

**Principles and Practices for Involving
Teenagers in Decision-Making about their
Care and Treatment:**

**A prospective participant-observation study
to inform policy and practice**

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Declaration

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

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Abstract

Background: Much research undertaken on teenagers with life-limiting-conditions has focused on the retrospective views and experience of health care professionals (HCP) and parents (Miller 2012, Woodgate 2010, Stevens 2002, Stenmarker 2010, Matsuoka 2012). This has left a gap in the academic and clinical knowledge base regarding teenagers' real-time perspectives of involvement and how, when or if they are involved in practice.

Aims: To understand the complex process of decision-making that takes place among HCP, families and teenagers, for decisions regarding the teenager's care and treatment.

Methods: Ethnographic methods, participant-observation, informal conversation and open-ended semi-structured interviews are employed. The interactionist perspective provides the overarching theoretical framework.

Data: Seven teenagers, 15 family members and 60 HCP were recruited. Data were collected from observations of consultations (147), HCP meetings (104) and informal discussions/interviews (253) with teenagers (86), parents (67), family members (6) and HCP (94). Observations were audio-recorded and transcribed verbatim.

Findings: Grounded theory analysis of interviews/informal discussions identified several principles (acting on the care and treatment preferences of the teenager, doing the right thing as determined by clinical consensus, following the HCP lead, information exchange) regarding the involvement of teenagers. Observations highlighted how these principles were enacted in practice, the immutable factors (disease course, decision, treatment window, legal responsibilities) and communication practices (presentation of options, bargaining, information seeking, delegation) that determined when, how and why principles took precedence.

Conclusions: Findings suggest teenagers with life-threatening-diagnoses want a different kind of involvement in decision-making than much policy advocates. Teenagers and parents express no desire for independent decision-making, nor do they encourage following the teenagers care and treatment preferences for decisions of consequence. Involvement is not static and consistent across the trajectory, nor is it dependent on chronological age. HCP and policymakers must reconsider the value of advocating one type of involvement focusing on providing 'honest' information, seeking teenagers' preferences for care and treatment and following their lead.

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Table of Contents

DECLARATION	2
ABSTRACT	3
ACKNOWLEDGEMENTS	4
CHAPTER 1: INTRODUCTION	11
1.1 OVERVIEW	11
1.2 ADDRESSING THE GAP	12
1.3 AIMS AND OBJECTIVES	13
1.3A RESEARCH AIMS	13
1.3B RESEARCH OBJECTIVES	14
CHAPTER 2: SITUATING THE RESEARCH	16
2.1 INTERACTIONISM	16
2.2 SOCIAL POSITION OF TEENAGERS	19
2.3 THE TEENAGE YEARS – A PERIOD OF DEVELOPMENT	21
2.3A MENTAL HEALTH IN THE TEENAGE YEARS	23
2.4 SYSTEMATIC NARRATIVE REVIEW OF DECISION- MAKING WITH TEENAGERS	24
2.4A OBJECTIVES	24
2.4B METHODS	25
2.4C THEORETICAL PERSPECTIVE	25
2.4D SUMMARY OF RESULTS	26
2.4E INTERPRETATION OF FINDINGS	27
2.4F IMPLICATIONS OF MULTI-ORIGIN RESEARCH	28
2.4G DEVELOPING THE THESIS	30
2.5 CONCEPTUAL MODELS OF DECISION-MAKING	31
2.6 CLINICAL GUIDELINES FOR DECISION-MAKING WITH TEENAGERS IN THE UNITED KINGDOM	33
2.6A EVOLUTION IN THINKING ON SHARED DECISION-MAKING	33
2.6B SHARED DECISION-MAKING WITH TEENAGERS	35
COMPETENCY AND LEGAL RESPONSIBILITY	37
2.6C SUMMARY AND IMPLICATIONS	39
2.7 TEENAGERS WITH A LEUKAEMIA DIAGNOSIS	40
2.7A AGE STRATIFICATION IN UK HEALTH CARE	40
2.7B OVERVIEW OF DIAGNOSIS AND PROGNOSIS	40
2.7C TREATMENT AND CLINICAL COURSE	43
2.7D THE DECISIONS	46
2.8 SUMMARY	49
CHAPTER 3: METHODOLOGY	76

3.1 ETHNOGRAPHIC RESEARCH	76
3.1A USE OF MULTIPLE DATA SOURCES	78
3.2 STAGES OF DATA COLLECTION	79
3.2A SETTING	79
3.2B STAGE 1 – HEALTH CARE PROFESSIONALS	79
3.2C STAGE 2 – DECISION-MAKING IN PRINCIPLE AND PRACTICE	80
3.3 THE METHODS OF DATA COLLECTION	82
3.3A PARTICIPANT-OBSERVATION	82
3.3B OPEN-ENDED SEMI-STRUCTURED INTERVIEWS AND INFORMAL DISCUSSIONS	85
3.3D REVIEW OF POLICY STATEMENTS AND GUIDELINES	86
3.4 CONDUCTING PARTICIPANT-OBSERVATION, INFORMAL ENCOUNTERS AND SEMI-STRUCTURED INTERVIEWS	86
3.5 THE PARTICIPANTS	88
3.5A TEENAGERS	93
3.5B PARENTS AND FAMILY MEMBERS	94
3.5C HEALTH CARE PROFESSIONALS	94
3.6 RECRUITING THE PARTICIPANTS	95
3.6A CONSENTING TO PARTICIPATE	95
3.7 ETHICAL AND INSTITUTIONAL APPROVAL	98
3.7A APPROVAL FOR STAGE 1	99
3.7B APPROVAL FOR STAGE 2	99
3.7C PROBLEMS ENCOUNTERED AND SOLUTIONS FOUND	99
3.7D ROLE OF PPI IN RESEARCH DESIGN AND DOCUMENTATION	100
3.8 ANALYSIS	103
3.8A USE OF GROUNDED THEORY	103
3.8B HANDLING OF DATA	105
3.9 PERSONAL REFLECTIONS	109
3.10 SUMMARY	112
<u>CHAPTER 4: HEALTH CARE PROFESSIONALS PRINCIPLES OF INVOLVEMENT – THE ROLES AND RESPONSIBILITIES OF HCP, PARENTS AND TEENAGERS</u>	<u>114</u>
4.1 DATA	116
4.2 DOING THE RIGHT THING AS DETERMINED BY CLINICAL CONSENSUS	116
4.3 ACTING ON THE CARE AND TREATMENT PREFERENCES OF THE TEENAGER	121
4.3A THE INFLUENCE OF THE FAMILY	125
4.4 GIVING THE TEENAGER A VOICE	129
4.5 COMMUNICATION OF INFORMATION	132
4.5A INDIVIDUALISED PROVISION OF INFORMATION	139
4.6 IMMUTABLE FACTORS RELATING TO THE DIAGNOSIS	140
4.6A UNCERTAINTY OF THE DISEASE COURSE	140
4.6B STAGE IN THE TRAJECTORY	142
4.7 SUMMARY	144

<u>CHAPTER 5: PARENTS AND FAMILY MEMBERS PRINCIPLES OF INVOLVEMENT – THE ROLES AND RESPONSIBILITIES OF HCP, PARENTS AND TEENAGERS</u>	148
5.1 DATA	150
5.2 RECOGNISING THE FAMILY UNIT	151
5.3 PARENTS AND FAMILY MEMBERS ROLES AND RESPONSIBILITIES	154
5.3A RESPONSIBILITY FOR ACQUIRING INFORMATION	154
5.4 TEENAGERS ROLES AND RESPONSIBILITIES	162
5.4A ACTING ON THE CARE AND TREATMENT PREFERENCES OF THE TEENAGER	162
5.4B DISTRIBUTING RESPONSIBILITY TO TEENAGERS	167
5.5 HCP ROLES AND RESPONSIBILITIES	168
5.5A FOLLOWING THE ADVICE OF HCP	168
5.6 SUMMARY	173
<u>CHAPTER 6: TEENAGERS PRINCIPLES OF INVOLVEMENT – THE ROLES AND RESPONSIBILITIES OF HCP, PARENTS AND TEENAGERS</u>	177
6.1 DATA	179
6.2 ACKNOWLEDGING CHANGING INFORMATION PREFERENCES	181
6.2A INFORMATION SEEKING	184
6.3 ROLE OF TEENAGERS	186
6.3A TEENAGERS DEFINING INVOLVEMENT	187
6.3B ACTING ON THE CARE AND TREATMENT PREFERENCES OF THE TEENAGER	188
6.4 THE ROLE OF HCP	190
6.4A FOLLOWING THE GUIDANCE PROVIDED BY HCP	190
6.4B RECOGNISING HCP DISTINCT ROLES IN DECISION-MAKING	192
6.5 THE ROLES OF PARENTS	195
6.5A RECOGNISING PARENTS AS HOLDERS OF INFORMATION	195
6.5B ACCEPTING ADVICE FROM PARENTS	197
6.6 INFLUENCE OF A LANGUAGE BARRIER	198
6.7 IMMUTABLE FACTORS	199
6.7A DIAGNOSIS CONSTRAINING TEENAGERS CHOICES	199
6.7B THE SIGNIFICANCE OF CHRONOLOGICAL AGE	202
6.8 SUMMARY	205
<u>CHAPTER 7: INVOLVEMENT IN PRACTICE – THE CONSULTATIONS</u>	210
7.1 OVERVIEW OF THE CONSULTATION	213
7.1A SPEAKERS	215
7.2 ACTING ON THE CARE AND TREATMENT PREFERENCES OF THE TEENAGER	217
7.2A MAKING THE TEENAGERS PREFERENCE KNOWN	219
7.2B THE HCP RESPONSE TO TEENAGERS CARE AND TREATMENT PREFERENCE	232
7.2C SUMMARY	244
7.3 DOING THE RIGHT THING AS DETERMINED BY CLINICAL CONSENSUS	245
7.3A PRESENTATIONS OF THE RIGHT THING AS DETERMINED BY CLINICAL CONSENSUS	246
7.3B SEEKING OUT THE ‘RIGHT’ THING	254

