled session (e.g. 1 hour)
- What was the total amount of scheduled guidance (e.g. 6 hours)?
- What was the content of the scheduled sessions? (e.g. monitoring, motivation, information)
- Did the individual delivering the intervention receive any specific training to do so?
- Did the individual delivering the intervention receive supervision?
- Were there any additional or unscheduled components e.g. (Yes/No, please specify)
- What was the total amount of unscheduled input (e.g. 60 mins)?
- How was health care professional adherence assessed or enhanced?
- Please provide information regarding the content of the telephone contact:

SECTION 5: Objectives

- Was satisfaction / acceptability / feasibility specified explicitly to be a main aim or primary objective of the study? (if yes, please specify)

SECTION 6: Outcomes related to satisfaction/ feasibility/ acceptance

- Was satisfaction/ feasibility/ acceptance identified as a main outcomes of the study?
- When were outcomes assessed ? (please specify how long after the intervention)
- How were outcomes to be measured ? (please specify any tools, their validity/ methodology)?
- Are all relevant outcomes reported in the analysis (specify any that were missing)

SECTION 7: Study design and outcome reporting

Section 7.1 Quantitative study design - (satisfaction/ feasibility/ acceptability data only)

- Number of groups, conditions or trial arms
- Unit of randomisation (i.e. who was randomised? e.g. patient / centre or group)
- Description of the method used to generate a random sequence including any details of restriction (e.g. blocking, stratification), (i.e. how was the random sequence generated? e.g. coin toss, computer)
- Risk of bias in random sequence generation (i.e. how likely is it to produce incomparable groups) - (HIGH, LOW, UNCLEAR)

- Method of allocation concealment (i.e. was this reported and how was it achieved? e.g. independently-hosted, sealed envelopes), clarifying whether the sequence was concealed until interventions were assigned
- Who generated the allocation sequence, who enrolled participants, and who assigned participants to their groups
- Risk of bias in allocation concealment (i.e. could intervention allocations be foreseen before or during enrolment?) (HIGH, LOW, UNCLEAR)
- Blinding of participants and personnel (i.e. how were those receiving and delivering the intervention blinded from the intervention received e.g. by offering a standard intervention, was it effective?)
- Whether or not those administering co-interventions were blinded to group assignment
- Risk of bias in blinding of participants and personnel (i.e. could participants & personnel have had knowledge of which intervention they had received) - (HIGH, LOW, UNCLEAR)
- Risk of bias in outcome reporting (i.e. are reports free of the suggestion of selective outcome reporting?) - (HIGH, LOW, UNCLEAR)
- Blinding of outcome assessors (i.e. who conducted outcome assessments and how effectively were they kept blind to the intervention received?)
- Risk of bias in blinding of outcome assessors (i.e. could assessors have had knowledge of which intervention they were assessing) - (HIGH, LOW, UNCLEAR)
- Were attrition and exclusions from the analysis reported with reasons (please specify numbers and causes where provided)?
- Risk of bias in incomplete outcome data (i.e. were incomplete outcome data analysed?) - (HIGH, LOW, UNCLEAR)
- Power calculation (i.e. was a power or sample size calculation reported?)
- Did they conduct an intention to treat analysis? (e.g. analysed all patients irrespective of adherence to treatment)
- Was there any early analysis of data/ why / outcomes?
- Any other potential biases (i.e. did the study have any other problems or characteristics that could put it at a high risk of bias?)

Section 7.2: Qualitative Study Design - satisfaction/ feasibility/ acceptability data

- Is a qualitative methodology appropriate? (did the research seek to interpret or illuminate the actions and/or subjective experiences of research participants?)
- Was the research design appropriate to address the aims of the research?
- Was it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- Did the researcher make the methods explicit (e.g. for interview method, is there an indication of how interviews were conducted, time lasted, or did they use a topic guide)?
- Were methods were modified during the study. If so, has the researcher explained how and why?
- Was there any early analysis of data/ why / outcomes?
- Did the researcher discuss saturation of data
- Did the researcher critically examined their own role, potential bias and influence during the formulation of the research questions?
- Did the researcher discuss their role in data collection, including sample recruitment and choice of location

Section 7.3 Questionnaire feedback (satisfaction/ feasibility/ acceptability data only)

SECTION 8: Ethics

- Was approval sought from the ethics committee

SECTION 9: Data analysis

Section 9.1 Quantitative Data Analysis - Satisfaction/ feasibility/ acceptance data

- Was there an in-depth description of the analysis process (inc. statistical procedures)
- Were there statistical methods used to compare groups for primary outcome(s); methods for additional analyses, such as subgroup analyses and adjusted analyses
- Is sufficient data provided to support findings?

Section 9.2: Qualitative Data analysis: satisfaction / acceptability /feasibility data

- Was there a description of the analysis process (if so, please specify, e.g. thematic analysis, coding etc.)
- Did the researcher discuss how the rigour of the research was ensured (e.g. transcript checks, verification of coding etc.) ?
- Is sufficient data provided to support findings?
- To what extent is contradictory data taken into account?

Section 9.3 Questionnaire data analysis (satisfaction/ feasibility/ acceptability data only)

SECTION 10: Results

Section 10.1: Results: Quantitative data– Satisfaction / feasibility/ acceptability data

- Is there a clear statement of findings
- Were the findings discussed in relation to the original research question

Section 10.2: Results: Qualitative data– Satisfaction / feasibility / acceptance data

- Is there a clear statement of findings?
- Were the findings discussed in relation to the original research question

Section 10.3 Results: Questionnaire data (satisfaction/ feasibility/ acceptability data only)

SECTION 11: Other

- Other comments / notes of interest

Appendix 5 – Rationale for exclusion of papers

Reason for rejection	Rejected papers from 1st search	Rejected papers from 2nd search
Incomplete information to confirm study inclusion criteria e.g. conference proceedings where no further information/ data available from authors	12	2
Failure to meet participant criteria e.g. <75% receiving treatment, not cancer diagnosis	14	8
Failure to meet intervention criteria e.g. patient initiated calls, not HCP delivered, videophone, telemedicine	44	19
Failure to meet outcome criteria e.g. not patient perceptions, not satisfaction data	54	27
Other e.g. not primary research studies	34	5
Total number of papers rejected	**158**	**61**

HCP – Healthcare Professional

Appendix 6 - Systematic review - Patient and Study Characteristics (Liptrott et al., 2017)

First author/ Date/ Country/ Study Quality	**Study population** *N*/ **age / %male** **Recruitment**	**Study design** **Intervention intensity/ duration/ other components / structure** **Delivery Agent** **Comparison Group (s)**	**Outcome type** **Method / instrument**	**Timing of assessment** **Acceptability Data (AD): N providing data (% of total receiving intervention)**	**Outcome data type (Quality)**
Alter *et al.*, 1996 USA *Medium*	Colorectal cancer pts receiving CT *N*=8 Range 59-79yrs (TSS only) 63% male Recruited via oncologist NOS	Quasi-experimental - Single group Interpersonal counselling 4 sessions bi-weekly over 8 weeks Semi-structured technique Nurse-led	Feasibility Discussion of intervention - NOS	6 weeks after end of study AD: *N*=7 (88%)	Qual (low)
Anderson, 2010 UK *Medium*	Prostate cancer pts receiving various treatments *N*=67 Range 67-97yrs (TSS only) 100% male Recruited via OP oncology clinic	Non-experimental - Single group Telephone FU for symptom and PSA monitoring 3, 6 or 12 monthly Intervention followed specific guideline Nurse-led	Satisfaction Likert scale – 12 q's (provided) Not validated	Pts still receiving intervention AD: *N*=43 (64%)	Quant (low)
Archer et *al.*, 2014 UK *Medium*	Gynaecological cancer pts post-surgery *N*=34 Mean 66yrs (range 53-80) 0% male Recruited via regional cancer centre	Non-experimental - Single group Enhanced Recovery Team telephone call post discharge - NOS Structure NR Enhanced Recovery Team – NOS	Experience Semi-structured interviews - NOS	Post intervention NOS AD: *N*=14 (41%)	Qual (high)
Badger *et al.*, 2013 USA *Low*	Breast cancer pts receiving treatment - NOS *N*=51 (TSS only) Mean a) 52 yrs – SD14, b) 58yrs – SD11, c) 47 yrs – SD12 (TSS only) 0% male Recruited via local cancer centre, oncologists offices, support groups, self-referral	RCT – 3 groups (patient & dyad) a) Telephone Health Education (n=18) b) Telephone Interpersonal Counselling (n=20) c) Video Interpersonal Counselling (n=13) 8 weekly sessions for patients (4 bi-weekly sessions for dyads) Protocol for counselling stated to be the same a) Information specialist, b) & c) Social Worker	Satisfaction Open ended questions (topic provided) - NOS	End of intervention period AD: a) THE *N*=9 (50%) b) TIC *N*=18 (90%) c) VIC *N*=13 (100%)	Qual (low)
Barsevick *et al.*, 2002 USA *Low*	Breast, lung, colon, prostate cancer pts receiving CT or RT a) Intervention *N*=80, b) Ctrl *N*=182 Age NR/ Gender NR Recruitment NR	nRCT – 2 groups a) Energy conservation and activity management for pts developing fatigue 3 sessions weekly (over 3 weeks in CT group and 5 weeks in RT group) Semi-structured technique Nurse-led b) Standard care	Acceptability / Helpfulness Interview with 10 closed q's (topics provided) Not validated	End of study (NOS) AD: Intervention group only *N*=64 (80%)	Quant (low)

Beaver *et al.*, 2009 UK *High*	Breast cancer pts post-surgery/ receiving RT / CT a) Intervention *N*=191, b) Ctrl *N=183* Mean 63yrs – SD10.1 (TSS only)/ 0% male Recruited via DGH or Breast Cancer Unit	RCT – 2 groups a) Telephone FU – general and symptom monitoring, support, long-term issues Timing in line with standard FU Structured intervention Nurse b) Standard hospital FU	Satisfaction Questionnaire designed & piloted - NOS Not validated	Start, mid and end of study AD: a) Intervention mid trial *N*=138 (72%) end trial *N*=154 (81%) b) Ctrl mid trial *N*=121 (66%) end trial *N*=145 (79%)	Quant (low)
Beaver *et al.*, 2010 UK *High*	Breast cancer pts receiving surgery, RT or CT *N*=28 Mean 61yrs (range 48-80) (TSS only)/ 0% male Computer selected random sample of patients receiving a telephone intervention [64]	Nested - Single group Telephone FU – general and symptom monitoring, support, long-term issues Timing in line with standard FU Structured intervention Nurse-led	Explore and describe views Semi-structured interviews (topics provided)	Timing of assessment not reported AD: *N*=28 (100%)	Qual (high)
Beaver *et al.*, 2012 UK *Medium*	Colorectal cancer pts receiving RT, CT or surgery a) Intervention *N*=31, b) Ctrl *N* =31 Mean a) Intervention 73.6yrs – SD7.6, b) Ctrl 72.4 yrs – SD8.2 a) Intervention 64% male b) Ctrl 52% male Recruited via hospital OP department	RCT – 2 groups a) Telephone FU - general and symptom monitoring, support, long-term issues Timing in line with standard FU Structured intervention Nurse-led b) Standard hospital FU	Satisfaction Adapted Likert scale – (topics provided) Not validated Likert scale - overall satisfaction Not validated	Baseline and one additional time point (chosen to maximize number of sessions received) AD: a) Intervention *N*=25 (80%) b) Ctrl *N*=25 (80%)	Quant (low)
Booker *et al.*, 2004 UK *Low*	Prostate cancer pts post RT *N*=36 Age NR 100% male Recruited via tertiary referral centre (convenience sample)	Non-experimental - Single group Telephone FU – symptom monitoring, addressing concerns, information provision Timing / duration NR Structured interview & proforma Nurse-led	Acceptability Closed q's (topics provided) Not validated Comments (qual data)	After telephone FU call AD: *N*=36 (100%)	Quant (low) Qual (low)
Campbell *et al.*, 2007b USA *High*	Prostate cancer pts (and partner) post prostatectomy or receiving HT or WW a) Intervention *N*=15, b) Ctrl *N*=18 Mean 59.8 yrs – SD8 100% male Recruited via urology clinic or self-referral from community	RCT – 2 groups a) Coping skills training - education, training, information, problem solving, motivation & coping skills 6 sessions weekly (over 6 weeks) Structured intervention with outline for each session Psychologist-led b) Standard care	Experience 1 open-ended question (provided)	After final session Intervention only AD: Intervention group only *N*=15 (100%)	Qual (high)

Cimprich *et al.*, 2005 USA *Medium*	Breast cancer pts receiving surgery, RT or CT combinations a) Intervention *N*=25, b) Ctrl *N*=24 Mean 48 yrs – SD8 0% male Recruited via cancer centre or oncology clinic	RCT – 2 groups a) Self- management and survivorship programme teaching skills, addressing concerns, providing information 4 sessions bi-weekly over 8 weeks (2 group sessions, 2 telephone sessions) Structured intervention with manual Nurse + health educator led b) Standard care	Usefulness Likert scale 1q (topic provided) Not validated 2 open-ended q's (topic provided) & comments	At end of 4th (final) session AD: Intervention group only *N*=22 (88%)	Quant (low) Qual (low)
Cirillo *et al.*, 2014 Italy *Low*	Variety cancer pts receiving CT or targeted agents *N*=81 Mean 68yrs (range 33-91) (TSS only) 46% male (TSS only) Recruited via medical oncology department	Quasi-experimental - Single group Patient monitoring service – information and support for side effect management Phone calls at days 7 & 14 after 1st treatment, then at day 14 of 2nd treatment (additional 2 face to face clinic visits) Patient self reported questionnaire as basis Nurse-led	Usefulness Rating scale – NOS Not validated	Timing of assessment NR AD: *N*=63 (78%)	Quant (low)
Cox *et al.*, 2005 UK *Low*	Variety cancer pts having received anticancer therapy - NOS a) Intervention *N*=47, b) Ctrl *N*=58 Mean 59.8yrs –SD11.6 (TSS only) 53% male Recruited via 2 cancer centres	RCT – 2 groups a) Trial exit intervention – information provision & emotional support 2 sessions, 2 weeks apart (one session face-to-face) Structured intervention following trial feedback sheet Research Nurse-led b) Standard care	Satisfaction Adapted MISS (26 items) Not validated	7-10 days post trial AD: Intervention group only *N*=44 (n=93%)	Quant (low)
Cox *et al.*, 2008 UK *Medium*	Ovarian cancer pts having completed initial cancer treatment - NOS *N*=52 Mean 62yrs – SD10.89 0% male Recruitment NR	Quasi-experimental - Single group Telephone FU post treatment – monitoring, information provision, support, practical advice, coping strategies 3 sessions, once every 3 months over 10 months Structured intervention with checklist Nurse-led	Satisfaction Likert scale (4 domains provided) Validated in other studies Open section on general views of care experienced - NOS	End of 10mth period AD: *N*=46 (100%)	Quant (low) Qual (low)
Craven *et al.*, 2013 UK *Low*	Colorectal cancer pts receiving targeted agents *N*=30 (random sample of 298 receiving intervention) Mean 67.3yrs – SD11.3 (TSS only) 54% male (TSS only) Recruited via large cancer centre	Non-experimental audit - Single group Telephone FU – monitoring, toxicity management, evaluation, support Phone calls at days 3 & 10 after 1st treatment, then at day 10 of 2nd treatment Protocol to be followed Colorectal cancer nurse specialist led	Satisfaction / Use / Helpfulness Questionnaire (topics provided) Not validated	Nurse led FU on-going AD: *N*=30 (n=298 already receiving intervention)	Quant (low)

Delaney *et al.*, 2009 Canada *Medium*	Neurological cancer pts post RT / CT *N*=13 Median 66yrs (range 45-67) (TSS only) 77% male (TSS only) Recruited via neuro-oncology OP clinic	Quasi-experimental - Single group Education and support in CT administration, side effect management, supportive therapy, medication interactions & questions 3 sessions – 1 hospital visit and calls at 1 and 5 days later (one session face-to-face) Standardised counselling Pharmacist-led	Feasibility / Usefulness Likert scale 2 q's (provided) Not validated	End of study - NOS AD: *N*=11 (85%)	Quant (low)
Dixon, 2010 Canada *Low*	Variety cancer pts post RT *N*=53 Mean 69yrs (TSS only) 63% male (TSS only) Recruitment NR	Quasi-experimental audit - Single group Telephone FU post RT – monitoring of side effects / information provision 2 sessions 1 and 4 weeks post RT Structured intervention (ESAS) Radiation therapist-led	Feedback/ satisfaction Comments during telephone calls	During intervention - NOS AD: N=38 (72%)	Qual (low)
Donnelly *et al.*, 2013 UK *High*	Gynaecological cancer pts having completed or receiving treatment - NOS (Patients having participated in RCT) *N*=31 Mean 55yrs (range 38-78) 0% male Recruited following invitation to all patients involved in RCT	Nested – sample from 2 groups a) Telephone contact - symptom checklist b) Telephone contact + physical activity program - levels of activity, barriers, goals, symptom checklist Weekly telephone calls –NOS – over 12 weeks NR - Telephone component Physiotherapist – Activity Program	Experiences Focus groups – open ended questions (topics provided)	Timing of assessment NR AD: *N*=16 (52%)	Qual (high)
Garrett *et al.*, 2013 USA *Low*	Variety cancer pts receiving surgery, CT or RT *N*=66 Range 20-69yrs 48% male Recruited via oncology clinics and rural community cancer centre	Quasi-experimental - Single group Cancer Survivor Telephone Education and Personal Support Program (C-STEPS) - Choice to participate in either / both modules: Uncertainty & Stress Management / Healthy Diet & Physical Exercise 6 weekly sessions Semi-structured intervention following worksheet Occupational Therapist led	Satisfaction / Helpfulness Likert scale questionnaire (topics provided) Not validated	After completion of program – NOS AD: *N*=46 (70%)	Quant (low)
Hafiji *et al.*, 2012 New Zealand (NZ) and UK *Low*	Non melanoma skin cancer pts post-surgery a) Intervention *N*=187, b) Ctrl *N*=54 Mean a) Intervention 64.5yrs (range 21-91) NZ, mean 64.8yrs (range 20-90) UK, b) Ctrl mean 64.5yrs (range 34-87) a) Intervention 57% male, b) Ctrl 56% male Recruited via 2 regional MMS centres	nRCT – 2 groups a) Telephone call – monitoring, information provision 1 call – the evening post surgery Semi-structured – specific and open Q's Surgeon-led b) Standard care	Satisfaction / Perception Likert scale – NOS Not validated Comments / feedback from patients	5-7 days after phone call AD: Intervention *N*= 187 (% unclear) Ctrl *N*=54 (% unclear)	Quant (low) Qual (low)

Hagopian and Rubenstein, 1990 USA *Low*	Variety cancer pts receiving RT a) Intervention *N*=27, b) Ctrl *N*=28 Mean 58yrs (range 22-84) (TSS only) 33% male (TSS only) Recruited via hospital RT Department	RCT – 2 groups a) Telephone FU during RT – side effect monitoring, information, anticipatory guidance, coping strategies, address concerns Weekly, continuing 4-6 weeks post RT Semi-structured, standardised set of topics Nurse-led b) Standard care	Satisfaction / Helpfulness Questionnaire – NOS Not validated Comments from patients	Timing assessment NR AD: Intervention group only *N*=18 (55%)	Quant (low) Qual (low)
Hegel *et al.*, 2011 USA *Medium*	Breast cancer pts receiving CT a) Intervention *N*=14, b) Ctrl *N*=15 Mean 52.6yrs – SD9.4 0% male Recruited via cancer centre OP clinic	RCT – 2 groups a) Problem solving- information provision, motivating, goal setting, support & problem solving 6 weekly sessions Semi structured intervention following work sheet Occupational Therapist-led b) Standard care	Acceptability / Satisfaction Likert scale 2 q's (topics provided) Not validated	6 weeks after the end of the intervention AD: Intervention *N*=9 (64%) Ctrl *N*=15 (100%)	Quant (low)
Heidrich *et al*., 2009 USA *Medium*	Breast cancer pts receiving surgery, CT, RT, HT combinations a) Intervention *N*=20, b) Ctrl *N*=21 Mean 72.5 yrs (range 68-86) 0% male Recruited via cancer centre OP clinic + community advertising	Pilot Study 1: RCT – 2 groups a) Individualized Representational Intervention to Improve Symptom Management – support, symptom monitoring, management plan and strategies, information provision 5 sessions (baseline, 2, 4, 6 and 8 weeks later) (Baseline session face to face) Protocol driven intervention Nurse-led b) Standard care	Acceptability / Satisfaction 8 q's (topics provided) Not validated	At 6 and 10 weeks post intervention AD: Intervention *N*=20 (100%) Ctrl *N*=21 (100%)	Quant (low)
Medium	Breast cancer pts receiving surgery, CT, RT, HT combinations a) Intervention *N*=9, b) Ctrl *N*=11 Mean 69.7yrs (range 65-82) 0% male Recruited via cancer centre OP clinic + community advertising	Pilot Study 2: RCT – 2 groups a) Individualized Representational Intervention to Improve Symptom Management – support, symptom monitoring, management plan and strategies, information provision 5 sessions (baseline, 2, 4, 6 and 8 weeks later) (Baseline session face to face) Protocol driven intervention Nurse-led b) Standard care	Acceptability / Satisfaction 8 q's (topics provided) Not validated	At 2, 4, 6, 8 and 16 weeks AD: Intervention *N*=9 (100%) Ctrl *N*=11 (100%)	Quant (low)
Low	Breast cancer pts receiving surgery, CT, RT, HT combinations *N*=20 Mean 67.9yrs (range 65-73) 0% male Recruited via cancer centre OP clinic + community advertising	Pilot Study 3: Single group Individualized Representational Intervention to Improve Symptom Management – support, symptom monitoring, management plan and strategies, information provision 5 sessions (baseline, 2, 4, 6 and 8 weeks later) (Baseline session face to face) Protocol driven intervention Nurse-led	Acceptability / Satisfaction 8 q's (topics provided) Not validated	At 2, 4, 6, 8 and 16 weeks AD: *N*=20 (100%)	Quant (low)

Inman *et al.*, 2011 USA *Medium*	Prostate cancer pts post-surgery a) Intervention *N* =30, b) Ctrl *N*=30 Mean 60.2yrs- SD6.99 100% male Recruited via academic centre	RCT – 2 groups a) Educational Intervention – monitoring, education, information provision 1 session, 3-5 days post discharge Intervention algorithm for educational reinforcement Nurse-led b) Standard care	Satisfaction / Helpfulness 1 closed q (provided) Not validated Comments from patients during calls	30 days after discharge AD: Intervention group only *N*=30 (100%)	Quant (low) Qual (low)
Jefford *et al.*, 2011 Australia *Medium*	Colorectal cancer pts receiving surgery, CT, RT, combinations *N*=10 Mean 55yrs (range 35-71) (TSS only) 50% male (TSS only) Recruited via cancer centre	Quasi-experimental - Single group Post treatment support package – education, information provision, monitoring, support, coaching, health promotion 4 sessions (1st at end of treatment, then 1, 3 and 7 weeks later) (one session face-to-face - package included DVD and written information) Semi-structured intervention – manual for 1st session Nurse	Satisfaction Interview - NOS	After 3rd pone call (NOS) AD: *N*=8 (80%)	Qual (low)
Jensen *et al.*, 2011 Denmark *Medium*	Prostate cancer pts following prostatectomy a) Intervention *N*=46, b) Ctrl *N*=49 Mean a) Intervention 64.1yrs (95%CI 62.5-65.8), b) Ctrl 62. 5yrs (95%CI 60.9–64. 2) 100% male Recruited via urology centre	RCT – 2 groups a) Telephone FU – NOS 1 session 3 days after discharge Semi structured intervention – manual for interview Nurse-led b) Standard care	Satisfaction Likert questionnaire (topic provided) – NOS Not validated	2 weeks post-op AD: Intervention only *N*=46 (100%)	Quant (low)
Kelly *et al.*, 1999 Canada *Low*	Ovarian cancer pts receiving CT *N*=50 Age NR 0% male Recruited via OP CT clinic	Non-experimental - Single group Telephone FU – symptom monitoring, information provision, support Calls 5-7 days post CT and once every 3-4 weeks during CT – NOS Semi-structured intervention – assessment tool to follow Nurse-led	Benefit / Acceptability / Helpfulness 4 closed q's (topics provided) Not validated 2 open q's (topics provided) Not validated	Evaluation time point NR AD: *N*=31 (62%)	Quant (low) Qual (low)
Kilbourn *et al.*, 2013 USA *Low*	Head & neck cancer pts receiving RT *N*=16 Mean 59.66yrs – SD9.78 (TSS only) 76.2% male (TSS only) Recruited via radiation oncology clinic (convenience sample)	Quasi-experimental - Single group Easing + Alleviating Symptoms during treatment – stress management, coping skills training, psycho-education to increase understanding of treatment related side effects 2-10 sessions (50% received 4-6 sessions) Structure NR Psychologist led	Satisfaction Likert scale 2 q's (topics provided) Not validated Exit interviews - NOS	Evaluation timepoint NR AD: Process evaluation *N*=11 (69%) Qualitative interviews *N*=8 (50%)	Quant (low) Qual (low)
Kim *et al.*, 2011 South Korea *Medium*	Breast cancer pts receiving surgery, RT, CT or HT a) Intervention *N*=23, b) Ctrl *N=22)* Mean a) Intervention 44.6yrs (range 26-69), b) Ctrl NR (TSS only) 0% male Recruited via cancer centre	RCT – 2 groups a) Individualised diet and exercise counselling – monitoring, motivation, support, information provision 12 weekly sessions Semi-structured – use of telephone counselling protocol Nurse-led b) Standard care	Feasibility / Helpfulness Likert scale (topics provided) Not validated	Baseline and 12 weeks after intervention AD: Intervention group only *N*=14 (61%)	Quant (low)

Kimman *et al.*, 2010b Netherlands *High*	Breast cancer pts receiving surgery, RT, CT or HT Study compared hospital FU groups (Ctrl a) + c)) vs telephone FU groups (Intervention b) + d)) b+d) Intervention *N*=120, a+c) Ctrl *N*=149 Mean b+d) Intervention 55yrs – SD9, (TSS only) a+c) Ctrl 56 yrs – SD10.7 0% male Recruited via 7 hospitals + 2 RT clinics	RCT – 4 groups a) Standard hospital FU - 4 sessions, 3monthly b) Telephone FU- 4 sessions, 3 monthly c) Hospital FU + Educational Group Program 2 EGP sessions within 3 months after treatment d) Telephone FU + Educational Group Program 4 sessions, 3 monthly and 2 EGP sessions within 3 months after treatment (Telephone FU – symptom monitoring, treatment side effect management, drug compliance) (Educational Group Program – education, information coping strategies, group discussion) (Groups c) + d) received 2 group sessions) Structured educational group sessions Nurse delivered telephone FU Nurse + psychologist delivered EGP	Satisfaction PSQIII Validated	Baseline, 3, 6 and 12 mths post treatment AD: Intervention *N*=120 (100%) Ctrl *N*=149 (100%)	Quant (low)
Leahy *et al.*, 2013 Australia *Medium*	Prostate cancer pts receiving HT, RT, brachytherapy, prostatectomy or WW a) Intervention *N*=86, b) Ctrl *N*=83 Mean a) Intervention 68.4yrs (range 49-80), b) Ctrl 70.2yrs (range 55-82) 100% male Recruited via cancer centre OP clinics	nRCT – 2 groups a) Telephone FU – general and symptom monitoring, PSA level review, information provision Once every 6 months – NOS Structured intervention following evidence based algorithms Nurse-led b) Standard care	Satisfaction Adapted Satisfaction with Consultation Scale Not re-validated	1 week after intervention AD: Intervention *N*=86 (100%) Ctrl *N*=83 (100%)	Quant (low)
Livingston *et al.*, 2010 Australia *Medium*	Colorectal cancer pts post CT *N*=59 Range 30-79yrs 63% male Recruited via 6 public + private health services	Quasi-experimental - Single group Screening for depression post CT – DIT completion, information provision, support, referral to psycho-oncologist 2 sessions (1st 7-10 days post recruitment, 2nd 4 weeks later) Intervention based on clinical practice guidelines Nurse-led	Experience / Perception / Satisfaction Likert scale questionnaire (topics provided) Not validated Telephone interview with open questions - NOS	1 mth after last call AD: *N*=45 (100%) NR	Quant (low) Qual (low)
Marcus *et al.*, 1993 USA *Low*	Breast cancer pts post adjuvant treatment *N*=30 Mean 49.9yrs (range 40-70) 0% male Recruited via 4 Hospitals + 1 cancer clinic	Quasi-experimental - Single group Telephone counselling – interviews assessing physical and psychosocial concerns – NOS Timing NR Structure NR Counsellor-led	Feasibility 1 evaluation indicator (provided) Not validated	Evaluation timing NR AD: *N*=30 (100%)	Quant (low)

Marcus *et al.*, 2010 USA *Medium*	Breast cancer pts post treatment a) Intervention *N=152*, b) Ctrl *N=152* 'About half the sample was 50 yrs of age or less' a) Intervention (range <40-70+) b) Ctrl (range <40-70+) 0% male Recruited in 21 hospitals & medical centres nationwide	RCT – 2 groups a) Booklet provided listing psychosocial + rehabilitation services in their community + telephone counselling over 12 months – 6 modules: living with uncertainty, physical change, self-change, sexuality, relationships, economic change 16 sessions - 9 sessions at bi-wkly intervals, 7 sessions monthly Structured – thematic modules, guides, worksheets (prioritised by participant) Psycho-oncology counsellors b) Booklet provided listing psychosocial + rehabilitation services in their community	Helpfulness Questionnaire on component of intervention which was most helpful (provided) Not validated	End of intervention AD: Intervention group only *N=129* (85%)	Quant (low)
Mordenti *et al.*, 2013 Italy *Low*	Patients receiving CT - NOS *N*=170 Age NR Gender NR Recruitment - consecutive patients invited - NOS	Quasi-experimental - Single group Telephone support post CT – monitoring, education and support One call the 1st day after 1st cycle of CT Structured (3q's) Nurse-led	Usefulness Survey (topics provided) Not validated	At the following visit AD: *N*=170 (100%)	Quant (low)
Munro *et al.*, 1994 UK *Medium*	Variety cancer pts receiving RT a) Intervention *N*=49, b) Ctrl *N*=51 Mean a) Intervention 63yrs (range 30-87), b) Ctrl 65yrs (range 37-88) Recruited via RT department	RCT - 2 groups a) Telephone intervention between clinic visits – general, side effect and symptom monitoring, information provision 4 sessions on days 4, 8, 14 and 18 post RT Semi-structured calls with open ended q's Radiographer, nurse or doctor led b) Standard care	Helpfulness Likert scale 1q (provided) Not validated	4 weeks after RT AD: Intervention *N*=49 (100%) Ctrl *N*=51 (100%)	Quant (low)
Reese *et al.*, 2012 USA *Medium*	Colorectal cancer pts post-surgery, RT / CT combinations (and partners) *N*=9 Mean 61.6yrs – SD14.5 56% male Recruited via cancer centre registry, medical record screening, GI cancer clinic, self- referral	Quasi-experimental - Single group Intimacy enhancement program – education, behavioural skills for coping, improving sexual intimacy, intimacy building activities Weekly sessions over mean 5.1wks (SD1.1) Manual provided Agent NR	Acceptability / Ease of participation / Helpfulness Likert scale 4q's (topics provided) Not validated	Evaluation timing NR AD: *N*=9 (and 9 partners) (100%)	Quant (low)
Reese *et al.*, 2014 USA *Medium*	Colorectal cancer pts post-surgery / on treatment (and partners) a) Intervention *N*= 10, b) Ctrl *N*=8 Mean a) Intervention 48.7yrs – SD11, b) Ctrl 57.4yrs – SD8.4 a) Intervention 60% male, b) Ctrl 60% male Recruited via cancer centre registry, medical record screening, GI cancer clinic, self- referral	RCT – 2 groups a) Intimacy enhancement program – education, behavioural skills for coping, improving sexual intimacy, intimacy building activities Weekly sessions over mean 4.8wks (SD2.5) Manual provided Psychologist-led b) Standard care	Acceptability / Ease of participation / Helpfulness Likert scale 3q's (topics provided) Not validated	Evaluation timing NR AD: Intervention group only *N*=10 (and 10 partners) (100%)	Quant (low)

Salonen *et al*., 2009 Finland *Medium*	Breast cancer pts post-surgery a) Intervention *N*=120, b) Ctrl *N*=108, Mean a) Intervention 57yrs (range 31-75), b) Ctrl 56 yrs (range 24-75) 0% male Recruited via departments of Oncology + Surgery	nRCT – 2 groups a) Social support – education, information provision, instructions for exercise, support, health education 1 session 1 week post surgery Semi-structured interview manual Physiotherapist-led b) Standard care	Perception Revised likert scale [80] Validated 1 open ended q (topic provided)	Within 2 weeks after discharge AD: Intervention group only *N*=unclear (unclear %)	Quant (low) Qual (low)
Sandgren *et al*., 2000 USA *Medium*	Breast cancer pts receiving surgery, RT, CT or HT combinations a) Intervention *N*=24, b) Ctrl *N*=29 Mean a) Intervention 51.23yrs – SD 12.5, b) Ctrl age NR (TSS only) 0% male Recruited via hospital – NOS	RCT – 2 groups a) Cognitive Behavioral Therapy – support, teaching coping skills, managing anxiety & stress, problem solving 10 sessions (weekly for 4 weeks then bi-weekly) Structure NR Clinical Psychology Masters Candidate-led b) Standard care	Value Likert scale 4q's (provided) Not validated	4 and 10 mth FU intervals AD: Intervention group only *N*=24 (100%)	Quant (low)
Sardell *et al*., 2000 UK *Medium*	Neurological cancer pts receiving surgery or RT *N*=45 Median 50yrs (range 23-69) (TSS only) 67% male (TSS only) Recruited via hospital - NOS	nRCT – 2 groups a) Telephone FU – general & symptom monitoring, medication issues, support, information, ADL assessment 3 sessions (monthly over 3 months) Semi-structured questionnaire Nurse-led b) Standard care	Satisfaction Satisfaction questionnaire (topics provided) Not validated	Unclear - pts still receiving telephone FU AD: Intervention group only *N*=22 (49%)	Quant (low)
Smithies *et al*., 2009 Canada *Medium*	Breast cancer pts receiving CT *N*=20 Mean 54yrs – SD8.2 0% male Recruited via hospital cancer centre	Quasi-experimental - Single group Telephone support post 1st chemotherapy – symptom monitoring, provision of information, support 1 session (average 3 days post CT, range 1-5) Checklist questionnaire Member of research team, nurse or doctor	Value / Utility Likert scale 1q (topic provided) Not validated Method NR	Post consultation - NOS AD: *N*=20 (100%)	Quant (low) Qual (low)
Steginga *et al*., 2008 Australia *Medium*	Prostate cancer pts receiving RT, brachytherapy, prostatectomy combinations or WW *N*=20 Mean 63yrs – SD6.7 100% male Recruited via hospital from treating urologist	Quasi-experimental - Single group Telephone counselling – decision support, stress management, preparation for treatment, adjustment to cancer, problem solving, coping strategies 4 sessions (2 pre-treatment and at 4 and 7 weeks post) Nurse-led Structured counselling protocols	Acceptability Likert scale 1q (topic provided) Not validated Verbatim responses (topics provided)	2 mths post treatment AD: *N*=20 (100%)	Quant (low) Qual (low)

Wilmoth *et al.*, 2006 USA *High*	Breast cancer pts receiving surgery, CT, RT, HT or no treatment a) Intervention *N*=35, b) Ctrl *N*=42 Mean a) Intervention 57yrs, b) Ctrl 59yrs 0% male Sample of patients participating in an RCT with a telephone intervention vs standard care Recruited via hospital + community - NOS	Nested – subjects from 2 groups a) Educational materials and telephone social support – information provision Unclear number of telephone sessions (initially weekly, then bi-weekly, then monthly up to 13 months post surgery) Semi-structured intervention with manual supporting educational materials Nurse-led b) Standard care + educational materials	Comments about the project Interview with schedule (topics provided)	End of study (13mths) AD: Intervention group only *N*=35 (100%)	Qual (high)
Young *et al.*, 2010 Australia *Medium*	Colorectal cancer pts post-surgery / receiving adjuvant therapy a) Intervention *N*=20, b) Ctrl *N*=21 Mean a) Intervention 66.9yrs, b) Ctrl 64.5yrs (TSS only) a) Intervention 60% male, b) Ctrl 50% male (TSS only) Recruited via hospital	nRCT – 2 groups a) Telephone support – general and side effect monitoring, information provision, emotional support, advice 5 sessions (day 3 and 10, 1mth, 3mths and 6mths post discharge) Standardised checklist screening for patients needs Nurse-led b) Standard care	Views of content and timing Questionnaire – NOS Not validated	6mths after hospital discharge AD: Intervention group only *N*=13 (65%)	Quant (low) Qual (low)
Young *et al.*, 2013 Australia *Low*	Colorectal cancer pts post-surgery a)Intervention *N*=387, b)Ctrl *N*=369 Mean a) Intervention 68.6yrs SD12.2, b) Ctrl 67.0yrs – SD12.1 a) Intervention 56.8% male, b) Ctrl 54.2% male Recruitment NR	RCT – 2 groups a) Telephone support – general and side effect monitoring, information provision, emotional support, advice 5 sessions (day 3 and 10, 1mth, 3mths and 6mths post discharge) Standardised checklist screening for patients needs Nurse-led b) Standard care	Views of intervention Likert scale 13 statements (provided) Not validated Semi-structured interviews - NOS	Questionnaire at 6mths Every 3 mths semi-structured interviews AD: Intervention group only Quantitative *N*=350 (90%) Qualitative n=29 (7%)	Quant (low) Qual (low)
Zhang *et al.*, 2013 China *High*	Rectal cancer pts post-surgery a) Intervention *N*=59, b) Ctrl *N*=60 Mean a) Intervention 52.9yrs – SD13.3, b) Ctrl 55.3yrs – SD13.7 a) Intervention 59.6% male, b) Ctrl 70.6% male Recruited via regional hospitals	RCT – 2 groups a) Telephone FU for post-op adjustment – monitoring, motivation, information provision 1st call 3-7 days post discharge, 2nd call on day 14-20, 3rd call on day 23-27 Structured program Nurse-led b) Standard care	Satisfaction Likert scale 1q (topic provided) Not validated	At 1 and 3 months after discharge AD: Intervention group only *N*=52 (88%)	Quant (low)

Zheng *et al.*, 2013 China *High*	Colorectal cancer pts post-surgery Random sample of patients receiving telephone intervention (*N*= 59 – main study) [31] Recruitment NR	Nested – Single group Telephone FU for post-op adjustment – monitoring, motivation, information provision 1st call 3-7 days post discharge, 2nd call on day 14-20, 3rd call on day 23-27 Structured program Nurse	Explore perceptions of telephone FU Semi-structured interviews (topics provided)	Evaluation timing NR AD: *N*=11 (NR)	Qual (high)

AD – Acceptability Data, CI – Confidence Interval, CT – Chemotherapy, DGH – District General Hospital, ESAS – Edmonton Symptom Assessment Score, FU – Follow up, HT – Hormone Therapy, MISS – Medical Interview Satisfaction Scale, MMS – Mohs Micrographic Surgery, NOS – Not Otherwise Specified, NR – Not Reported, nRCT – non-Randomised Controlled Trial, OP – Outpatient, PSQ III - Ware's Patient Satisfaction Questionnaire III, Qual – qualitative, Quant – quantitative, RCT – Randomised Controlled Trial, RT – Radiotherapy, SD – Standard Deviation, THE - Telephone health education, TIC - Telephone interpersonal counselling, TSS – Total Sample Size, VIC - Videophone interpersonal counselling, WW – Watch & Wait

Appendix 7 – Systematic Review Overall Study Quality (Liptrott *et al.,* 2017)

Table 1 - Tabulated data from study quality assessment of bias in RCT's and non-RCT's providing quantitative acceptability / satisfaction data from all cohorts (based on Cochrane Collaboration Risk Bias of Assessment Tool for RCT's and for nRCT's (Higgins and Green, 2011)) – (Liptrott et al., 2017)

First Author / Date	Sequence generation	Random allocation	Selection bias (nRCT's)	Performance bias (intervention)	Attrition reporting	Outcome reporting	Completeness of data reporting	Overall study quality
RCT's								
Badger *et al.*, 2013	H	H	N/A	L	H	H	H	L
Beaver *et al.*, 2009	L	L	N/A	L	L	L	L	H
Beaver *et al.*, 2012	L	L	N/A	H	L	H	L	M
Hegel *et al.*, 2011	H	H	N/A	L	L	H	H	M
Heidrich *et al.*, 2009 Pilot Study 1	H	H	N/A	L	L	H	U	M
Heidrich *et al.*, 2009 Pilot Study 2	H	H	N/A	L	L	H	U	M
Kimman *et al.*, 2010b	L	L	N/A	L	H	L	L	H
Munro *et al.*, 1994	U	U	N/A	L	L	L	L	M
Non-RCT's								
Hafiji *et al.*, 2012	N/A	N/A	H	L	U	U	U	L
Leahy *et al.*, 2013	N/A	N/A	U	L	H	L	H	M