7.3C SUMMARY	260
7.4 PROVISION AND EXCHANGE OF INFORMATION	260
7.4A THE TEENAGERS ROLE IN THE EXCHANGE OF INFORMATION	262
7.4B PARENTS ROLE THE EXCHANGE OF INFORMATION	269
7.4C HCP ROLE IN THE EXCHANGE OF INFORMATION	272
7.4D SUMMARY	280
7.5 RESPONSIBILITY AND ROLE DESIGNATION	281
7.5A HCP DESIGNATION OF ROLE AND RESPONSIBILITY	282
7.5B PARENT AND FAMILY MEMBERS ASSIGNING RESPONSIBILITY FOR DECISION-MAKING TO HCP	289
7.5C SUMMARY	290
7.6 SUMMARY	290
<u>CHAPTER 8: THE DISCUSSION</u>	<u>295</u>
8.1 RETURNING TO THE AIMS AND OBJECTIVES	295
8.2 PRINCIPLES IN PRACTICE	296
8.2A IMMUTABLE FACTORS	303
8.3 PRESENTING CHOICE TO TEENAGERS	307
8.4 UNPACKING INFORMATION EXCHANGE BETWEEN HCP, TEENAGERS AND PARENTS	310
8.4A HCP COMMUNICATION OF OPTIONS	312
8.4B THE DISTRIBUTION OF KNOWLEDGE	314
8.4C PROVIDING INFORMATION WHEN INFORMATION IS NOT WELCOMED	317
8.5 RESPONSIBILITY	320
8.5A THE DISTRIBUTION OF RESPONSIBILITY	321
8.5B THE PARENTAL RESPONSIBILITY	324
8.6 THE IMPORTANCE OF TIME	325
8.6A AGE	326
8.6B MENTAL WELLBEING OF TEENAGERS OVER TIME	329
8.7 STRENGTHS AND LIMITATIONS	330
<u>CHAPTER 9: CONCLUSIONS AND RECOMMENDATIONS FOR RESEARCH AND CLINICAL PRACTICE</u>	<u>336</u>
9.1 RECOMMENDATIONS FOR RESEARCH	336
PROSPECTIVE PARTICIPANT-OBSERVATION	336
RESEARCH WITH TEENAGERS WITH LIFE-THREATENING DIAGNOSES AND THEIR FAMILIES	337
EMBEDDING THE RESEARCHER IN THE FIELD	338
ENSURING THE RESEARCHER HAS ACCESS TO REGULAR SUPPORT OR CLINICAL SUPERVISION	339
FUTURE RESEARCH	340
9.2 RECOMMENDATIONS FOR CLINICAL PRACTICE	341
INFORMATION DELIVERY	342
THE ROLE OF THE TEENAGERS PREFERENCE	342
INVOLVING THE FAMILY	343
REASSESSING COMPETENCY	343
END OF LIFE	344

MENTAL WELLBEING	345
TRUST	346
IMPLEMENTATION OF RECOMMENDATIONS	347
9.3 CONCLUDING SUMMARY	349
<u>REFERENCES</u>	<u>352</u>
<u>APPENDICES</u>	<u>367</u>
I. SYSTEMATIC NARRATIVE REVIEW PUBLISHED ARTICLE	367
II. GLOSSARY OF MEDICAL TERMINOLOGY AND CLINICAL MEETINGS	382
III. INTERVIEW GUIDES	387
IV. CODE BOOK – DATA ANALYSIS	393
V. GUIDANCE ON PARTICIPANTS LOSS OF CAPACITY AND WITHDRAWAL	412
VI. PARTICIPANT INFORMATION SHEETS AND RECRUITMENT PATHWAYS	418
VII. PERSONAL REFLECTIONS	433
VIII. PRINCIPLES IN PRACTICE BY DECISION	435
XVI. LIST OF TABLES AND FIGURES	443

Chapter

1

Introduction

1.1 Overview

This thesis examines how teenagers, parents and health care professionals (HCP) view and experience involvement in decision-making regarding teenagers' care and treatment. As discussed in the chapters that follow, there has been limited work to date on the views and experience of teenagers themselves, and less still exploring the realities of involvement when these three parties come together in practice (Hinds et al, 2001). In this thesis, I focus on the views and experiences of teenagers aged 13-19 years, with a diagnosis of leukaemia, their parents, family members, and health care professionals involved in their care and treatment.

This work utilizes ethnographic methods to address this gap in the literature. I present an examination of how teenagers, parents and health care professionals understand and articulate involvement in principle and enact those principles in practice. I couple this with a comparison of how each party differs in their conceptions and enactment of involvement and its consequences for on-going interaction and decisions taken. By adopting the interactionist perspective that reality is formed through social interaction and relationships with other people, this research identifies the role of teenagers in connection to those around them. From this perspective teenagers are considered competent social actors before they are necessarily formally recognized as such (Qvourtrup 1985). Consequently, this research identifies the teenager as an active agent in the decision-making process. Attention is paid to how teenagers are positioned, and position themselves both in principle and practice in relation to the others with whom they engage.

There is limited understanding of what involvement should look like in practice for teenagers, with the terms involvement and participation used interchangeably in the literature. While both terms are commonly understood to mean an individual's inclusion in an activity, they are rarely defined with any degree of specificity. This thesis recognizes these terms as distinct but lacking any tangible difference, therefore the term 'involvement' is used throughout refer to the individuals' inclusion in an activity or process. Participation is a term used principally in Chapter 3, to refer to individuals' inclusion in this research project. Such ambiguity highlights the call for research investigating what constitutes involvement on the ground, in real-time. In this thesis I compare each party's conception and enactment of involvement as a first step in establishing what constitutes the complex issue of involvement.

Understanding conceptions of involvement alongside their enactment informs the development of evidence-based guidance for clinical practice regarding the teenager's role in decision-making.

1.2 Addressing the Gap

Much research undertaken to understand decision-making with teenagers with life-limiting conditions has focused on the views and experience of the health care professionals and parents caring for these teenagers (Miller 2011, Woodgate & Yanofsky 2010 Stevens 2002, Stenmarker 2010, Matsuoka 2012). This has left a gap in the academic and clinical knowledge base regarding teenagers' perspectives of involvement in decision-making (Bluebond-Langner et al 2013) and how, when or if they are involved in practice.

As discussed in the following chapter, a systematic narrative literature review was completed in May 2015 (Day et al, 2016) [See Appendix I], presenting a comprehensive account of research published to date. The review sought to assess current knowledge and understanding of decision-making for teenagers with all types of cancer using empirical research published internationally from

2001 to 2015. To reflect accurately the nature of research undertaken in this area, this review incorporated qualitative, quantitative and mixed method research. Findings demonstrate that research investigating the views of children and teenagers focused on younger children (aged less than 13 years), and often centred on retrospective recall of events (Hinds 2009, Hexem 2013). The review identified limited work to date on the views and experience of teenagers (over the age of 12) themselves, and still less exploring the realities of involvement when teenagers, their parents and healthcare professionals come together in practice (Hinds 2001). The review identified no published studies that investigated prospectively how teenagers diagnosed with potentially life limiting leukaemia are involved in decision-making regarding their care and treatment.

This project addresses this gap by focusing on interactions in real time between teenagers, parents and health care professionals when decisions need to be made about the teenager's care and treatment. The project examines these real time interactions and considers them alongside interview accounts and informal discussions with all parties dealing with their experiences of receipt and delivery of care. Through synthesis of these data, I aimed to understand the stated views of those involved as well as how these views play out and may be modified in practice.

1.3 Aims and Objectives

1.3a Research Aims

The main research aims for this thesis are:

- a. To understand the complex process of decision-making that takes place among health care professionals, families and teenagers independently, and together, when decisions regarding the teenagers care and treatment need to be made.
- b. To use the results of the study to inform the development of evidence-based guidelines for the role of teenagers, parents and health care professionals in decision-making regarding care and treatment.

1.3b Research Objectives

The main research objectives for this thesis are:

- a. To investigate the principles and practices for involving teenagers in decision-making regarding their care and treatment.
- To compare and contrast how teenagers, parents, and health care professionals view their role and the role of one another in decision-making.
- To document the role teenagers, parents, and health care professionals play in the decision undertaken.
- To track when and how teenagers participate and are invited to participate in decision-making about their care and treatment in practice.
- To compare and contrast understandings and conceptions of involvement in principle with the process in practice.
- b. To develop a conceptual model for decision-making, which can account for concordance, or lack thereof among parties, their professed views and practices.
- c. To develop recommendations and guidance for policy and practice.

To meet these aims and objectives I conducted an ethnographic study of decision-making for teenagers with leukaemia in a metropolitan tertiary referral centre in UK. I interpret the data collected using the theoretical perspective of interactionism, suggesting that people are active agents in the formation and interpretation of behaviour and action (Bluebond-Langner 1996, 1978, Rock 2007). Through the following chapters I report on this study and the theoretical perspective from which it originates.

Chapter

2

Situating the Research

In this chapter, I situate the thesis within the historical, social, and clinical settings from which the research and the researcher emerged. I begin with a reflection on the theoretical perspective this research aligns itself with, moving to a discussion of the social positioning of teenagers over the years. This is followed by a discussion of empirical literature on the role of teenagers with cancer in decision-making regarding care and treatment, as demonstrated by a systematic narrative review. I then explore UK policy and clinical guidance, as it stands for the involvement of teenagers in medical decision-making, finishing with an overview of current treatment, trajectory and prognosis for leukaemia and the types of specific decisions under study.

2.1 Interactionism

The theoretical perspective of interactionism provides the overarching framework for this research, where the social world is recognised as a place where meaning is formed through interaction between individuals (Rock, 2007). The interactionist perspective suggests that people attempt to make sense of the world by interpreting themselves and the behaviour and action of others in any given situation (Rock, 2007). Consequently, individuals are not seen as passive recipients of information but as active agents in the formation and interpretation of behaviour and action (Bluebond-Langner, 1996, 1978). Interactionism works on the premise that individuals hold fluid and changeable views about themselves, those they interact with and the world within which they interact. These views are brought to, and formed throughout, every interaction influencing the nature of each party's response to the other, and consequently the interaction itself.

In line with Cooley's early teachings, this research encourages observations of external behaviour whilst also attending to the meanings and definitions

individuals hold (Benzies & Allen 2001). I maintain this focus throughout, reflecting on the process of interaction between teenagers, parents and health care professionals in both principle and practice.

As expressed by Atkinson and Housley (2003), 'many of the key ideas of interactionism have become part of the contemporary mainstream of sociological thought. They are not however, always explicitly recognised as interactionist ideas'. I acknowledge that an interactionist perspective underpins this thesis from design through to analysis. In later chapters I draw on the interactionist perspective to help elucidate the research findings. Here I outline how some of the central tenets of interactionist theory relate to the methodological aspects of this work. Manis and Meltzer (1978, Pg6-8) outline several propositions of this perspective, which relate to the research objectives of this project and support the adoption of interactionism throughout.

1. The meaning individuals assign to specific situations and contexts are integral to their behaviours and actions, therefore to understand conduct you must understand meaning. Meaning is understood here to be the sense individuals make and the values they assign to things, situations or feelings. This project recognises the importance of uncovering the underlying perspectives teenagers, parents, and health care professionals assign to the decisions they encounter and their role within the process. These understandings were explored through semi-structured interviews and informal conversations with teenagers, parents and health care professionals.
2. Human behaviour is understood as more than individual responses and social rules; it is the product of human interaction. The roles of teenagers, parents and health care professionals are not pre-determined and can alter and develop over the course of interaction. This project recognises the interactive nature of the decision-making process, through participant-

observation of teenagers, parents, and health care professionals this process is documented over time.

3. Individuals are active participants in shaping behaviour. This project recognises all parties as active agents in the decision-making process. This encouraged focus on the ways in which teenagers, parents, and health care professional choose to involve or not involve themselves and others.
4. Individuals construct their behaviour over the course of time and interaction. The views each individual holds are developed through personal experience, the ethos of the community in which they operate and previous similar interactions of which they have been a part. Teenagers, parents, and health care professionals thus bring roles and responsibilities and become socialised into other roles over time. This project utilised interviews, informal discussions and participant-observation to evidence the foundation of these views and highlight how they played out in interaction.

This project thus recognises the dynamic, fluid and social nature of decision-making in this context, with each individual assigning meaning and actively shaping their behaviour and interactions in various situations. Given this perspective, the methods used to document and analyse decision-making must reflect the complex nature of the process. Much of the research done with seriously ill teenagers and their families is retrospective and is carried out following the death of the teenager, or years later when they have long since been in remission, or the disease has worsened. In contrast all aspects of this research were radically prospective. Participant-observation in multiple settings was employed as the core and definitive component of ethnographic research, and the primary method of data collection. This observation and audio recording of practice in real time provided rich accounts of the verbal and non-verbal exchanges as teenagers, parents and HCP interact to make decisions. Open-ended, semi-structured interviews and informal discussions provided significant insight into the views and understandings of these individuals with regard to decision-making and their role within it. This project offers a comprehensive

account of the decision-making process, and the perceived and actual role of individuals throughout that process in both principle and practice. A fuller discussion of the methodology employed is presented in the following chapter; here I move focus to the social positioning of teenagers over the years.

2.2 Social Position of Teenagers

The social position of teenagers in Britain has undergone great change since the 1800's, with the parameters of childhood fluctuating, and the perceived capabilities of teenagers and young people shifting. The 1870 Education Act recognised ten as the minimum school leaving age (Wells 2009). Consequently, during this period many children of this age entered into full time work. They were deemed competent, independent and capable of contributing to society. These children of pre-industrialisation provided financially for themselves and contributed to the family income; their economic value was undeniable (Qvortrup 1985). In modern Britain however, children and teenagers are placed in compulsory schooling until they are 18 years of age (Spielhofer, 2007). This not only restricts their ability to earn and contribute materially to the household, but also places teenagers in a subordinate position to adults for the majority of their childhood. There is no intrinsic value in being a student; the value of schooling is tied up in preparation for the future. This further engrains the notion that teenagers are not human beings, but 'human becoming's' lacking the competencies of the adult they will become (Uprichard, 2008). Further or higher education lengthens what is traditionally thought of as a childhood pursuit, prolonging the state of 'becoming' into adulthood.

The post Second World War period, extended the separation of children, adults and teens, as increased freedom gave rise to a distinct teenage culture (Hine 1999). Some have suggested that the creation of 'teenage' as a separate life stage has been detrimental to the facilitation of active engagement. Teenagers' abilities are often belittled by the stereotype of an unbalanced, hormone driven rebel (Hine 1999), positioned as impulsive, emotion led individuals who have

minimal risk awareness and no responsibility (Wakefield 2012). By 'infantilizing' youth in this way they are stripped of power and respect, as a generation they are deemed irresponsible and void of emotional maturity. This 'artificial extension of childhood' (Epstein 2007) now proceeds long into adulthood, and the adoption of full decisional authority over life education and health choices is further delayed. This modern western teenager is therefore poorly positioned to begin to actively engage with adults about serious life decisions.

The social depiction of teenagers in the 21st century is wrought with contradictions. In the UK, on the one hand children and teenagers are viewed as weak and defenceless, news reports frequently use the term 'cotton wool kids' to define a generation of mollycoddled children and adolescents who are being increasingly controlled and restricted, notably with how they spend their free time (Evans, 2015, Edwards 2013). While on the other, teenagers are depicted as dangerous, hooded youths (Braddock, 2011) becoming synonymous with 'broken Britain', a generation to be feared and avoided on the streets (Moran and Hall, 2011). This divergence creates uncertainty with regard to the competencies of teenagers and the extent to which we can expect them to accept responsibility for themselves. Nick Lee argues that this ambiguity associated with childhood conflicts with the 'rigorously applicable categories' of institutions, causing friction in the institution dominant adult world (Lee, 1999).

This change across the epochs of British history highlights the subjective and socially constructed nature of childhood. As is evident modern society deems the adolescent much less competent than history demonstrates they can be. As a result, the role and competencies afforded to teenagers in wider British society are often inconsistent and fluctuant.

This thesis attends specifically to the role afforded to this population as they enter one institution within British society – the NHS. Institutions represent collections of people attempting to put societal ideals into practice, be it the

education system, the prison system or the health care system. Many of the uncertainties associated with the place and competency of teenagers are magnified in the realm of medicine. As with other institutions, uncertainties are initially addressed by stratifying teenagers by age and assigning different legal rights and responsibilities to each band. This compulsion to clearly demarcate competency and role in line with chronological age overlooks the complexity of a teenager's role when they are diagnosed with a serious, life-threatening illness.

Continuing on I attend to the physiological developments associated with adolescence and how these, in combination with social processes, may influence the role of teenagers in medical decision-making before a choice is even presented.