N/A – Not applicable, H – High, L – Low, M – Medium, U - Unclear

Table 2 - Tabulated data from study quality assessment of bias in RCT's, non-RCT's and single group studies providing quantitative acceptability / satisfaction data from the intervention group only (based on Cochrane Collaboration Risk Bias of Assessment Tool for nRCT's (Higgins and Green, 2011)) – (Liptrott et al., 2017)

First Author / Date	Selection bias	Performance bias (intervention)	Attrition reporting	Outcome reporting	Completeness of Data	Overall study quality
Anderson, 2010	H	L	L	H	H	M
Barsevick *et al.*, 2002	H	L	U	H	H	L
Booker *et al.*, 2004	H	U	L	U	U	L
Cimprich *et al.*, 2005	L	L	L	U	U	M
Cirillo *et al.*, 2014	U	U	U	H	H	L
Cox *et al.*, 2005	H	L	U	H	H	L
Cox *et al.*, 2008	H	L	U	L	L	M
Craven *et al.*, 2013	H	L	L	U	U	L
Delaney *et al.*, 2009	H	L	L	H	L	M
Garrett *et al.*, 2013	H	U	H	U	U	L
Hagopian and Rubenstein, 1990	H	L	U	H	H	L
Heidrich *et al.*, 2009 Pilot Study 3	H	L	U	H	H	L
Inman *et al.*, 2011	U	L	L	U	L	M
Jensen *et al.*, 2011	U	U	L	L	L	M
Kelly, 1999	H	L	H	H	H	L
Kilbourn *et al.*, 2013	H	L	U	L	L	M
Kim *et al.*, 2011	L	L	L	H	L	M
Livingston *et al.*, 2010	H	L	L	L	U	M
Marcus *et al.*, 1993	H	H	L	U	U	L
Marcus *et al.*, 2010	H	L	U	L	L	M
Mordenti *et al.*, 2013	H	H	U	L	L	L
Reese *et al.*, 2012	H	L	L	L	L	M
Reese *et al.*, 2014	U	L	L	H	H	M
Salonen *et al.*, 2009	H	H	L	U	L	M
Sandgren *et al.*, 2000	U	L	U	L	L	M
Sardell *et al.*, 2000	H	L	L	U	H	M
Smithies *et al.*, 2007	H	L	L	U	H	M
Steginga *et al.*, 2008	H	L	L	H	H	M
Young *et al.*, 2010	H	L	L	H	H	M
Young *et al.*, 2013	L	L	L	U	U	L
Zhang *et al.*, 2013	L	L	U	L	L	H

H – High, L – Low, M – Medium, U – Unclear

Table 3 - Tabulated data from study quality bias assessment of studies providing high quality qualitative data (Critical Appraisal Skills Programme (CASP) tool (Critical Appraisal Skills Programme, 2013) – (Liptrott et al., 2017)

Author / Date	**Appropriate methodology**	**Appropriate design**	**Data collection methods**	**Data saturation**	**Researcher role in question formulation**	**Researcher role in data collection**	**Analysis**	**Rigour**	**Sufficient data**	**Clear findings**	**Findings discussed in relation to the original research question**	**Overall study quality**
Archer *et al.*, 2014	L	L	L	H	H	L	L	H	L	L	L	M
Beaver *et al.*, 2010	L	L	L	U	U	U	L	L	L	L	L	H
Campbell *et al.*, 2007b	L	H	L	H	H	H	L	L	L	L	L	H
Donnelly *et al.*, 2013	L	L	L	H	L	L	L	L	L	L	L	H
Wilmoth *et al.*, 2006	L	L	L	H	L	H	L	L	L	L	L	H
Zheng *et al.*, 2013	L	L	L	L	H	H	L	L	L	L	L	H

H – High, L – Low, M – Medium, U - Unclear

Appendix 8 – Systematic review - Acceptability / Satisfaction Data Quality - (Liptrott et al., 2017)

Qualitative Data

First Author / Date	Qualitative / open ended questioning	Sufficient data to support findings	Outcome descriptor	Acceptability data quality
Alter *et al.*, 1996	Y	N	Discussion of intervention - NOS	Low
Archer *et al.*, 2014	Y	Y	Semi structured interviews -NOS	High
Badger *et al.*, 2013	N	N	Open ended q's (topic provided)	Low
Beaver *et al.*, 2010	Y	Y	Semi structured interviews (topics provided)	High
Booker *et al.*, 2004	Y	N	Comments	Low
Campbell *et al.*, 2007b	Y	Y	1q – what was it like to undergo CST by telephone?	High
Cimprich *et al.*, 2005	Y	U	2 open ended q's (topics provided)	Low
Cox *et al.*, 2008	Y	U	Open section on general views of care experienced - NOS	Low
Dixon, 2010	U	U	Comments during telephone calls	Low
Donnelly *et al.*, 2013	Y	Y	Focus groups with open ended q's (topics provided)	High
Hafiji *et al.*, 2012	Y	U	Comments / feedback	Low
Hagopian and Rubenstein, 1990	U	U	Comments	Low
Inman *et al.*, 2011	Y	U	Comments from patients during calls	Low
Jefford *et al.*, 2011	Y	Y	Interview - NOS	High
Kelly, 1999	Y	U	2 open q's (improvements / positive effects)	Low
Kilbourn *et al.*, 2013	U	U	Exit interviews - NOS	Low
Livingston *et al.*, 2010	Y	N	Telephone interview with open questions - NOS	Low
Salonen *et al.*, 2009	Y	N	1 open ended q (most appropriate timing for call)	Low
Smithies *et al.*, 2009	U	U	Method NR	Low
Steginga *et al.*, 2008	Y	U	Verbatim responses (topics provided)	Low
Wilmoth *et al.*, 2006	Y	Y	Interviews with schedule (topics provided)	High
Young *et al.*, 2013	Y	U	Semi structured interviews	Low
Zheng *et al.*, 2013	Y	Y	Semi structured interviews (topics provided)	High

CST – coping skills training, N – No, NOS – Not Otherwise Specified, NR – Not reported, U – Unclear, Y - Yes

Quantitative Data

Author / Date	Qualitative / open ended questioning	Sufficient data to support findings	Outcome descriptor	Acceptability data quality
Anderson, 2010	N	N	Likert scale - 12 q's (provided) – NV	Low
Barsevick *et al.*, 2002	N	N	Interview - 10 closed q's (topics provided) – NV	Low
Beaver *et al.*, 2009	N	U	Questionnaire designed and piloted – NOS – NV	Low
Beaver *et al.*, 2012	N	Y	Adapted Likert scale questionnaire – (topics provided) – NV Likert scale - overall satisfaction – NV	Low
Booker *et al.*, 2004	N	Y	Closed q's (topics provided) – NV	Low
Cimprich *et al.*, 2005	N	Y	Likert scale 1 closed q (provided) – NV	Low
Cirillo *et al.*, 2014	N	U	Rating scale – NOS – NV	Low
Cox *et al.*, 2005	N	Y	Adapted MISS (26 items) - NV	Low
Cox *et al.*, 2008	N	N	Likert scale questionnaire (4 domains provided) - V	Low
Craven *et al.*, 2013	U	U	Questionnaire (topics provided) – NV	Low
Delaney *et al.*, 2009	N	Y	Likert scale 2q's – (provided) – NV	Low
Garrett *et al.*, 2013	N	N	Likert scale questionnaire (topics provided) – NV	Low
Hafiji *et al.*, 2012	N	N	Likert scale questionnaire – NOS – NV	Low
Hagopian and Rubenstein, 1990	U	U	Questionnaire – NOS – NV	Low
Hegel *et al.*, 2011	N	Y	Likert scale 2q's (topics provided) – NV	Low
Heidrich *et al.*, 2009 (PS1)	N	U	8 q's (topics provided) – NV	Low
Heidrich *et al.*, 2009 (PS2)	N	U	8 q's (topics provided) – NV	Low
Heidrich *et al.*, 2009 (PS3)	N	U	8 q's (topics provided) – NV	Low
Inman *et al.*, 2011	Y	U	1 closed q (provided)	Low
Jensen *et al.*, 2011	U	U	Likert questionnaire (topic provided) – NOS - NV	Low
Kelly, 1999	N	U	4 closed q's (topics provided) - NV	Low
Kilbourn *et al.*, 2013	N	Y	Likert scale 2 closed q's (topics provided) – NV	Low
Kim *et al.*, 2011	N	N	Likert scale questionnaire (topics provided) – NV	Low
Kimman *et al.*, 2010b	N	N	PSQIII – V	Low
Leahy *et al.*, 2013	N	N	Adapted Satisfaction with Consultation Scale – NV	Low

Livingston *et al.*, 2010	N	N	Likert scale questionnaire (topics provided) – NV	Low
Marcus *et al.*, 1993	N	N	Single evaluation indicator (topic provided) - NV	Low
Marcus *et al.*, 2010	N	Y	Questionnaire which component most helpful (provided) - NV	Low
Mordenti *et al.*, 2013	N	U	Survey (topics provided) – NV	Low
Munro *et al.*, 1994	N	N	Likert scale 1q (provided) – NV	Low
Reese *et al.*, 2012	N	Y	Likert scale 4q's (topics provided) – NV	Low
Reese *et al.*, 2014	N	Y	Likert scale 3q's - (topics provided) – NV	Low
Salonen *et al.*, 2009	N	Y	Revised likert scale questionnaire (Kaunonen, 2000) - V	Low
Sandgren *et al.*, 2000	N	N	Likert scale 4q's (provided) – NV	Low
Sardell *et al.*, 2000	N	N	Satisfaction questionnaire (topics provided) - NV	Low
Smithies *et al.*, 2009	N	Y	Likert scale 1q (topic provided) – NV	Low
Steginga *et al.*, 2008	N	Y	Likert scale 1q (topic provided) - NV	Low
Young *et al.*, 2010	U	U	Questionnaire – NOS – NV	Low
Young *et al.*, 2013	N	Y	Likert scale 13 statements (provided) – NV	Low
Zhang *et al.*, 2013	N	Y	Likert scale 1q (topic provided) - NV	Low

MISS – Medical Interview Satisfaction Scale, N – No, NOS – Not Otherwise Specified, NV – Not Validated, PS – Pilot Study, PSQ III – Patient Satisfaction Questionnaire III, U – Unclear, V – Validated, Y - Yes

Appendix 9 – Systematic review - summary of outcomes - (Liptrott et al., 2017)

	Intervention Category	**TFU post initial diagnosis and treatment**				**Side effect monitoring during/ post treatment**				**Psycho-educational interventions**			
	Data Type	Qualitative Data		Quantitative Data		Qualitative Data		Quantitative Data		Qualitative Data		Quantitative Data	
	Data Quality	High	Low	High *	Low	High	Low	High *	Low	High	Low	High*	Low
Positive Findings	**Convenience**	√	√		√	√	√		√	√	√		√
	Familiar environment / facilitating sensitive discussions	√	√							√	√		√
	Positive personal experiences	√				√	√		√	√	√		√
	Accessibility to HCP/ continuity of care	√			√	√	√		√				
	Support / reassurance					√	√		√	√	√		√
	Positive aspects of intervention structure	√								√			
	Positive Patient – HCP relationship				√		√		√				√
	Prefer telephone based intervention						√				√		
	Overall satisfaction				√				√		√		√
Negative Findings	**Lack of contact - Peer / HCP**	√											
	Negative Patient – HCP relationship	√							√		√		
	Barrier to emotional discussions					√							
	Not useful for all patients					√	√						√
	Changes to Intervention structure					√	√		√	√	√		√
	Lack of choice – receiving calls/ timing						√				√		
	Preference for other intervention methods								√		√		√

HCP – Healthcare Professional, TC – telephone consultation, *no high quality data, √ - at least one reported finding

Appendix 10 – Study 1: Ethical approval from the European Institute of Oncology, November 2014

IEO
Istituto Europeo di Oncologia

Istituto Europeo di Oncologia
Per quanto di competenza, il Direttore Scientifico
si prende atto.
Dott. Atanasio Nonis
Responsabile
Segreteria Tecnico Scientifica
Comitato Etico

R 1 C B/10/2014

R144/14 IEO 1ES
Seduta del 5/11/2014

Alla c.a. Dott Atanasio Nonis
Comitato Etico
Istituto Europeo di Oncologia
Via Ripamonti, 435
20141 Milano

Milano, 01 ottobre 2014

Oggetto: *TELEphone support for symptom management and supportive CARE in haemato-oncology patients: a qualitative study*

Con la presente la sottoscritta Sarah Jayne Liptrott, in qualità di Principal Investigator della sperimentazione in oggetto coordinata da IEO, richiede il parere unico del Comitato Etico IEO.

Lo studio multicentrico verrà condotto in IEO, presso la Divisione di ematoncologia e sarà rivolto a pazienti affetti da patologie oncoematologiche trattati presso la Divisione di ematoncologia negli ultimi 2 anni, che hanno ricevuto un supporto telefonico da personale infermieristico della divisione.

Lo studio si pone come obbiettivo principale di determinare quali possono essere i bisogni dei pazienti sia durante che dopo la fine del trattamento, valutare quali possono essere le "barriere" ed eventuali strumenti "facilitatori" alla partecipazione a un supporto telefonico durante il percorso clinico di un paziente e esplorare le percezioni dei pazienti al contatto telefonico.

Dichiaro inoltre che:

1. Lo studio viene presentato come multicentrico in quanto per garantire il giusto rigore scientifico i dati opportunamente resi anonimi saranno analizzati da personale facente parte dell'Università di Manchester
2. lo studio sarà condotto in conformità con le norme di buona pratica clinica;
3. trattandosi di uno studio osservazionale non interventistico non sono previste spese a carico del SSN

In allegato:

- protocollo di studio
- consenso informato
- riassunto progetto di ricerca
- Dichiarazione sulla natura osservazionale dello studio
- CV sperimentatore principale
- Scheda raccolta dati

Distinti saluti
Sarah Jayne Liptrott
Infermiera di ricerca

Mod. 1210

RIUNIONE 05/11/2014

COMPONENTI PRESENTI E QUALIFICHE

APOLONE Giovanni Esperto in metodologia sperimentale (Presidente)
BONARDI Maria Santina Rappresentante area professioni sanitarie
CERUTTI Sergio Esperto in dispositivi medici e ingegnere clinico
DE CARLI Luigi Esperto in genetica
GALLUS Giuseppe Biostatistico
GASTALDI Stefano Rappresentante del volontariato e dell'associazionismo di tutela dei pazienti
GOLDHIRSCH Aron Clinico Medico Oncologo
MARTINI Luciano Farmacologo (Vice Presidente)
MICCINELLI Pasquale Esperto in materia giuridica e assicurativa
NONIS Atanasio Farmacologo, esperto regolatorio
OMODEO SALE' Emanuela Farmacista IEO
PELLEGRINI Massimo Esperto in nutrizione
PELLEGRINI Maurizio Medico di Medicina Generale
RAMBALDI FELDMANN Enrico Esperto di bioetica
RANIERI Camilla Direttore Sanitario
REZZONICO Rossano Pediatra

Appendix 11 – Study 1: Ethical approval from the European Institute of Oncology, June 2015

IEO
Istituto Europeo di Oncologia

Centro Cardiologico
Monzino

Comitato Etico degli IRCCS Istituto Europeo di Oncologia e Centro Cardiologico Monzino
Tel +39 02 57 489 848 - Fax +39 02 57 489 781 - E-mail: comitato.etico@ieo.it

Milano, 24 giugno 2015
AN/dt

Dssa Sara Liptrott
IEO Sede

Oggetto: IEO 175 RE545/1 – TELEphone support for symptom management and supportive CARE in haemato-oncology patients: a qualitative study.

Con riferimento a quanto in oggetto, si informa che
il Comitato Etico nella seduta del 10/06/2015
preso atto di tutta la documentazione trasmessa con lettera del 03/06/2015
ha espresso parere favorevole a:
- emendamento 1, del 13/02/2015.
Si trasmette in allegato l'elenco dei membri partecipanti alla seduta.
Distinti saluti.

Dott Atanasio Nonis
Responsabile Segreteria Tecnico-Scientifica

IEO
Istituto Europeo di Oncologia

Centro Cardiologico
Monzino

Comitato Etico degli IRCCS
Istituto Europeo di Oncologia e Centro Cardiologico Monzino

RIUNIONE 10/06/2015

COMPONENTI PRESENTI E QUALIFICHE

APOLONE Giovanni Esperto in metodologia sperimentale (Presidente)
BONARDI Maria Santina Rappresentante area professioni sanitarie
DE CARLI Luigi Esperto in genetica
GALLUS Giuseppe Biostatistico
GASTALDI Stefano Rappresentante del volontariato e dell'associazionismo di tutela dei pazienti
GOLDHIRSCH Aron Clinico Medico Oncologo
MARTINI Luciano Farmacologo (Vice Presidente)
MICCINELLI Pasquale Esperto in materia giuridica e assicurativa
NONIS Atanasio Farmacologo, esperto regolatorio
OMODEO SALE' Emanuela Farmacista IEO
PELLEGRINI Maurizio Medico di Medicina Generale
REZZONICO Rossano Pediatra

Appendix 12 – Study 1: Ethical approval from the University of Manchester Committees on the Ethics of Research on Human Beings, July 2015

Research Governance, Ethics and Integrity
2nd Floor Christie Building
The University of Manchester
Oxford Road
Manchester
M13 9PL
Tel: 0161 275 2206/2674
Email: research.ethics@manchester.ac.uk

Ref: ethics/15005

Prof. Karina Lovell,
School of Nursing, Midwifery & Social Work,
Jean McFarlane Building.

20th July 2015

Dear Prof Lovell,

Study title: Liptrott et al.: 'TELEphone support for symptom management and supportive CARE in Haemato-oncology patients: a qualitative study' (our ref 15005)

Research Ethics Committee 4

As you know, your application was considered by the Committee at their meeting on 28th January 2015. I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation as submitted and approved by the Committee, following further review by the Research Ethics Committee in Milan where the research will be conducted.

This approval is effective for a period of five years. If the project continues beyond that period an application for amendment must be submitted for review. Likewise, any proposed changes to the way the research is conducted must be approved via the amendment process (see below). Failure to do so could invalidate the insurance and constitute research misconduct.

You are reminded that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a secure university computer or kept securely as a hard copy in a location which is accessible only to those involved with the research.

Reporting Requirements:

You are required to report to us the following:

1. Amendments
2. Breaches and adverse events
3. Notification of Progress/End of the Study

Feedback

It is our aim to provide a timely and efficient service that ensures transparent, professional and proportionate ethical review of research with consistent outcomes, which is supported by clear, accessible guidance and training for applicants and committees. In order to assist us with our aim, we would be grateful if you would give your view of the service that you have received from us by completing a feedback sheet [https://survey.manchester.ac.uk/pssweb/index.php/155676/lang-en].

We hope the research goes well.

Yours sincerely,

Dr Deborah Bentley
Secretary to University Research Ethics Committee 4

Appendix 13 – Study 1: Ethical approval from the European Institute of Oncology, June 2015

IEO
Istituto Europeo di Oncologia

Centro Cardiologico
Monzino

Comitato Etico degli IRCCS Istituto Europeo di Oncologia e Centro Cardiologico Monzino
Tel +39 02 57 489 848 - Fax +39 02 57 489 781 - E-mail: comitato.etico@ieo.it

Milano, 9 dicembre 2015
AN/dt

Dssa Sarah Liptrott
IEO Sede

Oggetto: IEO 175 RE682/2 – TELEphone support for symptom management and supportive CARE in haemato-oncology patients: a qualitative study.

Con riferimento a quanto in oggetto, si informa che

il Comitato Etico nella seduta del 25/11/2015

preso atto di tutta la documentazione trasmessa con lettera del 26/10/2015

ha espresso parere favorevole a:

- emendamento 2 del 15/10/2015

Si trasmette in allegato l'elenco dei membri partecipanti alla seduta.

Distinti saluti.

Dott Atanasio Nonis
Responsabile Segreteria Tecnico-Scientifica

IEO
Istituto Europeo di Oncologia

Centro Cardiologico
Monzino

Comitato Etico degli IRCCS
Istituto Europeo di Oncologia e Centro Cardiologico Monzino

RIUNIONE 25/11/2015

COMPONENTI PRESENTI E QUALIFICHE

BOELLA Laura Esperta di bioetica
BONARDI Maria Santina Rappresentante area professioni sanitarie
CERUTTI Sergio Esperto in dispositivi medici e Ingegnere clinico
DE CARLI Luigi Esperto in genetica
GALLUS Giuseppe Biostatistico
GASTALDI Stefano Rappresentante del volontariato e dell'associazionismo di tutela dei pazienti
GOLDHIRSCH Aron Clinico Medico Oncologo
MARTINI Luciano Farmacologo (Presidente)
MASTRILLI Fabrizio Direttore Sanitario IEO
MICCINELLI Pasquale Esperto in materia giuridica e assicurativa
NONIS Atanasio Farmacologo, esperto regolatorio
OMODEO SALE' Emanuela Farmacista IEO
PELLEGRINI Maurizio Medico di Medicina Generale
REZZONICO Rossano Pediatra

Appendix 14 – Study 1: Ethical approval from the University of Manchester Committees on the Ethics of Research on Human Beings, January 2016

MANCHESTER 1824
The University of Manchester

Amendments for University Research Ethics Applications

Please email the completed form and ANY supporting documentation that has been amended (PIS, consent form, etc) to research.ethics@manchester.ac.uk

Amendment Details

Investigator	Sarah Liptrott
Title of Ethics Application	TELEphone support for symptom management and supportive Care in haemato-oncology patients: a qualitative study
University Reference Number	ref 15005
UREC Committee that Reviewed Application (as detailed on approval letter)	Research Ethics Committee 4
Details of Proposed Changes	The protocol will be amended → version 3 - 15/10/15: - The inclusion criteria limiting participants to those who have received treatment within the last 2 years or at least one telephone call providing support or information within the last 2 years will be removed, allowing a wider range of patients fitting the inclusion criteria to participate. - The subgroup sampling frame (age – over / under 30, and patient residence – Lombardy or non-Lombardy region) will be removed, allowing any patient fitting the inclusion criteria to participate The eligibility form will be amended → version 2 – 15/10/15: - This will reflect changes in the inclusion criteria
Rationale (short) for Changes	During the recruitment process for the TELECare study, it has been observed that the inclusion criteria which limits participants to those who have received treatment within the last two years, and have received at least one telephone call providing support / information during or after treatment within the last two years, may exclude experiences of patients who were outside of this time frame but recall their experiences during this period and the telephone call(s) received. For this reason the researchers would like to modify the inclusion criteria to include any patients that recall their experiences during and after the treatment period and of the telephone call(s) received (always patients haematological malignancies treated at the EIO) Also during the recruitment process, it has been observed that the suggested sub-group sampling (age – over / under 30, and patient residence – Lombardy or non-Lombardy region) in the protocol, limits the numbers of participants, and as such, the researchers would like to remove the restrictions of numbers of participants within sub-categories. Total number of patients to be recruited would not change.
Have the change(s) been subject to an internal risk assessment? Please provide details	These changes have been reviewed by the Principal Investigator (PhD Student) and the co-investigators / supervisory team at the UoM (Prof. Karina Lovell and Dr Penny Bee)

v 1.0; 19.11.14

MANCHESTER 1824
The University of Manchester

For Office Use Only

Are changes major/minor?	Minor
UREC Secretary Comments (minor changes only)	
Approved by UREC Secretary (Electronic Signature) (minor changes only)	K. Hatto
Date	27-1-16
UREC Chair Comments (major changes only)	
Approved by UREC Chair (Electronic Signature) (major changes only)	
Date	

Appendix 15 – Study 1: Patient Information Sheet and Consent Form - Italian

Numero dello studio:IEO175 Informativa per il paziente	
Titolo dello studio:	Supporto telefonico per la gestione dei sintomi e sostegno ai pazienti affetti da malattia ematoncologica: Studio qualitativo
Titolo:	TELECare in emato-oncologia

Iniziali del paziente: **N° cartella clinica:**

Introduzione

Questo è un invito a partecipare allo Studio che si chiama TELECare in emato-oncologia (Contatto telefonico per la gestione dei sintomi e supporto ai pazienti affetti da malattia ematoncologica: Studio qualitativo).

Questa informativa e consenso, La informano dello Studio e spiegheranno i processi coinvolti nella partecipazione. La consapevolezza di cosa comporta può aiutarLa a decidere se vuole partecipare.

Le chiediamo di leggere attentamente l'informativa e di fare le domande su qualsiasi dubbio o chiarimento. Prima di decidere se vuole partecipare o no, se ritiene, può parlare ad un parente, un amico o consultare un altro professionista nell'ambito sanitario.

La partecipazione nella ricerca è volontaria. Se non vuole, non è obbligato\a. Le cure che riceverà non sarà influite. Se decide che vuole partecipare, è richiesta la firma del modulo di consenso. Firmando tale modulo, Lei afferma che:

- Lei capisce ciò che ha letto,
- Lei consente la partecipazione allo Studio
- Lei consente l'uso dei Suoi dati personali e sulla Sua salute come descritto.

Le verrà consegnata una copia dell'informativa ed il consenso da conservare.

Qual è lo scopo dello studio?

Lo scopo di questo studio è determinare i bisogni dei pazienti affetti da una malattia emato-oncologica, durante e dopo il trattamento. Vorremmo capire cosa pensa del supporto che ha ricevuto tramite il contatto telefonico. Vorremmo anche conoscere quali sono i potenziali problemi nel ricevere un supporto telefonico e il modo in cui questo può essere reso più semplice e più efficace. In questo Studio, vorremmo intervistare, in totale, circa 24 partecipanti.

Perché Le è stato\a proposto di partecipare a questo studio?

Lei è stato\a invitato\a a partecipare a questo studio perché ha ricevuto il contatto telefonico di supporto dagli infermieri della Divisione di Emato-oncologia dell'Istituto Europeo di Oncologia (IEO), durante o dopo aver ricevuto i trattamenti per la Sua malattia emato-oncologica. Riteniamo che la Sua esperienza del supporto ricevuto, possa contribuire a migliorare a capire il servizio che offriamo.

I Suoi dati sono stati ottenuti dai documenti dall'Istituto Europeo di Oncologia, in cui Lei ha già autorizzato ad essere contattato per ulteriori ricerche.

Deve partecipare?

La partecipazione a questo studio è completamente volontaria. Lei deve decidere SE vuole partecipare allo Studio. Insieme descriveremo lo Studio e discuteremo l'informativa. Se Lei decidesse di partecipare allo Studio, Le chiederemo di firmare il modulo di consenso. Lei è libero\a di ritirare il Suo consenso in qualsiasi momento, senza dover dare alcuna giustificazione. Questa decisione non influirà sulle cure che riceverà.

Cosa succede se decidesse di partecipare allo studio?

Se decidesse di partecipare allo Studio, Le sarà chiesto di partecipare ad un'intervista con l'infermiera Dott.ssa Sarah Liptrott (ricercatrice per questo Studio). L'intervista avrà una durata di 30 - 60 minuti e potrà avvenire sia telefonicamente che tramite incontro individuale in un ambiente dedicato presso l'Istituto Europeo di oncologia, in base alla Sua preferenza.

All' inizio del colloquio, l'intervistatore si assicurerà che Lei è a suo agio, se necessario, risponderà a tutte le domande che vorrà porle riguardo lo Studio. L'intervistatore Le farà domande sulla Sua malattia emato-oncologica e sul supporto telefonico che ha ricevuto, e le darà il tempo per condividere l'esperienza. Le domande saranno sulla diagnosi, la Sua esperienza durante il trattamento, le Sue esigenze in termini di sostegno durante questo periodo, e ciò che pensa del sostegno offerto telefonicamente. Eventualmente avesse riscontrato difficoltà da questo servizio, Le chiediamo suggerimenti per migliorarlo.

Se Lei non volesse rispondere ad alcune domande poste durante l'intervista, potrà chiedere di passare alla domanda successiva. Il colloquio sarà riservato e non prenderanno parte altre persone, a meno che non sia Lei a volere la presenza dei terzi. Lei è libero\a di ritirare il Suo consenso senza dare motivo e questo non influirà sulle cure che riceverà.

L'intervista verrà registrata digitalmente, e nessuno (tranne i co-ricercatrici e Data Manager) avrà accesso alle informazioni documentate durante l'intervista. Sulla registrazione digitale, NON sarà identificato\a con il Suo nome. La registrazione digitale sarà cancellata dopo averla trasferita su un supporto CD audio e conservata fino il completamento dello Studio, dopodiché verrà smaltito in modo sicuro.
L'intervista sarà trascritta parola per parola, e anche questo documento cartaceo sarà stoccato in modo sicuro per 3 anni dopo il completamento dello studio, dopo di che sarà smaltito in modo sicuro.

Raccoglieremo anche alcuni dati anagrafici pertanto accederemo alla Sua cartella clinica per raccogliere le informazioni relative alla Sua età, la località di residenza, oltre alle informazioni relative alla diagnosi, ai trattamenti ricevuti, gli eventuali ricoveri ospedalieri, e le informazioni relative all'intervento telefonico ricevuto.

Rimborsi
Non è previsto alcun compenso economico connesso alla partecipazione allo Studio.
Non è previsto alcun rimborso delle spese eventualmente sostenute per raggiungere l'Istituto presso il quale si svolge lo Studio.

Quali sono i possibili svantaggi e i rischi della partecipazione?

Le chiederemo di condividere con noi alcune informazioni molto personali, e potrebbe sentirsi in difficoltà emotiva nell'esposizione di alcuni argomenti. Non dovrà sentirsi obbligato/a a rispondere alle domande o partecipare all'intervista.

Qualora, dopo il colloquio, dovesse sentirsi in difficoltà per le informazioni condivise, l'Istituto Europeo di Oncologia le potrà offrire il supporto presso l'Unità di Psico-oncologia dell'Istituto Europeo di Oncologia o la possibilità di consultare un membro dell'equipe medica.

Il nostro obiettivo è garantire il sostegno psicologico sia durante che dopo la partecipazione all'intervista, quando necessario.

Quali sono I possibili vantaggi della partecipazione?

Non c'è alcun beneficio personale, ma la Sua partecipazione può contribuire ad aiutarci a conoscere meglio le soluzioni migliori per sostenere i pazienti affetti da una malattia ematoncologica.

Molte persone ottengono giovamento del condividere le loro esperienze nelle interviste, ma a volte possono sentirsi in difficoltà a parlare delle difficoltà che hanno dovuto affrontare. In questo caso, l'intervistatore farà in modo che Lei venga sostenuto\a sia durante che dopo l'intervista.

La partecipazione allo Studio sarà riservata?

Sì. Seguiremo tutta la pratica etica e legale e tutte le informazioni personali saranno trattate in modo riservato.

Non condivideremo tali informazioni al di fuori del team di ricerca. Le informazioni saranno strettamente confidenziali, e saranno conservate tutte in forma anonima utilizzando un numero univoco sui documenti in sostituzione del Suo nome. Solo i ricercatori possono conoscere il numero. Tutte le informazioni saranno conservate in luogo protetto e non di libero accesso.

Le interviste saranno tradotte in inglese e inviate ai co-ricercatori di questo studio presso l'Università di Manchester nel Regno Unito, dove le leggi sulla privacy sono applicate nella stessa misura di quelle in Italia. I dati trasferiti all'Università di Manchester saranno inviati in forma anonimizzata con un numero univoco sui documenti, e il codice per l'identificazione sarà mantenuto in forma riservata presso l'IEO. Saranno prese tutte le misure per garantire la privacy e tutti i dati che verranno condivisi saranno protetti con una password, per una maggior sicurezza.

La pubblicazione potrà includere dettagliate citazioni (pur mantenendo l'anonimato) al fine di dimostrare e migliorare la comprensione dei risultati – ma eventuali citazioni dalle trascrizioni non avranno il Suo nome collegato.

Che cosa succede se c'è un problema?

Se Lei avesse un dubbio su qualsiasi aspetto dello Studio, potrà parlare con la ricercatrice principale che potrà fornirLe i chiarimenti necessari: Dott.ssa Sarah Liptrott (tel. 02 57489 538).
Qualora fosse insoddisfatta e intendesse denunciare formalmente, potrà contattare l'Ufficio Relazioni con il Pubblico: 02 57489 310 (email: urp@ieo.it).

Che cosa succede se Lei non vuole partecipare più allo studio?

Se durante l'intervista, Lei non desiderasse continuare, dovrà informare l'intervistatore e il colloquio verrà interrotto. Se dopo l'intervista, decidesse di non voler più partecipare allo Studio, dovrebbe informare l'intervistatore e la registrazione digitale / l'audio CD e l'intervista trascritta saranno smaltiti in modo sicuro.

Che cosa succede ai risultati dello Studio?

I risultati dello Studio saranno presentati tramite una pubblicazione su una rivista scientifica di settore medica o infermieristica. Se Lei desiderasse avere una copia dell'articolo pubblicato, dovrebbe informare il ricercatore che provvederà ad inviarLe una copia.
Nella pubblicazione, i partecipanti dello Studio manterranno l'anonimato.

Chi sta organizzando e finanziando questo Studio?

Il promotore dello Studio è l'Istituto Europeo di Oncologia, il quale sta organizzando e finanziando questo Studio. Lo Studio fa parte di un programma di Dottorato di Ricerca che la Dott.ssa Sarah Liptrott sta eseguendo presso l'Università di Manchester nel Regno Unito.
La ricercatrice non riceverà alcun compenso economico per la Sua inclusione nello Studio.

Chi ha revisionato lo studio?

Questo Studio è stato approvato dal Comitato Etico dell'Istituto Europeo di Oncologia dell'Università di Manchester nel Regno unito, i quali hanno lo scopo di salvaguardare i diritti dei pazienti partecipanti.

Ulteriori informazioni e contatti

Se Lei avesse alcune domande riguardo lo Studio o volesse discutere più nel dettaglio alcuni punti, potrà parlare con i ricercatori i quali risponderanno a tutte le Sue domande:

Riferimento: Dott.ssa Sarah Liptrott, tel: 02 57498 538

CONSENSO INFORMATO SCRITTO

		Inserire le Sue iniziali
1.	Io sottoscritto dichiaro di aver letto e capito l'informativa relativa (versione 2, data 22/05 / 2015) allo Studio sopra menzionato. Ho avuto l'opportunità di considerare l'informazione e, di fare le domande e ho avuto queste risposte soddisfacentemente.	☐
2.	Comprendo che la mia partecipazione allo Studio è volontaria e che sono libero\a di ritirare il mio consenso senza dare motivo e questo non influirà sulle cure che riceverò.	☐
3.	Comprendo che le sezioni attinenti della mia cartella clinica e miei dati raccolti durante lo Studio possono essere rivisti dai ricercatori dall'Università di Manchester (UK), da autorità regolatore o dall'IEO, dove attinente alla mia partecipazione allo Studio. Io do permesso per questi individui ad aver accesso ai miei dati personali.	☐
4.	Comprendo che i miei dati resi anonimi saranno condivisa tra l'Università di Manchester e l'IEO, qualora fossero attinenti allo studio. Acconsento la condivisione.	☐
5.	Io accetto l'uso di audio-registrare, col possibile uso di quotazioni anonimati e descrittivi e.s. età e genere.	☐
6.	Comprendo che tutti i dati saranno archiviati in modo sicuro e nel rispetto delle leggi sulla privacy.	☐
7.	Fornisco liberamente, il mio consenso a partecipare a questo Studio.	☐

Nome (in stampatello)	Data	Firma
Nome di chi ha presentato l'informativa al paziente	Data	Firma

TUTELA DELLA RISERVATEZZA

La informiamo, ai sensi del Decreto Legge (DL) del 30/06/2003 N°196, codice in materia di protezione dei dati personali, che tutti i dati connessi alla Sua partecipazione a questa raccolta dati saranno trattati in modo strettamente confidenziale, in conformità con le norme di Buona Pratica Clinica (D.M. 15 luglio 1997 e successive integrazioni) e le altre norme vigenti in materia di sperimentazione clinica, e nel rispetto della normativa sopra richiamata. I suoi dati personali, come le iniziali delle generalità e le informazioni anagrafiche, oltre ai dati idonei a rivelare lo stato di salute – essendo questi ultimi dati sensibili ai sensi del Decreto Legge (DL) del 30/06/2003 N°196 – saranno gestiti e archiviati dal Titolare del trattamento, che è l'IEO, Istituto presso il quale l'indagine si svolge ed il Responsabile è il direttore sanitario dell'Istituto Europeo di Oncologia, via Ripamonti n°435 e dalle entità da questo incaricate, per le esclusive finalità connesse all'espletamento della presente raccolta dati. Tale gestione e archiviazione avverrà in forma cartacea e/o informatizzata, anche mediante trasferimento fuori del territorio nazionale e dell'Unione Europea. In ottemperanza a quanto previsto dal Decreto Legge (DL) del 30/06/2003 N°196, il Titolare del trattamento non provvederà al trasferimento dei dati qualora lo Stato di destinazione o di transito non assicuri un livello di tutela adeguato. Il trattamento dei suoi dati personali sarà sempre improntato ai principi di correttezza, liceità e trasparenza, tutelando la Sua riservatezza ed i suoi diritti.

Il conferimento dei suoi dati personali esclusivamente per le finalità sopra indicate, pur avendo natura facoltativa, risulta indispensabile ai fini dell'espletamento della presente raccolta dati, nonché per l'adempimento dei connessi obblighi di legge. La informiamo altresì che, in relazione alle finalità sopra specificate, I Suoi dati personali saranno comunicati esclusivamente alle Autorità sanitarie, come richiesto dalla legge. I dati personali potranno essere soggetti ad elaborazione statistica e, dopo essere stati trasformati in forma completamente anonima, potranno essere inseriti in pubblicazioni e/o presentati a congressi, convegni e seminari a carattere scientifico.
La informiamo infine che in qualunque momento potrà avvalersi dei diritti a Lei attribuiti dal DL del 30/06/2003 N°196, riguardanti la possibilità di conoscere e avere conferma del trattamento dei dati che La riguardano, e la possibilità di ottenere il loro aggiornamento, rettifica, integrazione, trasformazione o cancellazione.

Nome e Cognome dell'interessato *(in stampatello)* _____

Firma dell'interessato _____

Data _____

Appendix 16 – Study 1: Patient Information Sheet and Consent Form - English

Trial Number:IEO175 PATIENT INFORMATION SHEET	
Study Title:	TELEphone support for symptom management and supportive CARE in haemato-oncology patients: a qualitative study
Working Title:	TELECARE in Haemato-oncology

Patients initials: **Hospital Number:**

Introduction

This is an invitation for you to participate in this research project which is called TELECARE (TELEphone support for symptom management and supportive CARE in haemato-oncology patients: a qualitative study).

This Patient Information Sheet and Consent Form, tells you about the research project and explains the processes involved in taking part. Knowing what is involved will help you decide if you want to take part.

Please read the information carefully. Ask questions about anything that you don't understand or want to know more about. Before deciding whether or not you wish to take part, you might want to talk to a relative, friend or health worker.

Participation in the research is voluntary. If you do not wish to take part, you do not have to. Your care will not be affected in any way. If you decide that you do wish to take part, you will be asked to sign the consent section. By signing this, you are telling us that you:

- understand what you have read,
- consent to taking part in the research project
- consent to the use of personal and health information as described.

You will be given a copy of this Patient Information Sheet and Consent Form to keep.

What is the purpose of the study?

The purpose of the research project is to determine the needs of haemato-oncology patients during and after treatment. We want to learn what people think about of the support provided by telephone. We also want to find out what are the potential problems of receiving support by telephone and the ways in which this could be made easier and more useful. We want to interview approximately 24 patients in total in this study.

Why am I being asked to participate in this study?

You have been invited because you have received telephone support from one of the nurses of the Division of Haemato-oncology here at the European Institute of Oncology (EIO), whilst or after receiving treatment for a haematological malignancy. You are being invited to take part in this research because we feel that your experience of the support you received can contribute to our understanding and knowledge of the services we provide.

Your contact details were obtained by the European Institute of Oncology records where you agreed to be contacted for further research.

Do I have to take part?

Participation in this research project is entirely voluntary. If you decide to join the study., we will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect the standard of care you receive.

What will happen to me if I take part?

If you accept to take part in the research, you will be asked to participate in an interview with the nurse Sarah Liptrott (researcher for this study). The interview will take 30-60 minutes.
The interview may take place either by telephone or face to face in a dedicated room at the European Institute of Oncology. – whichever is more convenient for you.

The interview will start with the interviewer making sure you are comfortable and if necessary, answering any questions about the research that you might have. The interviewer will then ask you questions about your haematological cancer and the support by telephone that you received,

and give you time to share your experience. The questions will be about your diagnosis, your experience during treatment, what were your needs in terms of support during this period and what you felt about the support given by telephone. We would also like to know about your ideas about what things made this a more difficult or easy way to receive support.

If you do not wish to answer any of the questions asked during the interview, you may ask to move on to the next question. No one else but the interviewer will be present unless you would like someone else to be there. You are free to withdraw at any time and your care will not be affected if you decide to do so.