2.3 The Teenage Years – A Period of Development

Throughout this thesis I use the term 'teenager' to define the population. While some use 'young people' or broadly 'children', these categorisations include those under 13 years (children) and those over 19 years (young people) often up to 25 years. I believe 'teenager' accurately encapsulates the age group under investigation. As highlighted in the previous section, the social position of teenagers over time demonstrates the variable definitions of this teenage period, the world health organisation currently offers the following definition,

'The period in human growth and development that occurs after childhood and before adulthood, from ages 10 to 19. It represents one of the critical transitions in the life span and is characterized by a tremendous pace in growth and change that is second only to that of infancy'. (WHO 2016)

This 'tremendous pace in growth' has been shown by the physiological and neurological developments associated with this teenage stage. It would be neither feasible nor appropriate to the aims of this thesis to present a complete biological account of adolescent development here. However, it would be amiss to ignore the neurological changes that occur throughout, and as much research is now suggesting, beyond adolescence specifically related to decision-making.

Findings suggest that substantial brain development in adolescence occurs in the pre-frontal cortex (Konrad, 2013) an area of the brain associated with complex reasoning, decision-making and social interaction amongst other things. Research has shown that this reorganisation leaves teenagers particularly susceptible to external/ environmental influences (Konrad, 2013). Further suggestions have been made that adolescence is a time where decision-making is particularly regulated by emotions and social factors rather than reason (Blakemore, 2012), with teenagers making 'riskier' decisions in high emotion contexts (Blakemore, 2012). Commonly, focus has been placed on the negative influence of peers to engage in risk behaviours, however refocusing on teenagers with serious illness, the potentially increased susceptibility to the influence of HCP and parents in 'high emotion' decision-making should not be overlooked. As Johnson et al (2009) state 'empirical evidence linking neurodevelopmental processes and adolescent behaviour remains sparse', but as they go on to recognise this has not slowed the use of adolescent brain research to shape policy on when individuals should be considered mature. They acknowledge the necessity of multi-disciplinary research agendas to 'articulate the conditions under which adolescents' competence, or demonstrated maturity, is most vulnerable *and* most resilient', designating an individual as neurologically 'mature' is complicated in real life situations by a number of compounding factors, changing across time and with development. This thesis presents findings that illuminate the maturity and competence of teenagers in a unique real life situation, one where they are faced with the reality of their own mortality.

2.3a Mental Health in the Teenage Years

Research suggests that this period of brain development leaves children and teenagers particularly susceptible to mental health illness, with mental health disorders more likely to develop or become apparent during this period (WHO, 2012). The annual report of the UK Chief Medical Officer in 2012 stated that rates of mental health problems, including depression, anxiety, autism spectrum disorders and hyperactivity have risen gradually since 1975, with 1 in 10 under 16 years of age living with a mental health diagnosis in 2004 (Murphy and Fonagy, 2012). Reports have suggested soaring rates of anxiety and depression amongst teenagers in recent years; NSPCC reported a 142% increase in counselling about suicide with girls since 2010/11, and a 32% increase with boys (NSPCC, 2015). An area of growing concern therefore, is the mental health and wellbeing of teenagers. Consequently, the psychological impact of a life-threatening diagnosis at this life stage cannot be overlooked.

Research has investigated the impact of childhood cancer on mental health and psychological wellbeing later in life. Childhood cancer survivors are '80% more likely than their siblings to report clinically relevant impairment in mental health quality of life' (Zeltzer et al, 2009 page 2397). For leukaemia patients specifically, research has identified parents reports of increased depression, anxiety and social skills deficits compared with sibling controls (Zeltzer et al 2009).

While this thesis does not set out to investigate diagnosable mental health conditions in this age group, it is important to recognise the neurological and psychological development that teenagers undergo and the challenges they face. Similarly it is important to recognise the long-term psychological impact a diagnosis of this magnitude has at this life stage. For the teenagers in this study, this period of development is combined with the diagnosis of a life-threatening

condition and the care, treatment and hospitalisation that is consequently required. The uniqueness of this group of individuals cannot be understated.

Moving forward, focus is placed on the empirical research conducted and conceptual models produced that illuminate the place of teenagers as they negotiate medical decision-making alongside their parents and health care professionals.

2.4 Systematic Narrative Review of Decision- Making with Teenagers

When proposing a new research project it is important to recognise and understand the empirical work conducted previously both to incorporate existing knowledge and to guide research design. In the early stages of formulating my research project, I conducted a systematic narrative review of empirical literature. This review offered significant contribution to the thesis objectives, allowing thorough reflection on the empirical work emerging in the field of medical decision-making with teenagers. This review was accepted for publication in May 2016 and is available to view in Appendix I, where a full account of findings is presented.

2.4a Objectives

The review aimed,

- (1) To identify recent empirical research that investigated decision-making regarding care and treatment in 13-19 year olds with cancer, from the perspective of the teenager, their parents and families or their HCP.
- (2) To produce a narrative synthesis of existing evidence regarding the participation, role and place of teenagers, parents and HCP in the decision-making process.

(3) To identify gaps in the current literature with respect to findings, perspective methodology, and study design to inform the development of this research project.

2.4b Methods

The databases MEDLINE, PSYCHINFO, SCOPUS, CINHALL and EMBASE were searched to ensure inclusion of medical, social science and bioethics literature. For papers that were not accessible online, I contacted authors directly and requested copies. If authors failed to respond within 6 months, these papers were excluded. Following initial screening and quality appraisal, 28 papers were included in the final analysis (see Figure I PRISMA diagram).

The search was limited to papers published between 2001 and 2015. This timeframe was chosen as 2001 saw the publication of the UK NICE Guidance on Cancer Services Improving Outcomes in Children and Young People with Cancer (NICE, 2001), which set out to improve communication and informed choice with this age group. For full inclusion and exclusion criteria and screening and quality appraisal processes see Appendix I.

The review was developed in accordance with Popay's 'Guidance on the Conduct of Narrative Synthesis in Systematic Reviews' (2006). A narrative synthesis was adopted, in line with previous reviews (Belanger, 2011), which successfully used the approach to summarise existing research and to synthesise evidence on decision-making in a medical setting.

2.4c Theoretical Perspective

In the review I used interactionism as the overarching framework, in line with the theoretical framework of the thesis as a whole. The social world is recognised as a place where meaning is formed through interaction between

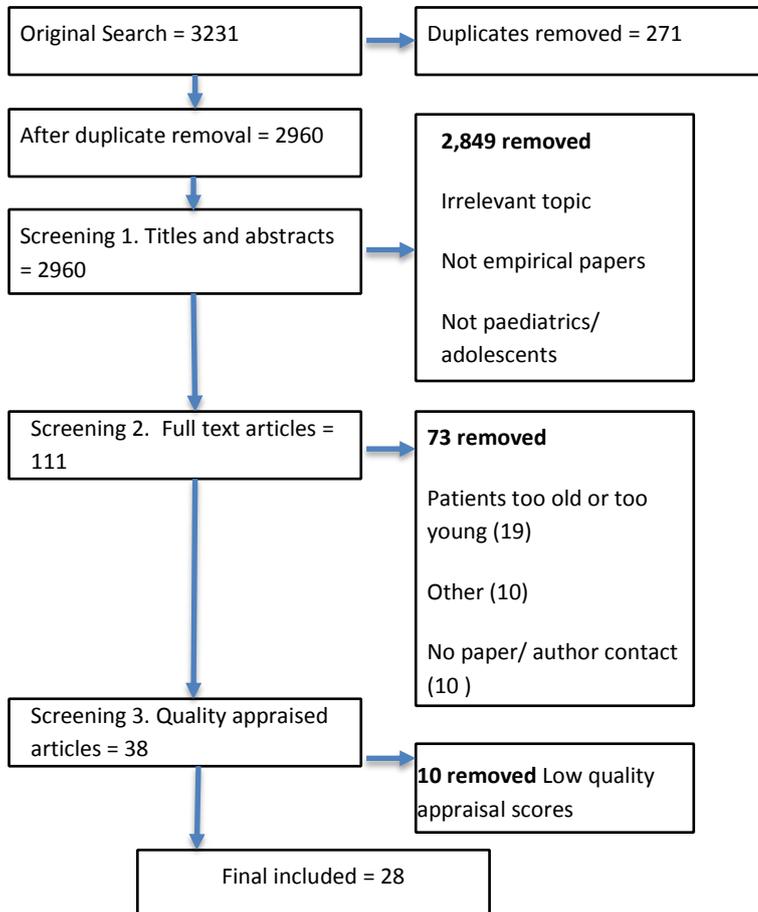
individuals, in this case teenagers, parents and HCP (Rock 2007). Behaviour is understood as more than individual responses and social rules; rather it is the product of human interaction, allowing the roles of teenagers, parents and HCP to alter and develop over time and place (Manis 1978) It is supposed that people attempt to make sense of the world by viewing and interpreting themselves in the context of the behaviour and actions of others in any given situation (Rock 2007). Consequently, individuals are not seen as passive recipients of information but as active agents in the formation and interpretation of behaviour and action (Bluebond-Langner, 1978, 1996). The term 'agency' in interacting with others refers to the ability of a person through expressing a thought or a wish, to make a difference to the activity in which he or she is engaged with others (Day, 2016). Agency does not equate to power or authority or dominance. It is often exercised through negotiation, a process of give and take (James, 2009, Mayall 2002). In the review, I used interpretive narrative synthesis to organize the current literature by focusing on the ways teenagers, parents and HCP interpret their own roles and the roles of those around them, defining their place in the decision-making process.