The interview will be digitally recorded, and is confidential, and no one (except the co-investigators and data manager) will have access to the information documented during the interview. You will not be identified by name on the digital recording. The digital recording will be deleted after being transferred onto an audio CD and stored until the completion of the study, after which it will be disposed of securely.
The interview will be transcribed word by word and this paper document will be stored securely for 3 years after the completion of the study, after which it will be disposed of securely.

We will also be collecting some demographic data so we will access your hospital notes to collect information relating to your age, domestic address, diagnosis, treatment received, hospital admissions, and the telephone intervention you received.

Reimbursments

You will not be provided with any financial incentive to take part in the research.
You will not be provided with reimbursement of expenses in order to attend the Institute where the study takes place.

What are the possible disadvantages and risks of taking part?

We are asking you to share with us some very personal and confidential information, and you may feel emotionally distressed talking about some of the topics. You do not have to answer any question or take part in the interview if you don't wish to do so

If you feel distressed about the information shared, or continue to be distressed after the interview, we will offer referral to the psycho-oncology department of the European Institute of Oncology, provision of any further information if you need, and we can offer you the possibility of talking to a member of the haematology medical team.

We aim to ensure that you are supported both during and after interview participation, if this should become necessary.

What are the possible benefits of taking part?

There is no direct benefit to you, but your participation is likely to help us to find out more about the best ways to support patients with haematological cancers.

Many people enjoy sharing their views in interviews but occasionally people can feel upset if they talk about something upsetting that has happened to them. If this happens, the researcher interviewing you will ensure that you are supported both during and after the interview.

Will my taking part in the study be kept confidential?

Yes. We will follow all ethical and legal practice and all information about you will be handled in confidence.

We will not be sharing information about you outside of the research team. The information will be kept strictly confidential, and any information about you will be kept anonymously by using a unique number on documents instead of your name. Only the researchers will know what your number is. All the information will be stored securely on hospital premises.

The interviews will be translated into English and sent to the co-investigators of this research project at the University of Manchester in the United Kingdom, where the privacy laws are applicable to the same extent as those in Italy. The data transferred to the University of Manchester will be sent in an anonymized form, with a unique number on the documents, and the code for identification will be stored confidentially at the EIO. All steps will be taken to protect your privacy and all data that will be shared will be password protected so that this can only be accessed by the authorised research team.

Publications may include direct quotes in order to demonstrate and enhance the understanding of findings – but any quotes used from the transcripts will not have your name attached.

What if there is a problem?

If you have a concern about any aspect of the study, you should speak to the lead researcher who will do their best to answer your questions : Sarah Liptrott 02 57498 538. If you remain unhappy and wish to complain formally, you can do this by contacting the Ufficio Relazioni con il Pubblico: 02 57489 310 (email: urp@ieo.it).

What will happen if I don't want to carry on with the study?

If during the interview, you do not wish to continue, you should inform the interviewer and the interview will be stopped. If after the interview, you decide you do not wish to take part in the research, you should inform the interviewer and the digital recording/ audio CD and transcribed interview will be destroyed.

What will happen to the results of the research study?

The results of the study will be submitted for publication to a scientific medical or nursing journal. If you wish to have a copy of the final published article, please inform the researcher and they will send a copy of the article once it has been published.

Participants of this research will not be identified by name within the publication.

Who is organising and funding the research?

The research is being organised by the European institute of Oncology in Milan.

The researchers are not being paid for including you in this study.

Who has reviewed the study?

This study has been approved by the Research Ethics Committee at the European Institute of Oncology and the University of Manchester in the UK, whose purpose is to safeguard the rights of patients participating.

Further information and contact details

If you have any questions about this research or would like to discuss this further, you can speak to one of the researchers who will do their best to answer your questions : Sarah Liptrott 02 57498 538.

CONSENT FORM

Please initial the boxes

1. I confirm that I have read and understand the research information sheet (version 2, dated 22/05/2015) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without my medical care or legal rights being affected. ☐
3. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals for the University of Manchester, UK, from regulatory authorities or from the EIO, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐
4. I understand that my anonymised data will be shared between the IEO and the University of Manchester in the UK, where it is relevant to my taking part in this research. I consent to the sharing of this data. ☐
5. I agree to the use of audio-recording, with possible use of anonymized quotations and descriptives i.e. age and gender. ☐
6. I understand that all data will be stored securely and is covered by the data protection act. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person Obtaining Consent	Date	Signature

PRIVACY

We inform you, pursuant to the Decree Law (DL) 30/06/2003 N ° 196, code regarding the protection of personal data, all the data related to your participation in this collection of information will be treated in strict confidence in accordance with the standards of Good Clinical Practice (Ministerial Decree July 15, 1997 and subsequent amendments) and other applicable standards of clinical trials, and in accordance with the above regulations. Your personal data, as the initial general and demographic information, as well as data pertaining to your state of health - the latter being sensitive data under the Decree Law (DL) 30/06/2003 N° 196 - will be managed and stored by the data controller, which is the IEO, the Institute where the research is carried out and the head is the Medical Director of the European Institute of Oncology, via Ripamonti 435 and to these entities is responsible, for the exclusive purposes connected to the performance of this data collection. The management and storage will be in the form paper and / or computerized, including by transfer outside the national territory and the European Union. In compliance with the provisions of the Decree Law (DL) 30/06/2003 N° 196, the data processor will not provide data transfer where the State of destination or transit does not ensure an adequate level of protection. The processing of personal data will always be based on principles of correctness, lawfulness and transparency, protecting your confidentiality and rights.

The provision of your personal data exclusively for the purposes indicated above, although optional, is essential for the performance of this data collection, as well as for the fulfilment of related obligations. We also inform you that, in relation to the purposes specified above, your personal data will be communicated exclusively to the health authorities, as required by law. Personal data may be subject to statistical processing and, after being transformed into a completely anonymous form, can be included in publications and / or presented at conferences, meetings and seminars of scientific character.

You are informed that at any moment you can rely on the rights granted to you by the DL 30/06/2003 N°196, regarding the opportunity to know and have confirmation of the management of data of concern, and the possibility to obtain the updating, rectification, integration, transformation or deletion.

Name and Surname of the interested party *(in capital letters)* _____

Signature of the interested party _____

Date _____

Appendix 17 – Study 1: Data collection sheet

Trial Number: IEO 175 Registration Form Version 1 – 12/08/2014

Istituto Europeo di Oncologia IRCCS	Title of Study: TELEphone support for symptom management and supportive CARE in haemato-oncology patients: a qualitative study.	
UPN: |__|__|__|__|__|		

REGISTRATION FORM

Patient demographics

Date of Birth: |__|__| |__|__| |__|__|

Sex: M / F

Age at consent: |__|__| |__|__| |__|__|

Patient address: Province |__|__|

Postal Code |__|__|__|__|__|

Lombardy Yes / No

Diagnosis (please check one):

Non hodkgin's Lymphoma	
Hodgkin Lymphoma	
Myeloma	
Other (please specify)	

Acute Lymphoblastic Leukaemia	
Acute Myeloid Leukaemia	
Chronic Lymphocytic Leukaemia	
Chronic Myeloid Leukaemia	

Date of diagnosis: |__|__| |__|__| |__|__|

Treatment details

Number of lines of treatment: |__|__|

For each line of treatment please specify treatment regimes received and number of cycles:

Name of 1° line treatment regime:_____Number of cycles received: |__|__|

Name of 2° line treatment regime:_____Number of cycles received: |__|__|

Name of 3° line treatment regime:_____Number of cycles received: |__|__|

Name of 4° line treatment regime:_____Number of cycles received: |__|__|

_____

_____

Last treatment date: |__|__| |__|__| |__|__|

Last type of treatment (please specify regime):_____

Details of telephone contact

Total number of telephone contacts recorded: |__|__|

For each telephone contact, please record the following information:

Telephone contact 1			Comments
Date of telephone contact:		|__|__|/|__|__|/|__|__|	
Age of patient at telephone contact		|__|__|/|__|__|/|__|__|	
Type of treatment in progress			
	Chemotherapy	Y / N (Please specify regime)	
	Radiotherapy	Y / N	
	Immunotherapy	Y / N (Please specify regime)	
	SCT	Y / N (Please specify regime)	
	Other (please specify)		
Phase of the treatment cycle			
	Patient still receiving treatment	Y / N (please provide detail of treatment being given i.e. oral therapy at home)	
	Patient recently finished a cycle of treatment	Y / N (please provide date of last treatment)	
	Patient recently discharges from in-patient unit	Y / N (please provide detail of reason for admission and discharge date)	
Nature of telephone contact (please indicate all that apply)			
	Support		
	Symptom management		
	Information giving		
	Not recorded		
	Other (please specify)		
Record of any advice given:			
Y / N (please provide detail)			
Record of any referrals made based on telephone:			
Y / N (please provide detail)			

Name of Researcher Date Signature

Appendix 18a – Study 1: Interview Topic Guide

The questions in the topic guide will included but were not limited to:

1. What are the needs and expectations of haemato-oncology patients during and post-treatment, and to what extent are these met?
2. What do patients think about the telephone support intervention?
3. What are the barriers and facilitators of a support intervention delivered by telephone?

Appendix 18b – Study 1: Adapted Interview Topic Guide – additional areas of interest

Issues surrounding the identification of needs and expectations of haemato-oncology patients during and post treatment, and to what extent these are met

- What type of support is needed?
- Do you think you could have been better supported in that period?
- Is it useful to deal with early fears rather than later support, or both?

Issues surrounding patients' perceptions of the telephone support intervention

- How did the calls make you feel?
- Was it useful to have a call rather than coming into the hospital to speak to someone?
- What were the benefits or drawbacks for you?
- Was it easy to speak over the telephone? Why? Why not?

Issues surrounding the barriers and facilitators of a support intervention delivered by telephone

- What would make the intervention work for you?
- Would a telephone call be useful in this phase or later? For what reason?
- Is there a gap that a support service delivered by telephone could adequately fill?
- If designing the service, what would you prefer?
    - How often would it be? When would be the ideal timing? Who would you like to be supported by?

Appendix 19 – Study 1: Distress Protocol

The following is provided as a guideline should a patient become distressed during the interview.

Strategies to assist those distressed during an interview.

Should a participant become uncomfortable or distressed while discussing their experience during the interview, the following actions will be taken by the interviewer:

1. The interviewer will confirm whether the participant wishes for the interview to be terminated.
2. If the participant wishes for the interview to be terminated, the interview will be stopped.
3. Time will be spent with the participant and assistance provided, within the scope of interviewers abilities, to discuss their concerns and support them, where appropriate.
4. The participant will be offered the opportunity to speak to a healthcare professional from the Psycho-Oncology Department within the hospital to discuss their concerns.
5. The participant will be offered the opportunity to speak to a member of the haemato-oncology medical team within the hospital to discuss their concerns.
6. The interviewer will contact the participant by telephone the following day to ensure that the participant is alright – further support will be offered as appropriate.

Appendix 20 – Study 1: Sample of quotes - Thematic chart for Theme 1.0: Personal emotional distress and coping strategies

	Sub theme 1.1: Experiences of personal emotional distress		
	Data Specific Coding		
Respondent Sex (age at contact) Locality	**1.1.1: Distress and the challenge of the unknown across the trajectory**	**1.1.2: Feelings of loss**	**1.1.3: The link between physical and psychological well-being**
P01 F (33) Lombardy	**Despair** P01: (3.02) *and then there's the moment of total despair when there's the diagnosis that's for sure ... then ... a first day is like this, the second, total outburst ...* **Worry impact of minor setbacks during treatment** P01: (7.00) *... or maybe I had a small complication .. ehh ... due to the drugs ... but ... nothing special ... but I always thought ... if this happens and I can't have the chemo, what happens ... and then maybe these worries* **Limiting recovery** P01: (12.50) *but sometimes because you're afraid ... maybe ...I stopped myself for six months, I followed to the letter what I was told because I was afraid ... well… of making a mess…*	**Loss of autonomy** P01: (14.55) *I was very autonomous as a person, very independent ... and the fact of delegating ...not being able to do things ... made me feel really bad ... 'now I'm a burden', I really felt that they're making a huge sacrifice for me*	**Physical well-being gave strength** P01: (4.20) *I've always been good to tell the truth ... I had no hassles ... it gave me the strength to move forward in a sense, because the body reacted well .. so ... there's even the possibility to do it ..* **Physical limitations caused suffering** P01: (28.15) *..I cried often at home especially when I was better, I was at home I have to be happy ... but there is always a moment of 'why'… it was too long and I suffered this period ...*
P02 M (30) Lombardy	**Anxiety waiting for results** P02: (25.25) *.....so that following week there, I was bad until I got the results of the … of the biopsy … I was bad because I was thinking of another disease …*	**Missed personal opportunities** P02: (21.35) *above all because …. I left my studies…. so already because of me, I wasted a lot of time… I should have … I should have already been graduated before I started this course*	
P03 M (67) Lombardy	**Fear of being able to get treatment** P03: (2.15) *my worries were always that the disease wasn't so advanced that there was nothing that could be done. This, I think, crosses the mind of everyone at least until your get the first ….. results, that confirm or not the extent of the disease.*		
P04 F (44) Non-Lombardy	**Alarm at cancer diagnosis** P04: (26.45) *… hearing someone say you've got cancer is like a cold shower*	**'Cancer' is imposed not chosen** 17504 (47.25) *I always say that an oncology patient, doesn't choose to be ill*	**Routine physical activities increase perception of returning to 'normal'** P04 (29.30) *I'm getting back to let's say my normal life so I take him* (referring to child) *…. I like taking him to the gym, sometimes I like collecting him from nursery … so slowly slowly I'm trying to … to return to my … to my normality*

P05 F (57) Non-Lombardy	**'In limbo' period before diagnosis** P05: (4.40) *so there were exactly 20 days of …stress… very very hard because … I was very worried* **Shock of clinical environment** P05: (2.40) *even before the place the EIO is a particular place so even before, coming here was enough of a shock* **Clinical environment as a marker of severity instils fear** P05: (3.22) **...** *and there my world fell apart because to come here, for me, it was something … devastating, I was really bad.*	**Loss of freedom – isolation** P05: (26.30) *then I was really frightened … for the 20 days … I was really frightened … the days in isolation tormented me, because I was afraid … I couldn't go out, I couldn't go to and get a coffee from the machine..* P05: (29.40) *I always had this thing on my mind that was the isolation that distressed me … close the door, it terrorized me … but in the end, when it came to it* **Loss of self confidence and frustration due to physical changes** P05: (64.20) *you're in a situation that everything is embarrassing (patient touches her face and hair) because you're embarrassed about everything … you feel bad … you've an ugly face … you cant eat everything, everything gets on your nerves …*	**Felling unwell exacerbates psychological distress** P05: (62.05) *one day … I pulled all the plates off the table … I was ill, I couldn't pick myself up … I was totally disheartened … I didn't know what I was up against, I got to the table, I wanted to vomit, I grabbed the tablecloth – the plates, everything fell that I'd pulled*
P06 M (69) Non-Lombardy	**Fear and uncertainty at diagnosis** P06 (1.05): *… I was terrified about how…. but…. but… knowing the disease…..I took it a bit badly* P06: (10.30) *I was traumatized by the tumour* **Defeated** P06: (5.20) *… I gave up…morale on the floor* **Fear of being in hospital** P06: (4.31) *… that was the …. my worry let's say, I was afraid, I tell you straightaway I was afraid …. before being admitted because …. I'm 70 years old, I've never been in hospital* P06: (10.30) *… I was already traumatized by the admission*		
P07 F (65) Lombardy	**Worries of the impact on daily life** P07: (3.35) *… let's say, a… a…desperation because however it's … I have a disabled son and so I didn't know how to manage the situation* **Fear of treatment side effects** P07: (4.35) *I could react to the chemo though, I was really really bad, also because I had a lot of allergies so..erm…I was terrified, I didn't live it at all well this thing*	**Lost self-confidence (self-image)** P07: (6.53) *…I also had already … 2 television events organized that he* (patients husband) *absolutely had to do so I put a wig on erm… seeing myself, and now in that moment I can see that my face was ..it was destroyed, despite the make-up, despite everything that I could do*	**Physical appearance as 'unwell' has psychological impact** P07: (6.53) *…I also had already … 2 television events organized that he* (patients husband) *absolutely had to do so I put a wig on erm… seeing myself, and now in that moment I can see that my face was ..it was destroyed, despite the make-up, despite everything that I could do*
P08 F (33) Lombardy	**Feeling confused at diagnosis** (3.00) *when I found out that I had this … this disease….my head … you can imagine where it was*		

P09 F (66) Non-Lombardy	**Filled with apprehension pre-treatment** P09: (4.12) *I was … waiting for this, this thing* **Feeling at risk leaving a safe hospital environment** P09: (3.00) *of course it was a risk because I was very weak at that time*	**Loss of a normal relationship with life** P09: (34.28) *now I can say with confidence, I was … analysing my self in-depth .. I've lost 15 years of my life…* **Loss of normality/ social integration** P09: (35.23) *…they take away your… normal relationship with life … I've become much less … sociable I happily stay alone more … because you can't always say to friends .. you know I don't feel like it I have to have a CT scan.. or I don't want to because I'm waiting for the results … it gets a bit … arduous … so I prefer to stay on my own a bit more…the only bad thing this disease has left me is this*	**Routine physical activities increase perception of returning to 'normal'** P09: (12.35) *regular .. I returned to the person I was before … I did everything.. really.. everything and more, I forced myself to do more than I should have done, really without problems, in fact everyone said to me 'you're really exceptional' in the sense that I'm … I saw many people that hadn't had the treatment I'd had and they're all (movement with hands and face sad)… I returned completely to normal*
P10 M (48) Lombardy	**Confirmed diagnosis gave security** P10: (8.26) *it gave me that security*	**Loss of strength - fragility** P10: (33.37) **...** *in sickness, one is weaker because he doesn't have … he can't defend himself...* P10: (34.16) *there he can't race, he has to be himself*	**Impact of physical and psychological well-being** P10: (16.20) *it's hard isn't it? Not only psychologically, but also physically so, when you have this physical problem and then also psychological but no type of help, you know …*
P12 M (51) Lombardy	**Worries about a definitive cure** P12: (5.20) *it's ugly …. it's a cancer and you don't know how it's going to end up, you don't know if you can cure it…*		
P13 M (64) Lombardy	**Feeling at risk out of safe hospital environment** P13: (19.25) *… I think I was discharged a bit too quickly... I vomited all night, I fell asleep about 4 and they told me that the day after, I could go home and so the day after I was discharged... I went to A&E .. because I had black feces … and I didn't know what it was. After 5 days that I'd been ill, it seemed to me, even if I was happy to go home .. but in the end it was too soon …*		
P14 M (61) Non-Lombardy	**Worry about survival** P14: (5.07) *erm….one who's ill with a tumour .. obviously you have in mind that … you hope to be cured … but there's also obviously the possibility that you won't make it*		
P15 F (63) Lombardy	**The tragedy of cancer** P15: (36.14) *"… even if you're cured, found the right hospital, it's always the person that is hit by this thing here, it's always tragic"*		
P16 F (55) Lombardy	**Fear of relapse** P16: (11.17) *And then the fear, the fear, a fear, night time, night time is horrendous … the night … even now at a distance of … 4 years, when I think about the moment when … when even maybe my leg hurts and it's nothing to do with the disease ….you're afraid … there's always the fear*	**Loss of functioning role within the family and difficulty in acceptance for patients and family** P16: (11.17) *like they're used to seeing you always operative always… then I've got a son and my husband, they were used to the fact that I did everything ehh…they worked, went out….it's … the home is managed by me and you find yourself there and … you don't want them to be lacking of anything but you haven't got the strength to do certain things*	**Physical illness fuelling feelings of abandon and hopelessness** P16: (16,36) *…they sent me home and they gave me the impression that I'd been abandoned… like saying there's nothing else we can do, we'll send her home*

P17 M (40) Non-Lombardy	**Physical limitations cause distress** P17: (33.19) *my boss let's say, doesn't let me do anything heavy, I do the lighter work but I feel useless, what can I say … if I have to get something that weighs a kilo, I can't do it, you feel terrible, terrible, really terrible, you feel really weak, how's it possible that I get short of breath so quickly …*	**Indirect costs of attending the hospital cause financial concerns** P17: (33.19) *its difficult economically, so even for this he'd (referring to the doctor) given me a Christmas present.. very nice 3 trips to Milan, you can imagine between the tickets and the hotels, I'd been really sorted out … …*	
P18 M (35) Non-Lombardy	**Life threatening diagnosis brings uncertainty and need for adaptation** P18: (9.19) *…you don't know how things are going to end up and so … and really … the risk to your life and then however it goes, you enter into a different routine, and you need a moment to get into the mindset … then after like everything … you get used to it, you adapt … it's not that … you adapt to it … like starting the treatment, after the first you know what you have to do and you do your course … but the most difficult period is that there… the beginning like*	**Future plans disrupted** P18: (7.57) *… you enter into a reality that you don't know .. that of the treatment, you have to treat a disease even for several years, and in a moment all the plans one has for what they want to do in their life vanish, it's like that…*	
P19 M (62) Non-Lombardy	**Emotional distress at diagnosis** P19: (9.00) *how did I feel? … I felt the world fall in on top of me*		**Minimal physical SE's helped to manage coping** P19: (36.36) *… I had a good experience with the chemo… because honestly it cured me and didn't make me suffer*
P20 F (25) Lombardy			**Continuing with normality is psychologically positive** P20: (15.28) *well…I think these two things go hand in hand, in the sense that even in my head I was well… I was …in the moment where I had maybe a bit of …a moment of discouragement … I had my mum who was close to me and I had my friends that I kept seeing, to tell the truth, it wasn't a complete upturn… I hadn't completely disrupted my… my life and so this psychologically … helped me and one thing helped the other, the mind helped the body … and then the fact that even physically I was well … it made me, it made me … I continued with this desire to be cured and to get better*
P21 F (31) Lombardy	**Fear of doing damage to self** P21: (20.53) *yes … yes, yes, I was a bit afraid to go to certain places, if someone came to the house, someone to my house, I'd have to be more careful*		**Ability to do 'normal' activities facilitate recovery** P21: (21.26) *…. my parents … we spoke and I also understood a bit that I was well … I'm not afraid of those things anymore*

	Sub theme 1.2: Adaptive coping strategies			
	Data Specific Coding			
Respondent Sex (age at contact) Locality	**1.2.1: Personal adaptive coping strategies**	**1.2.2: Emotion and meaning focused coping techniques**	**1.2.3: External sources of coping assistance**	**1.2.4 Support is not always necessary**
P01 F (33) Lombardy	**Proactive approach - Combating the disease** P01: (6.00) *..psychologically I had started and so ... I felt I was doing something for the disease ... so psychologically you feel better ... yes… it seems like a.. in the end ... you feel better ... I've started so … let's do it.*		**Formal support froma a psychologist objectives different to family & friends** P01(7.00) *... and so I had a stranger ... they don't know you ... to talk ... so ... it was good for me ... and she followed me all the way* **Psychologist assisted in developing complex coping techniques** P01: (14.55) *… she made me look at things from the other point of view ...sometimes my friends and my parents… she said that they do it because they want to do it ... it's...it's not that they do it because they feel obliged ... and then she said to get this out of your head and to take the help of those who offer when you need it ... things that maybe in the beginning, I didn't do much ... I tried to do everything alone ... everything ... so I had to change some parts of my character obviously ... and let go of things a bit more ... and not keep everything under control ... and delegate*	
P02 M (30) Lombardy	**Proactive approach - Hope** P02: (9.40) *….. even during the induction phase, I was chilled because the doctors had already said that the malignant cells were regressing*	**Transient nature of problems** P02 (17.45) *….so, you play – if I get a temperature it'll pass – I had a temperature…. I couldn't think, I vomited because of the headache, it doesn't matter it'll pass …. inside I was convinced that everything was transitory …. just as it comes it'll go away …*	**Informal support during treatment** P02 (19.30) *my girlfriend, my brother, my brothers and sisters, parents and family …. my friends surprised me as well, they came from (*name of town*) to see me… I do video calls on Facebook..*	**Support unnecessary** P02: (40.40) *… I didn't feel the need, me personally* **Providing support was other peoples need not that of the patient** P02: (20.45) *.. I'm fine on my own so …. don't worry … but …it was their thing rather than mine*
P03 M (67) Lombardy	**Pragmatic approach - Acceptance of long term side effects** P03: (7.20) *..however ..if that's the price to pay, you pay it* **Accepting follow-up controls as necessary** P03: (12.00) *… I believe that this is … a necessary control and you do it.*		**Informal support during treatment** P03 (6.40) *… family and everyone were very close…*	

P04 F (44) Non-Lombardy	**Pragmatic - Accepting possibility of side effects** P04: (16.47) *it's normal a path … a difficult path that you do so, I believe that these are all quite normal things.. the fact of feeling a bit tired, having days where you feel stronger, days in which you feel it a bit less*	**Comparing self with others** P04 (20.50) *I have … known people that have had big problems compared to me*	**Early formal support assists in cognitive reframing + adjustment** P04 (24.00) *…I think it's important to start it before starting everything… in my opinion, as soon as one knows …you need someone that will however help you to accept above all the disease* **Formal support important where informal was lacking** P04: (6.00) *I always had… doctors, nurses that… helped because however, I, the hospital stay I was alone, I didn't have family err… they were indispensible for me* (laughs)	
P05 F (57) Non-Lombardy	**Pragmatic approach to limitations and recovery** P05: (10.40) *I said come on tomorrow maybe …. today is maybe the peak … tomorrow probably will be better … and so I hoped always in the next day and slowly slowly slowly slowly slowly slowly I got there*	**Significance from the experience** P05: (35.20) *… I keep saying that I've learnt a lot, I've learnt a lot from this thing … I believe that it has made me stronger.. I'm sure it's made me stronger… this thing here doesn't do anything other than make you stronger* **Reprioritising** P05: (18.15) *…this thing here it has to teach you something, to overcome everything…this thing means that you've touched with your hands, with your heart, all this problem …and… you have to be above it … trivial things you put aside*	**Informal support pre-diagnosis** P05 (5.25) *…it helped me to have my husband there nearby so going privately having my husband, my husband was with me for 5 days …ehh…let's say that it helped me at least at the end we were 'us', my husband and, and the children at home…. we were a group and we were strong*	
P06 M (69) Non-Lombardy	**Adaptation to become active in self-care P06**: (16.20) *at the third injection …. the two women of the house told me to stop making a scene and to do it on my own (SL: do it alone?)… don't be so dramatic (*laughs*)*		**Positive experiences facilitate support seeking** P06: (20.30) *I called … that time there and they responded straightaway, the doctor, and helped me.*	
P07 F (65) Lombardy			**Availability facilitates support seeking** P07: (25.08) *they told me, that if I had a temperature, if I had a cough then I had to go there…they gave me a …a sheet where exactly, it told me that in case of … I had to do, I had to do these things, but I also had telephone numbers*	

P08 F (33) Lombardy	**Accepting potential side effects** P08: (20.20) *…and then you get really tired … but this is something that happens when you're doing the chemo… when someone's not well, it's normal*	**Personal reflection** P08: (6.18) *I did some soul searching to be a bit calmer…. I was getting ready to face this journey …*	**Formal support provides reassurance** P08: (3.00) ***…****the oncologist also helped me a bit, more than anything … because I … when I found out that I had this … this disease…the head … you can imagine where it was…so the oncologist …. calmly, absolute calm explained everything to me that, so I was reassured* **Importance of trust facilitating support** P08: (34.42) *I have always been very trusting when it comes to them …the things that they told me … so, they really reassured me*	
P09 F (66) Non-Lombardy	**Accepting that fears are a part of the pathway** P09: (36.25) *…these are things that happen….when you enter in this circle … it happens to you… you suffer mentally and are anxious*	**Comparing self with others** P09: (12.35) *I returned to the person I was before … I did everything.. really.. everything and more, I forced myself to do more than I should have done, really without problems, in fact everyone said to me 'you're really exceptional' in the sense that I'm … I saw many people that hadn't had the treatment I'd had and they're all (*movement with hands and face sad*)… I returned completely to normal*	**Positive communication give reassurance** P09: (10.11) *he cheered me up about the treatment, about things, he promised me that things would go in the right direction*	**Need for support is individual** P09: *… I don't know … I think it's just my problem... I don't know …*
P10 M (48) Lombardy	**Acceptance of possible relapse** 17510: (20.20) *with the knowledge that it can re-present like he told me…well it's a war.… to be fought … and we'll see*	**Staying positive is key** P10: (38.51) *I think that the best result is a positive approach that … then you can only improve… to have a good experience in inverted commas*	**Psychological support and a holistic approach** P10: (16.58) *…you create a type of relationship with the patient … that maybe … I don't know, it's, always helps to... in the care because it's not only a drug.*	
P12 M (51) Lombardy	**Active role in self care** P12: (16.14) *I defended myself with food…. because that weakness you have to, increase your intake – if you don't eat you're finished*		**Reasurance and encouragement** P12: (39.57) *I think it cheers you up, it gives strength to the patient … the support of a doctor means a lot … even how the disease goes … like*	
P13 M (64) Lombardy	**Pragmatic approach - acceptance** P13: (5.24) *I accepted the chemotherapy etc…I didn't really have …I didn't have any big problems psychologically … I accepted both this and that..*		**Feeling followed builds perceived support** P13: (35.28) *…but, all in all, it seems to me like coming home, and having a chat with a the doctor whom I found .. it's something that I like*	

P14 M (61) Non-Lombardy			**Availability facilitates support seeking** P14: (37.24) *…you have the necessary telephone numbers if something happens*	**Support unnecessary where no perceived dangers** P14: (37.24) *there aren't really dangers in that period between one visit and another, I don't think it's (support) necessary*
P15 F (63) Lombardy	**Determination, strength** P15: (11.13) *I decided to carry on and finish it, I decided to be strong*		**Formal support and reassurance after treatment** P15: (36.57) *and I was happy, not because I don't want to come here every 6 months, but really because she reassured me* **Importance of having contact** P15 (25.17) *I called as well sometimes, it's contact … there was contact and contact is really important, you know if you have any problem you can call and they'll respond*	
P16 F (55) Lombardy	**Pragmatic approach – preparing others for life after their death** P16: (12.46) *… I thought they weren't able to face certain things so I … already started organising things to that if anything happened to me, at least they'd have some time, have the house clean so I did this, and did that… I taught them to cook, I taught my husband to do this and do that … because they weren't able to use even the washing machine…*		**Formal support provides reassurance after treatment** P16: (26.55) *the doctor reassured me, he told me that the problems aren't a result of the … of the state of the tumour, they're caused by the consequences of what the tumour has left behind… and I went home cheered up … because the patient needs to be reassured*	
P17 M (40) Non-Lombardy	**Active role in self care, organization aids coping** P17: (10.03)*...I did everything, my pills that I had to take and the timer that rang on the hour.. every time I took one, I was .. I wrote on the block notes the medicines that I took and I had taken … every day .. during the day, and the day passed .. I went to the supermarket, did the shopping, went out early in the morning for a little walk, I had my day organized …*			
P18 M (35) Non-Lombardy	**Adaptation - uncertainty becomes familiarity** P18 17518: (9.19) *…you don't know how things are going to end up and so … and really … the risk to your life and then however it goes, you enter into a different routine, and you need a moment to get into the mindset … then after like everything … you get used to it, you adapt … it's not that … you adapt to it …*		**Informal support pre-diagnosis** P18: (2.25) *my family above all … they really helped me, and then I'm … I should say that I'm a Jehovah's Witness and so we're a united community and so we help each other a lot … so I felt my friends were very close*	
P19 M (62) Non-Lombardy			**Genuine communication + security facilitated support seeking** *P19: (21.04) I believe the support from the hospital was excellent, nothing else was possible … they did... they'd played all their cards … knowing what they were doing …professionalism … they all had … humanity*	

P20 F (25) Lombardy	**Investigations unpleasant but necessary**17520: (18.30) *I did everything with the thought that … well it's what needed to be done*		**Positive communication facilitates support seeking** P20: (7.29) *Dr XXX when she started to treat me she was always very very kind, and also in her way of being so… cheerful … she's a person that jokes and so that helped me as well …*	
P21 F (31) Lombardy			**Formal support from psychologist** P21: (6.32) *yes very yes … it helped me a lot …they're really good… I found it really good*	

	Sub theme 1.3: Maladaptive coping strategies and their contributors		
	Data Specific Coding		
Respondent Sex (age a contact) Locality	**1.3.1: Personal maladaptive coping strategies**	**1.3.2: Reticence in support seeking and its impact**	**1.3.3: Negative experiences of support seeking as a barrier**
P01 F (33) Lombardy			**Reluctance to seek support from healthcare professionals as perceptions of what is important differ** P01: (18.26) *I'm unsure... not to call the department for trivial things ... only if something happened …* P01: (26.25) *… perhaps because patients don't call the ward just to say 'so today I feel like this, like that' … you don't do it … erm … for doubts you say that 'I'll ask this when I'm there' … 'I'm not phoning for rubbish* **Concerns trivial** P01: (20.10) *… sometimes one doesn't say because maybe… they say 'we'll see', 'it maybe nonsense', these are the most important things to me…*
P02 M (30) Lombardy	**Delegating decision making** P02: (9.00) *…. I always said to the doctors to do everything ….. do everything and get rid of this disease, I've always …. I've always been like that.*	**Patients as providers of support for others** P02: 17502 (19.15) . *especially my mother was really bad, I consoled her ….* **Protecting others** P02: (27.10) *….my parents asked 'what did they say, what did they say',… I would tell them in another way ….in fact I'd filter the news a bit to my parents because I didn't want them ….because they …just a small thing was enough and they were bad*	**Rejection of formal support as personal preference** P02: (51.15) *if I was with the psychologist, I would be frequently annoyed, I said it's a personal thing*
P03 M (67) Lombardy	**Delegating decision making** P03: (2,00) ...*the only thing to do (*laughs*) is entrust yourself to the experts, you can't do anything else.*		
P04 F (44) Non-Lombardy		**Patients reassuring others** P04: (25.15) *and it's something that I did as well the first time, I tried … I was trying to make them feel … I reassured.. my family*	**Reluctance of others to help** P04: (42.13) *often you find those family members that … even if they offer help, they don't want to give it, because even this is, I repeat, there are people that understand the disease, people that think that you've got a common cold*

P05 F (57) Non-Lombardy	**Dependence on healthcare professional** P05: (9.05) *I can assure you that you put yourself in their hands… you feel protected* P05: (30.40) *patients put themselves in the hands of the … the doctor looking after them the… the nurse on duty*	**Hiding fears from others** P05: (15.52) .. *but they come to you, these fears come … unfortunately… even, even if.. I didn't say anything to anyone … l kept it for myself* **Withdrawal from support network (avoid indepth conversations)** P05: (18.55) *I stayed vague, I didn't want to be … commiserated …not me, It wasn't for me …. poor woman …. what's … no absolutely… absolutely … it wasn't for me.*	**Lack of support** P05: (17.40) *I thought I had 2 sisters that could help me instead… maybe they were afraid, they ran off … even now…… a reaction like that …. stupid… they didn't understand because they stop and look at the trivial things …* **Not wanting to disappoint the healthcare professional** P05: (24.11) ..*when I arrived home and I saw that my temperature was going up, I said oh my God, he trusted me, instead my temperature's going up …and so I said look, he trusted me and I behaved*
P06 M (69) Non-Lombardy			**Lack of informal support through lack of understanding** P06: (10.58) *we live a bit in a world where we are ill but the people that aren't, often don't understand*
P07 F (65) Lombardy		**Inability of others to cope** P07: (4.35) *I had lots of fainting episodes, my husband didn't know how to manage them, so practically, I requested to stay in hospital and I went home only 2 days a week, so these 6 months I was hospitalized.. at least I liked living in hospital, I was a bit less worried*	**Family members are a source of stress** P07: (13.10) *but the fact is … that I couldn't … however he made me anxious, he made me anxious at home, he made me anxious in the hospital* **Physical illness barrier to peer support** P07: (6.35) *but….in a certain sense it should have helped me being with the public… but I was so bad, but so bad that even staying one hour seated for the transmission and I was destroyed*
P08 F (33) Lombardy	**Depending on healthcare professional** P08: (5.02) *I put myself in his hands, to say don't worry, he gave me a way not to worry… I was in their hands in their hands … how can I say …. I was in good hands*		
P09 F (66) Non-Lombardy	**Distractions to overcome loneliness** P09: (3.00) *the intervention took a short time, and then I had all of the rest of the day empty and alone here .. I couldn't do it … I tried … so I said, no, if I have to do it, now I prefer to occupy my time on the train where I can see someone*	**Social withdrawal** P09: (35.32) *I've become much less … sociable I happily stay alone more …because you can't always say to friends .. you know I don't feel like it I have to have a CT scan.. or I don't want to because I'm waiting for the results of the CT scan … it gets a bit … a bit arduous …* **Hiding fears** P09: (36.25) *you suffer mentally and are anxious .. but try not to seem too …*	**Avoiding peer support where negative** P09: (11.43) *I've known lots of people who are down, that was really something… it was also annoying sometimes because it … it brought me down as well* (laughs)
P10 M (48) Lombardy	**Distractions to maintain a sense of normality** P10: (15.51) (talking about attending work) *because if a patient begins to let go … the treatment … its hard to do because then…still they're…you have to be in form in inverted commas for what you have to face, the treatment the week after*		

P12 M (51) Lombardy	**Avoidance techniques - language** P12: (referring to chemotherapy) (4.55) *yes, so as to play it down, I called it weedkiller (*laughs*) …the stuff that you put in the garden for the… to kill everything.. it doesn't leave anything.. to play it down …. because there if you think about it for a moment you really want to cry*		**Support seeking only in extreme situations** P12: (14.45) *… I called only when I couldn't carry on anymore (*laughs*) like, because you're really afraid... really scared… no you don't call… no… a bit yes…. like, you hold back don't you?* **Being a burden to the medical staff** P12: (13.40) *well you know the doctor afterwards, it's not that they have a lot of time to speak to you, let's say that that he speaks with me he gives you everything… he explains everything, afterwards, one rightly so is afraid to disturb him, because after… it's not that there is only me, there's a load that are a bit like that*
P13 M (64) Lombardy			
P14 M (61) Non-Lombardy			**Oriented to ask certain questions to certain healthcare professionals** P14: (34.34) *these are things that you ask …. more….. willingly to a nurse rather than a doctor so as not to waste the doctors time don't you?…you have to ask the things that are more…. important….to the nurse, you ask… about loosing your eyebrows, hair, will I loose the hair on my legs?, things like that … that you ask more willingly to a nurse rather than a doctor*
P15 F (63) Lombardy	**Work as a distraction** P15: (9.42) *with my lipstick, I did my make up with my hair the wig, I adjusted it all the time*	**Avoid seeking support from those who are unwell** P15: (2.55) *because my husband who was ill, I hadn't said anything to him* A**void worrying family members / hiding illness** P15: (8.56) *when the chemo was finished I came home, I did it even without my husband knowing where I was, what I'd done, my husband thought that I was at work … in the afternoon… I let my children see that I.. I was ok like so they wouldn't worry… one day I burst out crying, because I said 'goodness, my husband is ill and I'm here, I have to be well*	
P16 F (55) Lombardy	**Avoidance with activities** P16: (coping for tension) (34.02) *then there were always people that came to see me and I wanted to make a good impression so I carried on cleaning and doing those things there …and like a, because I was.. to get rid of … the tension*	**Patients providing support for others** P16: (31.20) *because it was me cheering them up … I was supporting the others …because you see people crying at home … my husband, my sister, my … my husband, my husband cried… I had to cheer the other's up*	**Concerns trivialised and care unholistic** P16: (62.17) *…I said that I'd been ill, that I'd had these problems that but they didn't say anything… she (the doctor) didn't read anything … she didn't even take it into consideration …I had to take the documents, go to my GP and she sent me to a neurologist … I repeat, they, they follow only what's theirs and that's it …. and now it's a routine that they're doing and that's it.* **Psych support necessary for pt and family** P16: (30.13) *me ..I didn't want a psychologists help, but no, now I understand that I really needed it …me myself and also my family*

P17 M (40) Non-Lombardy	**Hiding feelings to maintain control** P17: (7.50) *… I don't want … that they treat me like I'm a patient for example.. no, instead I was normal, I was ok, I wasn't ok but I was ok... to me I was ok .. I reacted .. how can I say .. differently form the people that I've seen and I'm sorry that they're beaten up but .. instead no …*	**Reluctant to worry others** 17517: (3.03) *of course from the family because they were there.. but to tell you the truth I was always, even when I wasn't well, I was always… how can I say … like I was well .. if someone asked me 'how are you?', I'd say 'I'm ok'…*	**Paternalism of others blocks asking for support** P17: (8.46) *I rented an apartment here, I was on my own for 8 months, and I took care of myself because I know how to cook, I know how to do lots of things and my family wanted to come, I said 'no'*
P18 M (35) Non-Lombardy		**Distress of causing anxiety to others:** P18: (23.31) *it's not pleasant knowing that the others are anxious.. that there yes …a little bit yes … after well I wasn't bad but even knowing that the others are bad because of you, surely isn't something pleasant*	**Paternalistic approach from family** P18: (22.50) *I felt that they were a bit anxious, a bit headteacher-ish at certain times yes*
P19 M (62) Non-Lombardy			
P20 F (25) Lombardy	**Distractions to maintain a sense of normality** P20: (17.01) *… if it had stopped me doing those things, probably psychologically I wouldn't… I'd have felt … well ill… someone else, and I wouldn't' have …been able to finish this course and so… I'd have felt a ..a stronger effect of the disease on the course of my life*		
P21 F (31) Lombardy			

Appendix 21 – Study 2: Ethical approval from the University of Manchester Committees on the Ethics of Research on Human Beings, March 2016

MANCHESTER 1824

The University of Manchester

Ref: ethics/16063

Miss Sarah Liptrott
School of Nursing, Midwifery and Social Work
Jean McFarlane Building
Manchester, M13 9PL

Research Governance, Ethics and Integrity
2nd Floor Christie Building
The University of Manchester
Oxford Road
Manchester
M13 9PL
Tel: 0161 275 2206/2674
Email: research.ethics@manchester.ac.uk

17 March 2016

Dear Miss Liptrott,

Study title: HealthCare Professionals perceptions of TELEphone based support for symptom management and supportive Care in haemato-oncology patients

Research Ethics Committee 4

I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form and supporting documentation as submitted and approved by the Committee.