2.4d Summary of Results

The 28 studies identified for this review are heterogeneous in methods, in the nature of the data presented and in types of decisions and issues studied (see Table I Descriptive Characteristics of Included Studies (Day et al, 2016) at the end of the chapter). The evidence ranges from records of audio and video taped consent conferences, retrospective surveys of parents, teenagers and HCP, to reports of preferences and recommendations concerning the decision-making process. The evidence is a mixture of what was observed to have happened, what is recalled as having happened and what participants would ideally like to occur. Against the backdrop of an interactionist perspective the review presents a synthesis of findings from these studies, identifying to what extent three stakeholders (teenagers, HCP and parents) are able to participate in decision-making. Synthesis highlights the impact of protocols, the loss and re-establishment of agency, the roles and information preferences of each party

and participation in practice as highlighted in current literature (Day et al, 2016). See Appendix I where results are presented in full.

Figure 1 PRISMA Diagram



2.4e Interpretation of Findings

Evidence suggested that participation in decision-making for both teenagers and parents is compromised at diagnosis. The overwhelming obstacle to their participation and agency is a lack of choices offered by HCP as a result of a programme of care determined by the rigid clinical pathways and professionally mandated protocols HCP adopt [these are authorised predominately by NHS England, the National Institute of Clinical Excellence, and the General Medical Council]. There is a diminution or loss of agency for both teenagers and parents as they face life-threatening illness, unfamiliar and intimidating new environments, and information that are difficult to comprehend.

While the roles of parent and HCP are well defined, the role of teenagers in the process is not. Maturity and disease experience, not age, is an important factor affecting participation roles for teenagers (De Vries 2012, Crawshaw 2009, De Vries 2009, Olechnowicz 2002, Talati 2010, Zwaanswijk 2007). The role of parent is defined as advocate and protector of the teenager, not as surrogate or proxy decision-maker (Holm 2003, Inglin 2011, Matsuoka 2012). Parents rather than teenagers are more often seen as the primary figure in decision-making yet teenagers are, in the main, approving or accepting of this dynamic, especially when parents are aware of teenagers views (Broome 2003, Crawshaw 2009, Zwaanswijk 2007, Yap 2010, Young, 2010). The review identified no evidence that parents or teenagers indicate a preference for a high degree of independence in decision-making, instead cooperative partnership appeared to be desired. This collection of research suggests that teenagers and parents preferences for information and participation vary between individuals and over time. Consequently, this thesis aims to uncover the complexities of interaction between teenagers, parents and HCP when decisions are made across the disease trajectory.

2.4f Implications of Multi-Origin Research

Importantly as Table II demonstrates, this review synthesized research designed and carried out all over the world.

Table II. Origin of Research Included in Narrative Systematic Review

Continent of Origin	Country	Number of Studies
North America	America	15
	Canada	1
Europe	Switzerland	1
	Finland	1
	Netherlands	6

Continent of Origin	Country	Number of Studies
	Sweden	1
	UK	1
	Belgium	1
Other	Japan	1
	Australia	1
	New Zealand	1

Research groups from North America and Europe have made the largest contribution to this field of study, notably the USA and Netherlands. As in the UK, both USA and the Netherlands recognize 18 as the age of majority (with the exception of four US states where majority is not reached until 21).

Despite the difference in location, the research presented focuses predominately on a western ideal of medicine, adolescence and young adulthood. Although discrepancies emerge across countries with regard to age of consent and legal responsibilities afforded to teenagers the fundamental characterization of 13-19 years as a period of physical growth and mental development hold true. Similarly, research represented here has been carried out in countries benefiting from an established health care system where the treatment of childhood and teenage cancer is routine. Though this thesis focuses on teenagers' involvement in medical decision-making in the UK, some of its findings and conclusions may also be relevant to other countries with similar conceptualizations of adolescence.

2.4g Developing the Thesis

This review provided valuable insight to develop the direction and focus of the thesis. Firstly, it was evident that further work was needed to increase understanding of how teenagers, and others, view the role of teenagers in making decisions for their own care and treatment both in principle and in practice. Accessing these views is at the heart of this thesis, and central to the objectives outlined earlier.

Secondly, the majority of studies utilised similar methods, calling on semi-structured interviews, focus groups or surveys to elicit the views of parents, HCP and occasionally teenagers on decisions that they had recently made. Although interview studies were often categorized as prospective (Baker 2013, Hokkanen 2004, Kars 2011, Broome 2003, Hinds 2005) they remained dependent on recall, employing interviews and focus groups anywhere between seven days and several years after a decision had been made. Three studies were identified that included observations of real time interactions (Miller 2014, Olechnowicz 2002, Simon 2003). They focused on one decision at a single time point, thus suggesting that each party's role in decision-making can be understood by examining a single decision in isolation. Notably, none of these studies included interviews or informal conversations with teenagers themselves. It can be argued that such studies constrain understanding of participation in decision-making by reducing the process to the amount of verbal communication, the number of questions asked or the amount of information given, whilst ignoring the effect of time. The research presented in this thesis has thus been designed to address these gaps in pre-existing work, focusing on interactions between teenagers, HCP, and parents in a truly prospective way, accessing views and understandings as decisions are being made.

Finally, this review identified that important changes take place over time as parents and teenagers gain experience with the hospital and treatment protocols, and familiarity with the HCP providing care. Hinds (2005) suggest that decision-making toward the end of life may have distinct characteristics

(Hinds 2005). The methodological consequence of this for this thesis is that teenagers, HCP and parents were followed over time and across decision points. Interaction was observed as decisions were made across the trajectory, including end of life.

In sum, this empirical review of the literature situates the study conducted for this thesis within the research and clinical literature, revealing a clear gap in knowledge and suggesting an approach and methodology which would allow me to begin to fill that gap. In the following section I move to situate the research in the context of current conceptual models of decision-making, moving to a discussion of policy and clinical guidance for involving teenagers in decision-making in the United Kingdom.

2.5 Conceptual Models of Decision-Making

Many researchers have formulated conceptual models of decision-making to explain, describe and aid the process. Models of decision-making are often discussed on a spectrum ranging from paternalistic decision-making, through shared decision-making to informed decision-making (Charles 1999). Information exchange, deliberation and the final decision led by HCP or patients in varying degrees across the spectrum (Charles 1999). Researchers have attended to these models over time and some accept that the model adopted can change across, and even within interactions, flexibility and responsiveness to the interaction as it unfolds is considered essential.

As I go on to discuss in the following section the NHS champions the shared-decision model of decision-making. Therefore, increasing focus has been placed on enacting models of collaborative, shared decision-making in the health care setting. Elywn and colleagues present a shared decision-making model for clinical practice that aims to 'confer agency' by providing information and supporting the decision-making process (Elywn 2012). Acknowledging the

model is not prescriptive; they propose a step-wise process that moves from choice talk (make patients aware options are available), to option talk (more detailed information on options) to decision talk (considering preferences and deciding what is best). There is no distinction made between the process as it plays out with adults, teenagers or children.

Unsurprisingly, there are fewer models that focus specifically on decision-making with children and teenagers. However, Whitney and colleagues propose a model that attends specifically to the involvement of children and teenagers in paediatric cancer. The Decisional Priority in Pediatric Oncology Model combines what they deem to be 'two critical aspects of decision-making' with this patient group, firstly the probability that the cancer can be cured and secondly whether or not there is a treatment approach that is superior (Whitney 2006). Interestingly their model includes example scenarios that highlight where decisional priority sits in relation to these critical aspects. They state that for an adolescent with relapsed ALL, where the chance of cure is unprecedented and no best option exists the decisional authority sits with the adolescent. Whether or not this is the case with adolescents facing relapsed ALL in this study is discussed in the following chapters.

This thesis attempts to move thought away from binary, linear and step-wise models of decision-making and involvement. Importantly, models such as these do not acknowledge the different types of decisions a teenager facing a certain diagnosis or period in the trajectory may encounter. Although decisional authority may sit with them for decisions relating to feeding or stopping disease directed treatment, it may not for decisions relating to DNAR orders. In addition, general shared-decision-making models assume an ideal level or type of involvement and decision-making; good practice and bad practice that is largely assumed to rely on HCP communication skills. This thesis acknowledges the dynamic and fluid contribution of HCP, parents and teenagers in interaction to shape and enact involvement.

As mentioned earlier, the NHS champions the shared decision-making model. It is important therefore to address how this translates to the clinical guidelines for decision-making with teenagers in the NHS.