This approval is effective for a period of five years. If the project continues beyond that period an application for amendment must be submitted for review. Likewise, any proposed changes to the way the research is conducted must be approved via the amendment process (see below). Failure to do so could invalidate the insurance and constitute research misconduct.

You are reminded that, in accordance with University policy, any data carrying personal identifiers must be encrypted when not held on a secure university computer or kept securely as a hard copy in a location which is accessible only to those involved with the research.

Reporting Requirements:

You are required to report to us the following:

1. Amendments
2. Breaches and adverse events
3. Notification of Progress/End of the Study

Feedback

It is our aim to provide a timely and efficient service that ensures transparent, professional and proportionate ethical review of research with consistent outcomes, which is supported by clear, accessible guidance and training for applicants and committees. In order to assist us with our aim, we would be grateful if you would give your view of the service that you have received from us by completing a feedback sheet UREC4 feedback

We hope the research goes well.

Yours sincerely,

Karen Lythe
Secretary to University Research Ethics Committee 4

Appendix 22 – Study 2: Participant Information Sheet and Consent Form

HealthCare Professionals perceptions of TELEphone based support for symptom management and supportive Care in haemato-oncology patients

Participant Information Sheet

This is an invitation for you to participate in this research project which is called HCP TELECare Perceptions (HealthCare Professionals perceptions of TELEphone based support for symptom management and supportive Care in haemato-oncology patients).

You are being invited to take part in a research study which is the third phase of a post-graduate doctorate research program at the School of Nursing and Midwifery, at the University of Manchester (UK), aimed at developing an acceptable patient focused telephone intervention for individuals undergoing or having undergone treatment for their haemato-oncological malignancy.

Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for taking the time to read this.

Who will conduct the research?

The research is being conducted by Sarah Liptrott, PhD Student at the University of Manchester, and Professor Karina Lovell, and Dr Penny Bee, based at the University of Manchester, School of Nursing, Midwifery and Social Work, The University of Manchester, Jean McFarlane Building, Oxford Road, Manchester M13 9PL, UK.

What is the purpose of the research?

The purpose of the research project is to determine qualified healthcare professionals perceptions of the needs of haemato-oncology patients during and after treatment. We want to learn what people think about telephone based supportive interventions, whether there are particular groups of patients that would benefit from support and whether telephone based delivery is feasible. We also want to find out what are the potential problems of delivering support by telephone and the ways in which this could be made easier and more useful.
We aim to perform 2 focus groups with approximately 6 participants in each.

Why have I been chosen?

You are being asked to participate because you are an expert qualified healthcare professional, working with haemato-oncology patients, and because we feel that your experience can contribute to our understanding and knowledge of services provided and service developments.

What would I be asked to do if I took part?

If you accept to take part in the research, you will be asked to participate in a focus groups with other qualified healthcare professionals (i.e. nurses, psychologists, doctors etc.) facilitated by Sarah Liptrott (researcher for this study). The focus groups will take approximately 90 to 120 minutes.
The focus group will take place in a dedicated room – location will be communicated.

The facilitator will begin the focus group making sure you are comfortable and if necessary, answering any questions about the research that you might have. The facilitator will then ask participants to introduce themselves (without giving their name) including information such as country of residence, current role, no. years in care of patients with haematological malignancies.
The facilitator will then ask questions about your experience and give you time to share this with the group.
The questions will be about perceived needs of haemato-oncology patients and to what extent are these met, perceptions and experiences of telephone based supportive interventions, utility, and feasibility. We would also like to know your ideas about what things make this a more difficult or easier way to deliver receive support from both patients and healthcare professionals perspectives.

If you do not wish to answer any of the questions asked during the focus group, you may ask to move on to the next question and you are free to withdraw at any time.

What happens to the data collected?

The focus group will be digitally recorded, confidential, and no one (except the co-investigators) will have access to the information documented during the focus group. You will not be identified by name on the digital recording. Audio files will be password protected, be transferred onto the server of the University of Manchester, and will be deleted from the digital recorder. A transcribed verbatim version will be available as a password protected electronic file. Data will be stored securely in line with University of Manchester data management arrangements on the password protected server. At the end of the study transcripts and electronic records will be archived for 5 years after the project's completion, after which it will be disposed of securely.

How is confidentiality maintained?

We will follow all ethical and legal practice and all information about you will be handled in confidence.
We will not be sharing information about you outside of the research team. The information will be kept strictly confidential, and any information about you will be kept anonymously by using a unique number on documents instead of your name. Only the researchers will know what your number is. All paper records e.g.

original consent form etc. will be stored in secure storage facilities at the University. Personal identifiable paper records will be stored separate from anonymised paper records. The data transferred to the University of Manchester will be sent in an anonymized form. Focus groups will be digitally audio-recorded, and audio files will have password access only, be transferred onto the University server, will be password-protected, and will be deleted from the digital recorder. A transcribed verbatim version will be available as a password protected electronic file. Data will be stored securely in line with University data management arrangements on the password protected server

Publications may include direct quotes in order to demonstrate and enhance the understanding of findings – but any quotes used from the transcripts will not have your name attached.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw without giving a reason and without detriment to yourself, however after the publication or presentation of the findings and results of this study, it is no longer possible to withdraw your contribution.

Do I have to take part?

Participation in this research project is entirely voluntary. If you decide to join the study, we will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason and without detriment to yourself.

Will I be paid for participating in the research?

You will not be provided with any financial incentive to take part in the research.

You will not be provided with reimbursement of expenses in order to attend the location where the focus groups take place.

What is the duration of the research?

The expected total duration of participation in the study for each participant will depend on the length of the focus group, which is expected to last approximately 90-120 minutes in total.

Where will the research be conducted?

The focus groups will be held in Spain in April 2016 (date to be confirmed)

Will the outcomes of the research be published?

The results of the study will be submitted for publication to a scientific medical or nursing journal. If you wish to have a copy of the final published article, please inform the researcher and they will send a copy of the article once it has been published.

Participants of this research will not be identified by name within the publication.

Who has reviewed the research project?

This study has been reviewed and approved by the University of Manchester Research Ethics in the UK, on 17/03/2016.

What if something goes wrong?

We are asking you to share with us personal and confidential information, and you may feel emotionally distressed talking about some of the topics. You do not have to answer any question or take part in the focus group if you don't wish to do so.

The focus group facilitator will check if you are happy to continue or wish to pause throughout the focus group. If you feel distressed about the information shared during the focus group, you can ask to stop and support will be offered by the researcher. If then you feel able to carry on, the focus group will resume, however if you do not feel able to continue, you will be shown to a quiet area. You should contact your GP or mental health provider (or the researcher may do this with your consent). Following the focus group, the researcher will call you (if you agree) or encourage you to call her if you experience increased distress in the hours/days following the focus group.

We aim to ensure that you are supported both during and after interview participation, if this should become necessary.

What if I want to make a complaint?

Minor complaints

If you have a minor complaint then you need to contact the researcher(s) in the first instance, who will do their best to answer your questions :

SARAH LIPTROTT: sarah.liptrott@postgrad.manchester.ac.uk Tel: 0039 02 57498 538

Formal Complaints

If you wish to make a formal complaint or if you are not satisfied with the response you have gained from the researchers in the first instance then please contact the Research Governance and Integrity Manager, Research Office, Christie Building, University of Manchester, Oxford Road, Manchester, M13 9PL, by emailing: research.complaints@manchester.ac.uk or by telephoning 0161 275 2674 or 275 2046.

What Do I Do Now?

If you have any queries about the study or if you are interested in taking part then please contact the researcher **SARAH LIPTROTT: sarah.liptrott@postgrad.manchester.ac.uk Tel: 0039 02 57498 538**

This Project Has Been Approved by the University of Manchester's Research Ethics Committee [UREC reference number: ethics/16063].

MANCHESTER 1824

The University of Manchester

APPENDIX B

HealthCare Professionals perceptions of TELEphone based support for symptom management and supportive Care in haemato-oncology patients

CONSENT FORM

If you are happy to participate please complete and sign the consent form below.

Please initial box

1.	I confirm that I have read the attached information sheet (Version 1: Dated 16/12/2015) on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.	
2.	I understand that my participation in the study is voluntary and that I am free to withdraw at any time up to the point of anonymised transcription, without giving a reason and without detriment to my treatment/service/self.	
3.	I understand that my data will remain confidential.	
4.	I understand that the interviews will be audio-recorded.	
5.	I agree to the use of anonymous quotes.	

I agree to take part in the above project

Name of participant	Date	Signature
Name of researcher	Date	Signature

This Project Has Been Approved by the University of Manchester's Research Ethics Committee [UREC reference number: ethics/16063].

Appendix 23 – Study 2: Focus Group Topic Guide

The questions in the topic guide will include but are not limited to:

4. What are the needs of haemato-oncology patients during treatment and post-treatment phases of the cancer trajectory and to what extent are these met?
5. What are the perceptions / experiences of the telephone based supportive interventions of patients with HM's?
6. Are there particular groups of patients with HM that would benefit from support and do you think a telephone based intervention is feasible?
7. What are the barriers and facilitators for patients in participation in a telephone support intervention?
8. What are the barriers and facilitators to qualified HCP's in delivery of a telephone support intervention?

Appendix 24 – Study 2: Distress Protocol

The following is provided as a guideline should a participant become distressed during the focus group.

Strategies to assist those distressed during the focus group.

Should a participant become uncomfortable or distressed while discussing their experience during the focus group, the following actions will be taken by the researcher/facilitator:

7. The focus group will be stopped and the researcher / facilitator will offer immediate support.
8. The researcher / facilitator will confirm whether the participant wishes for their participation in the focus group to be terminated.
9. If the participant feels able to carry on, the focus group sill resume.
10. If the participant wishes to terminate their participation, the participant will be removed from the discussion and shown to a quiet area.
11. Time will be spent with the participant and assistance provided, within the scope of researchers/ facilitators abilities, to discuss their concerns and support them, where appropriate.
12. The participant will be offered the opportunity to speak to a healthcare professional from the Psycho-Oncology Department within the hospital to discuss their concerns.
13. The participant will be advised to contact their GP or mental health provider (or the researcher / facilitator may do this with the participants consent).
14. The interviewer will contact the participant by telephone the following day (if the participant consents) to ensure that the participant is alright and further support will be offered as appropriate OR the participant will be encouraged to call if s/he experiences increased distress in the hours/days following the focus group.

Appendix 25 – Study 2: Quotes - Thematic charts for theme 2.0: Applicability of telephone support

	Emerging theme 2.1: Meeting patients' needs and service needs				
	Data Specific Coding				
Respondent	**2.1.1: Utility of telephone support**	**2.1.2: Use of call-in telephone 'hotlines' for symptom management/ reporting**	**2.1.3: Nurse initiated calls providing support (routine / ad hoc)**	**2.1.5: Benefits of telephone use for nurses and organisations**	**2.1.6: Appropriateness of HCP initiated telephone contact**
E01 Unit Manager	**Benefit -reassurance pt and HCP** *E01: 10.10 … I would think that it would reassure a patient ...and I think on the other hand, for nurses it's also … it's also a reassurance* **Convenience – reassurance** E01: (12.14) *I mean it saves time...if a patient is that worried they would come in but I think that it saves time.. for the patient then… it's the travel time, then there's quick reassurance rather than then them waiting to come to their next appointment.. it saves time for the nurses as well… it's sometimes easier as well to say, you know… to talk to them over the phone and to troubleshoot and make decisions from that as well*	**Effective method** E01: (7.08) *I think it is ...on the whole, it does work very well*	**Routine pre CT assessment clinics MM** E01 (7.08) *however and I know a colleague of mine who is running…..pre chemotherapy….. assessment via the telephone with patients that are on Velcade* **Routine post CT FU calls** E01: (8.52) *one of the things that we do is 24 to 48 hours later, the nurse who has done the pre-chemo assessment should follow that up with a phone call…we don't have a checklist no, no, it's just purely a phone call .. check and see if they have any questions and just to confirm the appointment with them…so really it is a… let's say unstructured and also an opportunity if there are any queries to go through that again* **Routine calls: Content: unstructured to solicit questions** *E01: (11.16) we don't have a checklist no, no, it's just purely a phone call .. check and see if they have any questions and just to confirm the appointment with them, and that's… yeah…* **Routine calls with structure allows assessment and signposting** E01: (19.34) *yeah …and with that you would need the… the structure then there to…* SL: (19.38) *and then if there are particular problems do they refer …. they would escalate yeah, yeah*	**Pre chemotherapy telephone clinics: Benefit - ↓ wait ↓visits** E01: (8.14) *yes it is shortening their waiting time… one less visit as well* **Benefit -reassurance pt and HCP** E01: (10.10) … *I would think that it would reassure a patient ...and I think on the other hand, for nurses it's also … it's also a reassurance* **Time saving** E01: (12.14), *it saves time for the nurses as well… it's sometimes easier as well to say, you know… to talk to them over the phone and to troubleshoot and make decisions from that as well* **Reducing visits** E01: (17.50) *… obviously it would be time… for the nurse erm… to do that… but then again , the benefits…. would be one less visit for the patient, perhaps…. troubleshooting beforehand… avoiding admissions, complications*	

E02 Clinical Nurse Specialist	**Reassurance** E02: (54.15) *... like some of them can be just it's 2 minutes reassurance they need… 'yes, you're taking, your doing your temperature correctly'* **Pre-empt problems** E02: (52.34) *there are a lot of times that we can actually circumvent problems and some of them can be fixed over the phone* **Provides opportunity for timely support** 02: (1.32.37) *it's not as post-traumatic stress whatever, but they are very anxious and concerned, and those types of things that even just a two minute phone call could… circumvent months of, weeks of anxiety because they know they have somebody they could ring*	**Reduce visits, more appropriate use of resources** E02: (1.15.11) *… with a telephone triage system … we've actually in ways cut down on some of the visits to…and people being brought, in because what was happening was people were ringing their CNS and they were saying 'I'm sick, I'm nauseous' or whatever, and because they were running from A to B, they were going booking people into clinic and somebody comes into clinic for something that is solvable in 2 minutes on the phone…. so in ways we've actually reduced workload and made it more appropriate…*	**Ad hoc calls for symptom management** E02: (1.04.56) *I think, I think we all do it, we'll all do this it kind of symptom management by phone, whether it's patients ring us or we ring them just to see how they are getting on… but, if you turn round and say do you have a very formal structure by how you do, it I would say no* **As hoc calls for patients living a distance away** E02: (1.38.47) *but again, because of distance involved for some of the patients that I see, similar to you, without a telephone system, being able to ring people and do things over the phone, my job would be impossible..(all in agreement)…*	**Reducing workload** E02: (5.23)….. *support mechanisms in place that can actually reduce the workload on Day Wards, on inpatient units and on the Clinical Nurse Specialists looking after them…. a lot of things around self-care…*	**Calls as a means to empower patients** E02: (1.32.27) *… and I thought okay is that really necessary to be reminded, but the more I think about it, actually that idea that they're even just… that they know that that telephone follow-up is done… if that person, if they decide never to ring you back… whatever… you know, if you were never going to hear from them again… but sometimes that thing of being able to instigate that enables them*
E03 Unit Manager					**Expectation that patients are proactive** E03: (1.22.01) *well it depends on your philosophy, so we also have the philosophy… patients have to call us… we don't call them, they have to call us… and also when they don't call early enough we will be angry (all laugh)*
E04 Staff Nurse	**Timely advice** E04: (47.23) *when they have doubts they always phone us, in the inpatient ward because we always say that if you have any doubts you are not sure, tell us. We'll give you the information.. for example 'tomorrow in the outpatient clinic' or 'go immediately to the…accident and emergency*				**Delayed calls are inopportune** E04: (51.24) *I think about that most of the patients calls are during the night or during the weekend, because they miss something or forget something and always I think, but why are you phoning me during the Sunday, there is no specialised doctor or why you wait so long before phone*

E05 Nurse Specialist	**Contact to reduce anxiety** E05: (26.03) *Some of the patients, I'm phoning weekly as well just to get some… reducing of the anxiety… listening to their complaints*		**Ad hoc calls to provide support** E05: (49.51) *… having no beds is really stressful for patients who are so ill and at home… so if you need to, you give them follow up by phone if you cannot meet them… we need to support them by phone [09: (50.10) how frequently… and how frequently do you think..]* *05: (50.12) it depends… sometimes daily… till they get better… sometimes daily ….and it only needs a few minutes…. it doesn't need to last forever the phone call, just let the patients know that 'okay I'm been taking care of'* **Not all centers use a structured approach to questions** E05: (1.14.55) *but you… you have your structured questions… we don't have those structured questions*		**Expectation that patients are proactive** E05: (1.04.32) *but then the patients who I ring, I tell them I will ring them…. they know how to ring me. They have my number, they had my email* **Pt reluctance to call** E05: (52.14) *well maybe they are afraid to phone and they hope they'll get better* **Expectation that patients are proactive** E05: (1.22.21) (PATIENTS) *well they are responsible for themselves*
E06 Nurse Specialist		**Hotline for symptom management** E06: (49.00) *we have a hotline so any patient… not just haematology any patient can call this hotline to say you know, I've got symptoms, I've got a pyrexia, I'm vomiting or whatever it might be, and then they're triaged and all haematology patients go through to our Nurse Clinicians or one of the medics, so they can decide then what happens whether they go to a local hospital, whether they go to the GP surgery, or whether they are admitted and come to us so again we never have any beds but.. they're triaged that way essentially through, through our… our hotline which is… which is run by our outreach team isn't it really but yeah….*	**Ad hoc calls to give reassurance** E06: (1.02.49) *not every patient will…or desperately need it, but you can just tell that some of these patients are really really anxious, and want that information sooner than the next clinic appointment, so it's erm…just a bit of reassurance for them…* **Ad hoc calls to give updates, address anxieties/ concerns - depend on pt and situation - individualized** *E06: (1.01.27) I think other than that I will phone patients occasionally post clinic if there's been anxieties or if they've got concerns about whether they've got a donor, so as soon as I've got a donor reported, then I will just give them a call and just say look, you know, I've got some good news..or… this is what's going on really, just for that reassurance if they're not back in clinic for another week rather than stressing about it but that… does depend to be… patient … patient led really*	**Call to confirm organization and medication adherence** E06: (1.01.27) *yes so it's really… mainly it's the mobilisation side of things really, so they'll have the mobilisation chemotherapy say on the Monday and then Friday we'll give them a call and just see how they've been over the week to make sure that they're okay to come in for the following Monday* **Calls to ensure programmed procedures are not delayed** E06: (1.01.27) *and just warn them that if they get any backpains over the weekend, you know, the pulsating pains and things, you know because, a lot of the patients will go into A&E because they think they are having a heart attack or something because they have got sort of like sternal pain or something, and we just say just don't stop your G-CSF, you need to phone hotline but don't stop the G-CSF, because we've had a few where they've gone in and*	**Unfeasible for all patients – preference for ad hoc** E06: (1.17.58) *no, I don't think it's feasible that we contact every patient because again is like (NAME) said, if you don't phone them then… they're just waiting on the call, we don't necessarily tell our mobilisations that we will phone on Friday it just happens that we do that, so they're not waiting on our call like you say because, sometimes you're just stuck in clinic and it just ends up like 4 o'clock on a Friday afternoon and the patient may be just like thinking 'is the phone gonna ring, is the phone gonna ring' so we don't do that* **HCP inaccessibility causes stress** E06: (1.24.58) *and often then it comes back to us any way regardless of whether we know the patient or not, but the patients do get stressed if they can't get hold of the CNS, 'I've tried to phone you 3-4 days in a row and you just…', that's an important factor*