2.6 Clinical Guidelines for Decision-Making with Teenagers in the United Kingdom

This thesis specifically attends to the care and treatment of teenagers within the United Kingdom. As demonstrated by the systematic review, the majority of empirical work has originated from the United States and the Netherlands where healthcare systems and conceptualisation of adolescence differ slightly. Moving forward it is my intention to situate this research in the context from which it derives. Unless otherwise stated, where law or legal precedent is mentioned it can be assumed reference is being made to the law as it stands for NHS England.

2.6a Evolution in Thinking on Shared Decision-Making

It is first necessary to acknowledge that guidance for children and teenagers sits against a backdrop of guidance for the increased involvement of adults in health care. The term ‘shared decision-making’ has received much attention in adult health care literature and practice, defined as “an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elywn, 2010). A policy move away from patriarchal medicine was employed in April 2013, when NHS England formally took responsibility for embedding Shared Decision-making within the NHS. Prior to this, and extensively since, there has been a drive within the NHS to ‘promote patient centred care, to increase patient choice, autonomy and involvement in decision-making’ (NHS 2013).

Interestingly, a systematic review that focused on shared-decision-making and its occurrence in the literature identified no shared definition of the concept

(Makoul 2005). The Kings Fund produced a report in 2011 to demystify and unify the concept. They state that shared decision-making is 'viewed as an ethical imperative by the professional regulatory bodies which expect clinicians to work in partnership with patients, informing and involving them whenever possible.' (Coulter and Collins, 2011). The authors believe shared decision-making is possible at every decision point, as ultimately there is always a choice to act or not act. Despite this they recognise shared decision-making is not yet the norm in the NHS, and HCP ultimately have the responsibility to share decisions with patients and implement this model. Similarly, The Health Foundation Report highlights evidence that shows shared decision-making improves patient satisfaction, involvement in their care and knowledge of their condition (Da Silva 2012). 'No decision about me, without me' is the central principle echoed throughout guidance for involving adults in their health care. To open a full discussion of this guidance is beyond the remit of this thesis, but awareness that guidance for children and teenagers does not sit within a vacuum is essential.

In light of this principle of shared decision-making emanating through adult health care it is unsurprising that it is emerging as a dominant principle in paediatric and young adult health care. The extent to which adults incorporate views or preferences of children and teenagers into the educational (Mayall, 2002), health (Wakefield, 2012, Nitschke, 1982) and social (John, 2003) policy that concerns them has been increasingly pulled into focus. Many scholars and policy makers suggest children and teenagers should be actively engaged in decisions that concern their welfare. A common thread that runs through most policy for children and teenagers is reference to the United Nations Convention of the Rights of the Child [UNCRC]. UNCRC recognizes three core principles: participation, provision and protection,

'States Parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.' (Article 12.1, UN 1989)

Much institutional guidance for children and teenagers builds on this foundational statement, adopting the fundamental principle that children and teenagers have a right to a certain level of involvement in matters that concern them. Whilst the broad principle holds true, it is the responsibility of each institution to apply the notion to their practice. To write that children's views be 'given due weight in accordance with the age and maturity of the child' begs the question of what 'due weight' means in a practical sense. Similarly, to write of 'the child who is capable' calls for a definition of capability. Thus, in the National Health Service guidance has built on this ideal and policy makers have attempted to further define concepts of capability and competency in a medical institution to assist care providers in knowing when to involve teenagers in decision-making.

2.6b Shared Decision-Making with Teenagers

It should be noted here that policy and guidance regarding the specific needs of 13-19 year olds (the group on which this thesis is focused) when making decisions about care and treatment, are lacking. Much guidance recognises a distinction between adults (18 years and over) and children (0-18 years), neglecting the variance within these broad stratifications. To present guidance for involvement in decision-making that groups teenagers together with toddlers overlooks the obvious disparities between these age groups.

General Medical Council (GMC) guidance on making decisions with 0-18 year olds is one such policy, stating,

23. You should involve children and young people as much as possible in decisions about their care, even when they are not able to make decisions on their own. (GMC 2007)

The GMC (GMC, 2007) goes on to present criteria for assessing the capacity of teenagers to consent. They suggest that doctors and health care professionals 'must make sure that all relevant information has been provided and thoroughly

discussed before deciding on whether or not a child or teenager has the capacity to consent’.

An independent advisory group of health care professionals and representatives, namely The Children and Young Peoples Health Forum, produced a report providing evidence-based advice to improve standards of care for children and young people (CYPHOF, 2012). The report points to the benefits of involving young people in decision-making suggesting ‘where health outcomes are better it is because children, young people and their families are involved in decisions about their care, having received relevant and age-appropriate information, and that care is provided in environments appropriate for their age’ (CYPHOF, 2012 page 8). Once again the provision of relevant information is central to how guidance conceptualizes the involvement of young people in decision-making.

The Nuffield Council on Bioethics recently published their report on the involvement of young people in decisions relating specifically to research participation (Nuffield Council on Bioethics, 2015). They issued guidance on how and when to involve teenagers in clinical research. Several recommendations were issued, including: that research should be carried out with and not on children, that research participation be a shared decision between young people and parents, and that young people should be as involved as they want to be. The report also concludes that ‘the best way’ of making sure children and young people are not vulnerable in research is by researchers involving them when designing studies and taking their opinions on board. As Whitney and colleagues succinctly state ‘decision-making in paediatric oncology can look different to the ethicist and the clinician’ (Whitney 2006). Although we can purport an idealised view of decision-making in principle the reality of clinical practice and the legal responsibilities of each party often interrupts this.

Competency and Legal Responsibility

GMC guidance on consent states,

‘It is a general legal and ethical principle that valid consent must be obtained before starting treatment or physical investigation or providing personal care for a person’ [DoH 2009 page 5]

In setting out the legal framework HCP must adhere to, they acknowledge that the legal position concerning consent and refusal of treatment by those under age of 18 is different from that of adults. Reference is made to Gillick competency, and principles are mandated for the involvement of teenagers in decision-making.

Gillick competency and the Fraser guidelines are often referenced as aides to determine the competency of children and teenagers under the age of 16 to ‘understand and appraise the nature and implications of a proposed treatment, including the risks and alternative courses of action’ (Wheeler, 2006). This notion that teenagers are in some instances able to make decisions independently of their parents regardless of age, originated from a legal case regarding the prescription of contraception to girls under the age of 16 without parental consent. While the Fraser guidelines remain more closely aligned with issues surrounding contraception, the Gillick judgment has been extended and widely used in other areas of medical treatment and consent (Wheeler 2006, Hayhoe 2008). Teenagers under the age of 16 must therefore be deemed ‘Gillick competent’ to be recognized as capable, whilst those over age 16 are automatically recognized as such.

Alongside the general guidance for involving teenagers in decision-making and the tools to determine competency there are also more explicit guidelines stipulating the level of mandatory or maximum involvement and decisional priority individuals should have in certain decisions.

For decisions relating to participation in clinical trials guidance states that ‘patients should be told how the proposed treatment differs from the usual

methods, why it is being offered and if there are any additional risks or uncertainties' (DoH pg 18). HCP are encouraged to share up to date information regarding the effectiveness of the treatment and possible side effects, though considered good practice this is not mandated. As with adults teenagers are required to give their consent to any trial or treatment before it is commenced. Again, in line with guidance for adults it assumed that consent is valid until it is withdrawn by the individual. However, guidance for treatment refusal offers an example of how guidance for teenagers' involvement and decisional authority differs from that mandated for adults.

Notably, health care professionals and parents can overrule the refusal of treatment for anyone under the age of 18, if refusal may lead to 'death or severe permanent injury' (DOH 2009). HCP are also able, with the help of the courts, to overrule the refusal of a parent to life-sustaining treatment (DoH 2009). For adults over 18 years, guidance dictates that any refusal should be respected. Thus, whilst teenagers 16-17 years are able to consent to treatment and trial participation, they are not able to refuse life-saving treatment until they are 18 years of age. The implication being that though 16-17 year olds are considered competent to consent to treatment, they are not considered fully competent to make a life and death decision until 18 years of age. Guidance acknowledges that refusal of treatment by a child with capacity must be taken 'very seriously', and despite it being legally possible to do so, continuing treatment may not always be in the best interest and therefore is not a legal requirement (DoH 2009). This demonstrates a clear distinction for decisional authority held by teenagers and adults.

For decisions regarding end of life, more specifically the decision to withdraw life-sustaining treatments, legal principles are extensively laid out by the GMC. For children or teenagers who lack capacity GMC guidance suggests that it is 'good practice to involve the child as far as possible and appropriate in the decision', there is no legal mandate to explicitly discuss the decision with the child or teenager. For children and teenagers with capacity guidance states that along with adults they do not have the legal right to demand treatment that is not clinically indicated. Importantly, the GMC also state that the graveness of

such a decision requires 'a very high level of understanding, so that many young people who would have the capacity to take other decisions about their medical care would lack the capacity to make such a grave decision'. In both cases, HCP have the responsibility to determine what is in the teenagers' best interest and act accordingly; only best practice determines whether a decision is discussed with the teenager.