		There's a protocol of what to do		*everybody is freaking out about it so it's just to warn the patients as well…*	
E07 Nurse Specialist	**Access for later questions** E07: (56.42) *after the six months, then they start calling me and asking me questions like… which food they can take or eat, or how to cook things in the kitchen is like everyday stuff*		**Ad hoc calls to provide regular on-going support** E07: (22.53) *I think it's a difference because, they know from the beginning on, that it is a chronic disease (ALL agree), and that it's a lifelong treatment and they want to be cured and what I see in the work of (NAME) is that he calls, gives them phone calls every week and he really like it and they phone him back and ask for his guidance* **Nurse initiated service - not identified formally by patient need** E07: (55.29) *yes, well when we started our Clinical Nurse Specialist career, then we both tried what would work and what not,* **Ad hoc calls for successful in monitoring MM patients** E07: (55.29) *he pursues monitoring the multiple myeloma patients* **Frequency of ad hoc calls depends on individual need** E07: (59.14) *I think it's as other people said… it's depending on the patients… some patients he has to call two times a week and some of them they're doing really fine* **Documentation of all calls / plan of action - clinic appointment or next call planned** E07: (1.00.10) *I mean he is documenting every call and… I think if a patient has symptoms then he's doing an appointment with these patients so 'I'll give you a call in three days and ask how are you doing with your nausea or fatigue or whatever..'*		**Expectation that patients are proactive but HCP is inaccessible** E07: (57.06) *they call me… they can call me whenever they want, or can write me an email… mostly they won't reach me because I am running around*
E08 Nurse Specialist					
E09 Nurse Specialist					**Pt reluctance to call** E09: (57.13) *do you have some time that you say okay… there are patients won't call all by themselves.. with my experience …also I always tell them, please call when there are problems after*

					allogeneic transplantation.. call us, call us, call us… but there are a lot of patients who won't call is not their character of calling…
E10 Unit Manager			**Ad hoc calls to monitor patients** E10: (1.28.25) *if there is an issue that comes up in clinic, for me it tends to be skin related or something like that, so topical treatment suggested, but you know in your head, you've got that time, that right you're working through -well if that doesn't work then I'd suggest that, then I'd suggest that… so you've mentally got that plan ready - are you really gonna drag that patient back in every single week?*		**Communication should empower patients** E10: (1.28.25) *You know so…or every two weeks, once you need to review it but you can, you know, you can text me, call me in a couple of weeks let me know how you're getting on, if I don't hear from you, I'll assume everything is fine and I will annotate that… you know, so, so the onus is on them… I agree that we can't be chasing everybody up but you know it's their body, if it's not working then they've got a motivation to call you, and then you've already* E10: (1.29.55) *but that's survivorship anyway… I mean that's, the whole point is we've taken all the control away from them, by definition we've had to… when they're in an acute… when they're acutely ill… part of that whole survivorship process is for them to be able to then reengage and sort of retake… get that whole locus of control…back to themselves, so they can be empowered to move forward and use us as a resource (all in agreement) rather than us nannying and sort of parenting them if you will* E10: (1.35.25) *I'll just say to them send me a text to remind me… if you wanna know, if you're not bothered it's fine, if you send me a quick text, it will give me a prompt to ring you back and let* *you know what the results are, so again you're being accessible, they don't worry that they're going to bother you or whatever because they know I can read it when I like, but it also reminds me that they are worried and then I'll call them back with the results*

CNS – Clinical Nurse Specialist, CT – chemotherapy, FU – follow-up, GP – General Practitioner, HCP – Healthcare Professional, MM – Multiple Myeloma, SCT – Stem Cell Transplant, SE's – side effects, SL- Sarah Liptrott (author/ focus group facilitator)

	Emerging theme 2.2: Limitations to the application of telephone support				
	Data Specific Coding				
Respondent	**2.2.1: Patient related issues**	**2.2.2: Dealing with sensitive issues by telephone**	**2.2.3: Lack of visual contact**	**2.2.4: Alternative remote monitoring**	**2.2.5: Caller related issues / concerns**
E01 Unit Manager	**Communication difficulties** E01: (12.53)*... if there are communication difficulties you know, with language problems I think that, that would be very difficult* **Reticent to discuss** E01: (13.18) *I'm thinking of patients who will be like… 'yes, I'm just calling, I feel like…', who are a bit reticent and like… 'yeah no, it's nothing'…. and you think hmmmm… I wonder whether all is okay?...however, if they would come in and do the same thing…. I don't see how that would make any difference unless you, unless you actually observe that something is….*	**Difficulty instigating discussions** E01: (20.00) *… I suppose it could make it easier not to face someone and talk about emotional things but I would imagine that it would be easier to instigate that… that conversation face-to-face with the patient however if they brought it up over the phone, you know, but to bring it up yourself… I don't know… I don't think that would be…* **Telephone facilitates disclosure** E01: (21.06) *yeah, so there's two sides to it… it might be easier because it's easier to talk without seeing… you know, over the telephone rather than being with someone* **HCP preference for face-to-face** E01: (21.06) *…. but it's also easier to ask further, delve deeper…. be more personal when you're sitting with…. together and talking about things, yeah*	**Lack visual cues** E01: (7.08) *it also depends on some factors like the patient as well because I suppose some patients… might not tell you…. it's not the same as sitting in front of someone, when you're feeling or you can see that there's something or that there's, you know…* **Lack visual cues** E 01: (13.18) *I'm thinking of patients who will be like… 'yes, I'm just calling, I feel like…', who are a bit reticent and like… 'yeah no, it's nothing'…. and you think hmmmm… I wonder whether all is okay?...however, if they would come in and do the same thing…. I don't see how that would make any difference unless you, unless you actually observe that something is….*		
E02 Clinical Nurse Specialist	**Patients don't want contact with the hospital** E02: (29.21) *… 'I'm well, I will ring you when I have a problem because I want to put this to the back of my mind as much as I can'* **Patients perceiving calls / frequency as indicator of**	**Telephone not too impersonal** E02: (1.27.48) *I would disagree a little bit*			**Inaccessible patients – time wasted for nurses** E02: (1.20.11) *and I think doing that thing of... anything that is… reliant very much on a structured time and you saying to a … to certain patients that you're going to ring them at X time…… and the other thing is the amount of patients that go around leave the mobile phone in the other room and you never get to contact them, you end up spending an awful lot*

	illness E02: (1.24.22) *... the system falls down because then what happens is you potentially have a patient come back in and saying 'she's getting a call twice a week and I'm not, why? does that mean she…' or another patients going 'does that mean I'm sicker than they are?', or you know, 'you don't trust me but you trust her' and you know it's … there's difficulties with it*				*of time trying to contact people that you can't get* **Unreliability of HCP call -** E02: (1.04.56) *... if you don't get to ring when they think you're going to ring because… okay you woke up this morning and you have the 'flu so you're not going to go to work, and you don't ring that day and there's nobody covering for you to do it, it has the same problem… (all in agreement)* **Unreliability of HCP call - trust** 02: (1.03.04) but the difficulty, if you say you are going to ring on day X and you don't ring on day X (all laugh) and ask those questions, you have the added problem that that in itself causes a problem (all in agreement)… **Calls will promote delay in symptom reporting** E02: (1.03.04) *I think… the reason a lot of us don't do a very structured approach of it, is that you will have the patient that says 'well they're due to ring me tomorrow so I'm not going to bother doing anything – I'm sitting here and I am feeling really sick or I've got a bit of a temperature, I'm not going to tell anybody about it because (NAME) or (NAME) or whoever, is going to ring me tomorrow morning, so it can wait till then…. so I think that's where particularly within a haematology setting there has been a little bit of a reluctance…..*
E03 Unit Manager					
E04 Staff Nurse		**Phone too impersonal for dealing with support and survivorship issues** E04: (1.27.25) *yes, because by phone I think these things, it's not good for patients because it's too impersonal, it's too cold and instead for 'what to do from now on', it's better face-to-face, to see the patient*			

E05 Nurse Specialist	**Not necessary if patient has no needs** E05: (1.23.00) *but if the patient has no needs, you don't have to do it*		**Need to see patient initiate intervention** E05: (1.00.29) *yeah I was just thinking about starting interventions by telephone… I am not really fond of it because… I like to see my patients, and so when you start thinking of starting an intervention you need to see your patient, not only hear the patient's voice by phone, but see, see the patient, but to evaluate effectively the intervention…* **Telephone use limited to monitoring** E05: (1.00.29) *you can do it by telephone ….but not the whole way… but somewhere in-between you can phone and see are we … are moving on the right way, but as soon as you need to change some intervention* **Visual assessment is not always necessary** E05: (1.07.56) *always no, I do not need to see them always* **Visual assessment at key moments** E05: (1.08.05) *well, when there's pain and when there's skin problems, rash, fever, malaise, they say I've a fever, I feel ill, you want to see them* **Lack visual cues** E05: (1.10.54) *they'll come into the clinic and I know this is*	**Alternative technologies to patient-HCP communication** E05: (1.05.41) *I heard from an older patient of mine he's 80+, and he has contact with home care by tablet. So he has been given a tablet by home care nurse and three times a week he has to phone in, like Face-time, and he has contact with the home care…* **Alternative technologies to overcome lack of visual cues by telephone** E05: (1.06.51) - *I want to see him and want to have a look at him, and then coming to your hospital is always ideal but the tablet I could…. I could try and work with tablet* E05: (1.08.48) (FACETIME) *you can see them by face time and then you can say 'okay, you come to our ER, you are not well'* E05: (1.09.39) (FACETIME) *and that's because the nurse, the nurses…. they do not have to get physically to those patients, so they… it's a more efficient way of working and we have much more older patients in their home situation is so they need these systems*	

			different to being on the end of the telephone, although they'll be saying 'yeah, I feel okay' but actually they've come in to clinic and they look dreadful or vice versa		
E06 Nurse Specialist	**Patients being unwell** E06: (1.16.58) *'no she's too unwell, she can't come into hospital' and I think that's a really important thing as well is actually getting to … to speak to the patient and then… stressing the importance that they do need to be seen as well*		**Possible to evaluate with non-verbal cues by telephone i.e. voice changes** E06: (1.09.02) *don't you think that you can gauge that… intensity of how unwell the patient was by a telephone call? Do you think that, you know, by seeing somebody, you know, if they sort of like say I feel absolutely dreadful, you can usually…. hear it in their voice*	**Challenge to other technologies (internet)** E06: (1.09.02) (FACETIME) *I mean I can see I think it's a very good idea, it's actually really lovely, but I guess it does rely on sort of like Internet access* **Visual contact builds trust** E06: (1.09.55) (FACETIME) *…if my patients, if they could… you can build that trust as well I guess because they know that they're talking to you on the end of the phone* **Challenge to other technologies (internet)** E06: (1.09.55) (FACETIME) *I can also see that there's sometimes limitations you may be in a bad signal area, they may not have the Internet access*	
E07 Nurse Specialist	**Patients are coping without need for extra support** E07: (29.03) *..there are some patients who… do not want to have calls, managing by their own …* **Inconvenience for patients** E07: (29.03) *…and there are patients that are coming back to work for a few hours…* **Frequent visits means calls are unnecessary** E07: (55.29) *acute leukaemias and they were always were fine and said 'no I'm going tomorrow, I have another visit in the hospital, I*				

	have no problems', so I stopped calling them because my impression was that they are really well monitored during the first six months and they get all their chemotherapy cycles because…. in our hospital they are inpatients the whole time, they have just one week at home and mostly they have two outpatient visits in this one-week at home so they actually have to 2 days at home and another two days				
E08 Nurse Specialist					
E09 Nurse Specialist					**HCP preference for combined support methods** E09: (1.26.44) *I think for…I also want to see the persons… the patients, and the life after in the first year I see them in what I say earlier, but sometimes I think it's good to see them in the second year after transplant… maybe one or two times and maybe in the third year…I think it's okay* SL: (1.27.08) *is that something you could do by telephone though or ..?* 09: (1.27.11) *maybe but if they…I think if they are coming to the hospital to see the doctor I will plan a consultation to my schedule and it's okay, I can see them*
E10 Unit Manager			**Visual assessment at key moments** E10: (16.22) *it tends to be in a clinic setting …because it's usually assessing…skincare*		**Inaccessible patients – time wasted for nurses** E10: (1.21.37) *and the other side of the, of that is that erm… if you can't get hold of them, what do you do? are you not getting hold of them because they are unwell…. particularly if it's a land line or if they gone out for a meal and forgotten that they were going or whatever, so you're then left with this big question mark - what the heck do I do with this now?*

HCP – Healthcare Professional

Appendix 26 - Needs of haemato-oncology patients – a summary of evidence

		Study 1: Qualitative study with patients (needs of patients)	Study 2: Qualitative study with expert nurses (perceived needs of patients)	Summary of needs / areas for focus
General		• Needs are shifting and temporal	• Needs are shifting and temporal • Support should reflect patients wishes and be based on a needs assessment	• Periodic assessment with patients is necessary to identify needs
Psychological and emotional	Personal emotional distress (PED)	• Dealing with the unknown • Feelings of loss – role and identity • Link between physical and psychological well-being	• PED evident across the cancer trajectory • Challenges to familial and societal role functioning	• Information to address 'unknown' • Facilitating identity adjustment • Promoting physical well-being
	Coping strategies employed	Adaptive coping • Personal adaptive coping • Importance of external sources of support (formal and informal) • Support seeking Maladaptive coping • Self-preservation • Reluctance to seek support (informal and formal sources - perceived burden) • Prior negative experiences of external support	Adaptive coping • Personal adaptive coping • Importance of external sources of support (formal and informal) • Some patients require more intensive support from HCP • Reluctance to seek support (informal and formal sources -perceived burden)	• Encouraging adaptive coping • Evaluating existing support network • Availability of HCP for greater support where necessary • Facilitating support seeking
	Formal and psychological support	• Perceived to be lacking	• Psychological support necessary at diagnosis • Nature of support depends on the nature of the diagnosis – chronic vs acute	• Periodic assessment of need for psychological support (including nature – formal / informal support)
	Barriers to getting support from HCP's	• Shifting relationship • Lacking personal approach		• HCP self-awareness • Personalising care
	Other	Suggested improvements to support provision • Individualised care • Issues relevant to patients	On-going need for reassurance in relation to persistent SE's, impromptu events and LTFU	• On-going support • Individualised care
Continuity of care	General observations	• Formal support and rehabilitation lacking • Post discharge contact with hospital lacked continuity • HCP caring for 'cancer' in LTFU and not the 'patient' as a whole • Lacking access to long-term care from specialist centre	• Need for on-going management of SE's following discharge • Need for reassurance in LTFU • Importance of a trusting relationship (HCP-patient)/ security/ single point of contact • Security of the specialist team creates dependency – services not always available	• Formal rehabilitation services required • Continuity between patient and HCP • Early post discharge support • Holistic approach to care • Greater access to services at specialist centre
Information needs	General observations	• Early period greater need • Information from HCP's is fundamental • More information wanted on SE's - needs revisiting • Lacking information on late effects • Practical advice and self-care behaviours	• Information needs greater in transition periods and should be tailored • HCP is gatekeeper to information • Information retention issues (recall/ age/ complexity/ need reassurance) / on-going info needs	• Regular assessment of information needs and individualised approach (including reiteration) • Importance of HCP role in information provision
	Other	Suggested improvements to information provision • Stepped information provision • Positive presentation of what patient can do (not only limitations) • Dedicating time • Proactive approach • Ability to ask questions outside of clinic visits	Approaches to information provision • Use of a fragmented approach to information provision and mixed methods • Need to be flexible to answer questions/ issues as arise	• Tailoring approaches and timing of information provision according to individual needs • Ensuring protected time allocation • Positivity • Flexibility of access to information

HCP's – Healthcare professionals, LTFU – Long Term Follow-up, SE's – Side effects

Appendix 27 - Acceptability of a telephone intervention – a summary of evidence

		Literature Review	Study 1: Qualitative study with patients	Study 2: Qualitative study with expert nurses
Positive perceptions	Convenience	X	X	X
	Patient focused	X	X	X
	Accessibility to HC team	X	X Opportunity to ask questions	X
	Continuity of care	X	X	X
	Facilitates communication	X		X
	Provides support	X	X	X
	Pre-empt complications			X
Preference for telephone method	Preferred	X	X	
	No strong preference for / against	X	X	
	Telephone method disliked	X	X In some cases preferred method was not feasible and therefore telephone was acceptable	
Telephone should not replace opportunity to call in			X	X

HC – Healthcare

Appendix 28 – Nature and content of a telephone intervention – a summary of evidence

		Literature Review	Study 1: Qualitative study with patients	Study 2: Qualitative study with expert nurses
Who should the intervention be aimed at?	Patient choice	X	X	X
	Patient characteristics		• Physical problems ongoing • FU of clinical conditions • Long-distance patients	• Based on patients' needs • Experienced nurse to identify patients • Post treatment calls to older adults • Post discharge following complex treatments (HDCT/ SCT) • Provide ongoing support for chronic diseases
When are calls inappropriate?			• Patient too unwell / emotional to talk • Not as a replacement to care but as additional	• Patient unable to talk • Language difficulties • Patients already seen frequently in hospital • Patients do not want calls • Dealing with sensitive issues • Where visual cues are key to patient assessment • Not as a replacement to care but as additional
Call content	What it should be		• General well-being • Reiterate information • Provide further information (e.g. diet,& activity, future, LT SE management) • Give chance to ask questions • Provide reassurance • Reflect individual needs	• Nature and structure of intervention depends on patient and need being addressed • SE and symptom monitoring, reassurance, advice, medication adherence • Reiterate results • Holistic needs assessments • Flexible to investigate non-standard issues arising
	What it should not be		• Giving diagnosis • Giving complex information • Formal psychological support	
Call timing	Dependent on individual need		X	X
	Key time points		• Diagnosis • Waiting for treatment to start • During treatment • In early post discharge phase • During protracted visits • For a few months post allogeneic SCT	
Call frequency	Dependent on individual need		X	X
	Other		• Monthly • Whether calls should be planned or improvised is individual choice	
Caller characteristics	Experienced HCP (nurse)		X	• Experienced in care of patient group • Intuition where lacking visual cues
	Skills			• Ability to refer on to other HCP's • Need for telephone based communication skills training
	Existing relationship		X	• Preferable but not necessary • Facilitates picking up nuances • Facilitates individualising care • Increases patient engagement
Organisational support				• Must provide evidence of benefit • Measurable outcomes to demonstrate improved patient experience • Minimal material resources • Needs to be a validated aspect of nursing role with dedicated and protected time

FU – Follow-up, HCP's – Healthcare professionals, HDCT – High dose chemotherapy, LTSE's –Long Term Side Effect(s), SCT – Stem cell transplant

Appendix 29 - Questions for the Consensus Meeting

1. The appropriateness of a telephone intervention to meet patients needs

   1.1 The evidence describes a variety of needs of haemato-oncology patients across the trajectory. To what extent can these needs be met through a telephone intervention?

   a. Continuity of care
   b. Information needs
   c. Reassurance and emotional support
   d. Practical support
   e. Personalised holistic care

   1.2 Given the existing evidence regarding patient preference for telephone interventions, how should patients be informed of the service and agreement be obtained to receive the calls?

2. Intervention description

   2.1 Given the diversity in evidence, who are the patients within the local setting that would benefit from an intervention to address their needs? Who should identify these patients?

   2.2 Knowing what needs could be addressed by a telephone intervention, what do you think the telephone intervention would look like?

   a) Evidence suggests that support is useful at diagnosis, prior to and during treatment, following discharge and in the short term follow up period. Is it feasible with existing resources to deliver an intervention at these time points? If not, when is it feasible? When is the optimal timing to initiate these calls?
   b) Evidence suggests that needs are individual and temporal. How can we assess individual patients needs over time?
   c) How can the individuality of needs be addressed?
   d) What are the core elements of the intervention to respond to patients needs?

e) Are there any other elements that have not been identified by the evidence shown, that you feel should be incorporated?
f) Given the evidence (or lack of it), could you indicate the appropriate number and frequency of intervention calls?
g) Based on the evidence, what do you think the ideal duration of the call should be?
h) Over what period of time would you suggest the intervention calls should continue?
i) Do you think calls should be made by appointment or ad hoc?

2.3 Given the evidence could you indicate what practical resources are necessary to deliver the intervention in the local context? Are these readily available?

2.4 Having identified the needs to be addressed via the telephone intervention, what personnel resources are necessary?
a) How can the intervention be integrated into routine clinical practice within the local setting?
b) What specific skills/ characteristics should the nurse delivering the intervention and addressing such needs have?
c) Does the nurses existing skills set provide the necessary competencies to deliver the components of the intervention (information support, emotional support, practical support, reassurance) or is further education and training necessary?

3. Intervention evaluation

3.1 What methods can be employed to evaluate such an intervention?