The stance taken by this guidance has a significant impact on how involvement can be enacted in practice, the role the teenager can adopt and the responsibilities they are afforded. Further, it mandates the involvement of an adult in the decision-making process, be it a parent/ guardian or HCP to hold decisional authority where death or severe injury is likely.

2.6c Summary and Implications

The rhetoric is generally unified, asserting that children and teenagers should be involved. Moving in the same vein as adult health care, a more active role for the teenage patient is being championed by policy makers and commissioners. The provision of relevant and appropriate information by health care professionals is deemed integral to the teenager's involvement in decision-making. However, what this involvement looks like in practice, in the face of numerous decisions of varying complexity and severity is unclear. Policy stipulating the involvement of children and teenagers rarely focuses on teenagers with high risk, life-threatening conditions. Crucially therefore, policy for involvement does not provide an effective framework for involving seriously ill teenagers in decisions of consequence. The research presented in this thesis focuses on the involvement of these teenagers, as they face decisions at diagnosis of serious conditions, when curative treatment is no longer working, and at all points in-between.

Returning to guidance from the GMC, they write of the importance of assessing 'maturity and understanding on an individual basis and with regard to the complexity and importance of the decision to be made' (GMC, 2007 page 12).

With this in mind, the next section focuses on the specific types of decisions that teenagers with leukaemia may be confronted with over the course of their illness.

2.7 Teenagers with a Leukaemia Diagnosis

2.7a Age Stratification in UK Health Care

There have been various age stratifications in UK policy, guidance and practice, notably 0-18 years, 0-14 years, 15-24 years, and 13-19 years (see below). As stated at the outset, the work in this thesis focuses on the care and treatment of teenagers aged 13-19 years, with a leukaemia diagnosis. This age group was chosen to reflect the stratification of patients in UK hospitals, under the care of a teenager cancer team. Teenage specific cancer units, funded by Teenage Cancer Trust, provide inpatient care and treatment to people aged 13 – 19 years old. Despite the legal recognition of adulthood at 18, teenage cancer units continue to look after these adults until they turn 20, when they are then transitioned to an adult service. It is for this reason that I include teenagers beyond their 18th birthday, up to their 20th birthday. Similarly, these units only accept teenagers after they have turned 13 years old, children under 13 are treated on a separate ward and occasionally at a designated children's hospital. It is for this reason I do not include anyone younger than 13 years old in this study.

2.7b Overview of Diagnosis and Prognosis

The patient populations for this study are those aged 13-19 years who have been diagnosed with Acute Myeloid Leukaemia (AML) or Acute Lymphoblastic Leukaemia (ALL). Both are forms of cancer affecting the blood and bone marrow. Treatment primarily includes cycles of chemotherapy and occasionally stem cell transplant (National Cancer Institute, 2014) [See Appendix II Glossary for Medical Terminology]. These diagnoses were selected for investigation in this study for several reasons. Firstly, there is limited research published to date prospectively investigating the involvement of teenagers in decision-making

when facing a diagnosis of AML or ALL, and care and treatment as the illness progresses. Secondly, their prognostic uncertainty raises important issues about the timing and implication of particular decisions made between health care professionals, parents and teenagers.

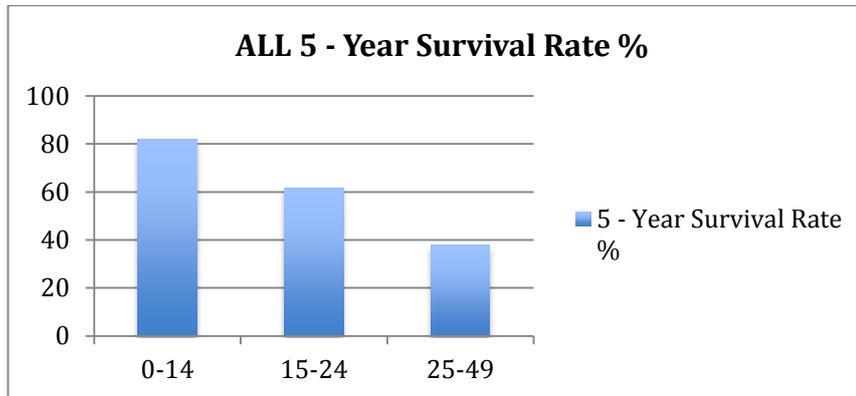
The age stratification employed by clinicians, statisticians and epidemiologists in the UK makes accurate statistics for incidence and survival of teenage patients difficult to assess. Some provide facts and figures for the teenage and young adult population 15-24 year olds, others provide statistics on adults generally 15-99 year olds, and others provide information on childhood population 0-16 years. Since 15-24 years encapsulates the majority of the patient population of this thesis, attention is paid to this banding.

On average 178 teenagers and young adults (15-24) are diagnosed with leukaemia every year in the UK [Cancer Research UK, 2015]. Incidence is higher in males than females with 109 (61%) of these diagnoses accounted for by young men. Survival rates vary by type of leukaemia and age at diagnosis. Death can occur as a result of the disease itself or as a result of the toxicity of treatment, particularly intercurrent overwhelming infection. A recent report published in the Lancet presented Europe-wide data confirming that adolescents and young adults (15-24) show poorer survival than children for 'eight important cancers' including ALL and AML (Trama et al 2016).

Acute Lymphoblastic Leukaemia (ALL)

ALL is the most common leukaemia, accounting for 46% of all leukaemias in 15-24 year olds (Cancer Research UK 2015). The 5-year survival rate for 15-24 year olds with ALL is reported at 61% for males and 62% for females (O'Hara 2012). Those aged 15-18 years had a 17% higher 5-year survival than those aged 19-24. In line with this trend, the survival rate for 15-24 year olds is 20% lower than that of 0-14 year olds, but 23% higher than 25-49 year olds (O'Hara et al, 2012).

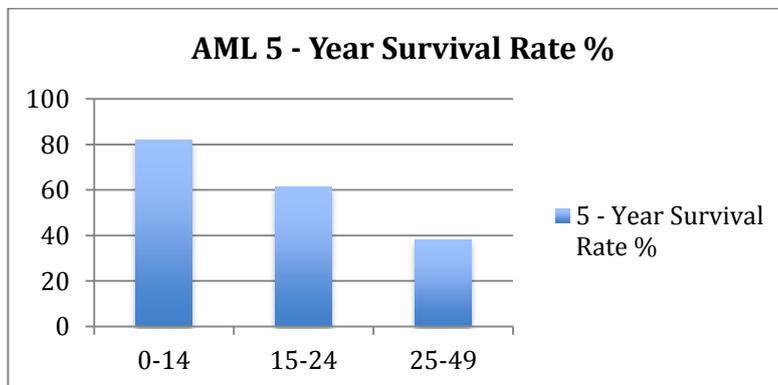
Figure II. ALL 5-Year Survival Rate



Acute Myeloid Leukaemia (AML)

Overall 5-year survival rates for AML patients vary depending on a number of factors relating to the clinical presentation of the disease (such as presenting white cell count, genetic subtypes and whether AML is secondary to prior chemotherapy or myelodysplasia) and biological make-up of the individual (i.e. Chromosomal abnormalities). On average 5 year survival is reported as 57% for 15-24 year olds. This increases to 61% for 0-14 year olds and decreases to 51% for 25-49 year olds. As with ALL, the survival rate for 15-18 year olds is slightly higher at 58%, than 19-24 year olds at 56% (O'Hara et al, 2012).

Figure III. AML 5-Year Survival Rate

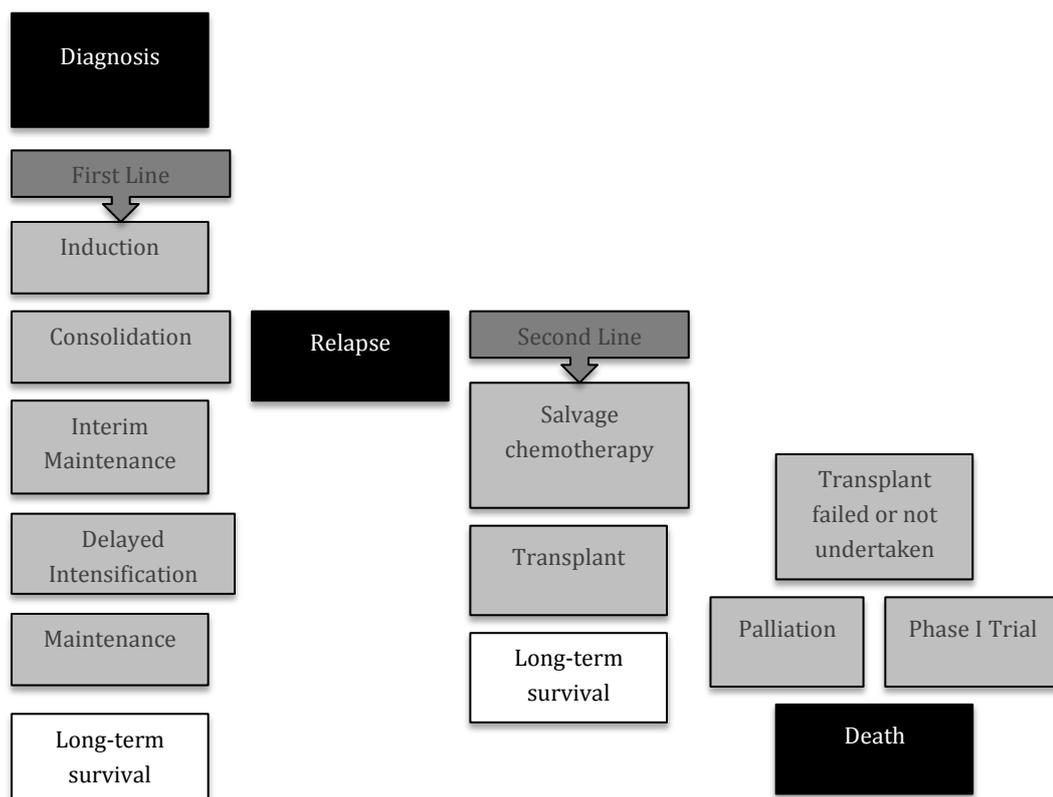


2.7c Treatment and clinical course

ALL

Initial treatment for teenagers diagnosed with ALL lasts around two years for females and three years for males. As demonstrated in Figure IV typical initial chemotherapy treatment consists of five stages, which varies slightly if a teenager opts to participate in a clinical trial. Combinations of chemotherapy drugs are administered in cycles of treatment. Allogeneic stem cell transplantation is used rarely in first line therapy and is generally reserved for those who respond inadequately and those who relapse (see below).

Figure IV. Simplified typical treatment trajectory for teenagers diagnosed with ALL

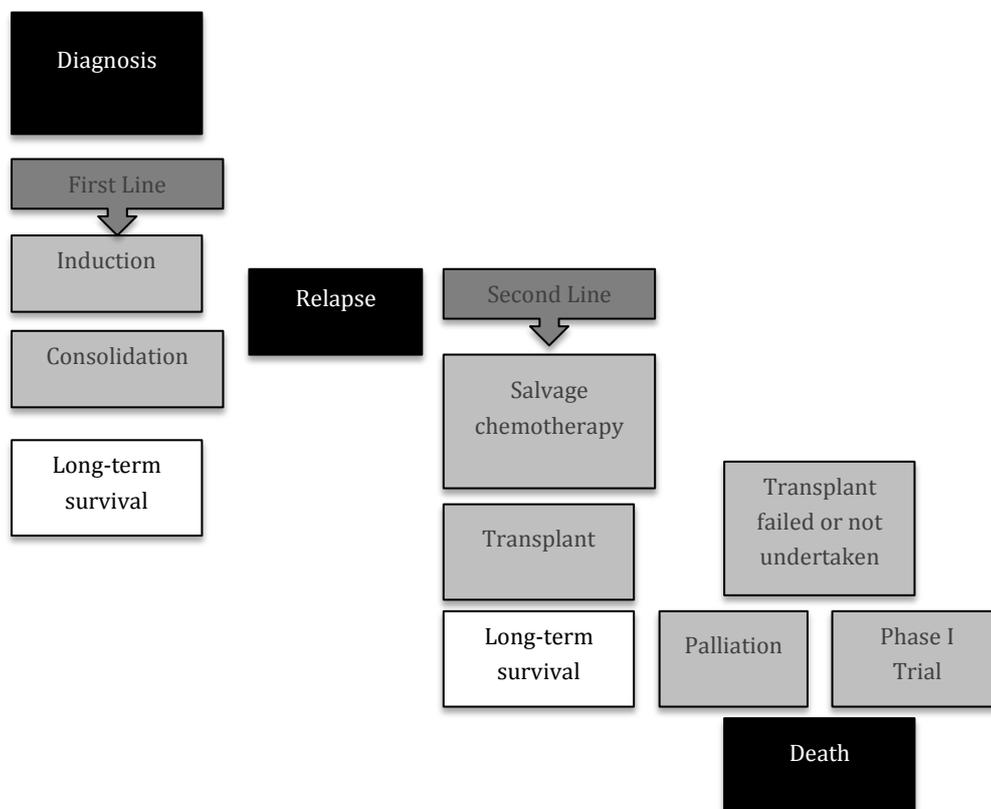


AML

Initial treatment for teenagers diagnosed with AML lasts approximately 6 months, however, treatment may last longer depending on how an individual

responds to treatment. Teenagers with AML receive chemotherapy in several stages as demonstrated in Figure V. Depending on the specific sub-type and the disease characteristics a combination of chemotherapy drugs are given in four cycles of treatment and rest. If this treatment is unsuccessful a stem cell transplant is often offered. For both AML and ALL bone marrow is regularly monitored for signs of relapse.

Figure V. Simplified typical treatment trajectory for teenagers diagnosed with AML



Clinical Trials

Clinical trials are offered to teenagers at various stages of their trajectory at designated trial centres throughout the NHS. At diagnosis teenagers often have a choice between the current standard treatment and a clinical trial if a relevant trial is open at their treatment centre. When this study was in progress a Phase

III trial was open for teenagers and young people diagnosed with ALL, and a trial for adults diagnosed with AML had recently closed.

UKALL2011

This randomized Phase III trial is open to all newly diagnosed ALL patients aged between one and 24 years old, until April 2019. The trial consists of five stages and two randomisations. The first randomisation occurs immediately and modifies the scheduling of the steroid drug dexamethasone, administering either a 14-day high dose or a 28-day standard dose. The second randomisation occurs after the consolidation phase of treatment and modifies the dose of methotrexate teenagers receive, the number of intrathecal methotrexate injections given, as well as the dose of steroid and vincristine 'pulses' received. The trial is designed to 'assess whether changes in the way some of the standard anti-leukaemic drugs are given can reduce the side effects associated with treatment' (National Institute for Health Research, 2016). Consent is sought prior to both randomisations, giving the teenagers the option to come off trial treatment if they wish to do so after the first stage. For those who did not consent to randomisation at either stage, were not eligible or were diagnosed prior to the trial commencing standard chemotherapy treatment was administered. Standard treatment involves lower dose dexamethasone for 28 days followed by vincristine and dexamethasone pulses.

AML17

This Phase III trial closed for recruitment on December 31st 2014. The trial was open to adults under 60 years of age with a diagnosis of AML. The study had two discrete parts. One part focused on Acute Promyelocytic Leukaemia (APL), a sub-type of AML, randomizing participants to standard chemotherapy treatment or to a combination of arsenic trioxide and all-trans retinoic acid (ATRA). The second part focused on AML patients randomizing to one of five possible treatment arms based on the potential presence of a mutation in the leukemic cells of participants (National Institute for Health Research, 2016).

Transplant

In some instances, where first line treatment is unsuccessful, teenagers will be offered a stem cell transplant. The infusion of healthy stem cells from a donor (allogeneic transplant) is preceded by a treatment plan of chemotherapy and radiotherapy to destroy the diseased bone marrow. Stem cell donors can be siblings with the same tissue type, or an unrelated donor found through the Anthony Nolan Register. Worldwide data suggests that 10-19 year olds with AML or ALL who undergo an allogeneic transplant have a 18% (AML) to 32% (ALL) chance of survival in remission 2 years following transplant (Wingard et al, 2011) For those that survive for at least 2 years, 10 year survival for both AML and ALL post transplant is reported at 84% (Wingard et al 2011).

Symptom Care

As part of the daily management of leukaemia and the treatment that is given, teenagers often have a host of symptoms to contend with. Symptom control, or symptom management attempts to reduce the pain, nausea and vomiting that are commonly associated with leukaemia treatment. Whilst the clinical treating team often manage this, a specialist symptom control team are also available to assist and advise the clinical team, parents and teenagers. Medications can be administered orally, intravenously, via continuous subcutaneous infusion or via patient control analgesia (PCA) pumps.

2.7d The Decisions

Teenagers with a diagnosis of AML or ALL, their parents and health care professionals face a number of decisions throughout the disease trajectory. This thesis does not intend to offer an exhaustive examination of all of the decisions associated with a cancer diagnosis, or even diagnosis of AML or ALL. Decisions relating to fertility, body image and education amongst others were considered, however they were not particularly pertinent to this group of teenagers. Consequently, attention is paid to six decisions that have emerged

repeatedly throughout the project as key decisions that help illuminate the role of teenagers. Here I present a brief description of each key type of decision.

Feeding

Teenagers, parents and health care professionals face decisions relating to the teenagers intake of food, the nutritional support provided and the method of intake (principally nasogastric tube- NG, percutaneous endoscopic gastrostomy- PEG, oral). These decisions are encountered throughout the disease trajectory, becoming more prominent when a teenager undergoes chemotherapy or a stem cell transplant and side effects of treatment make oral intake difficult. For day-to-day care these decisions are not considered particularly serious. However, should a teenager lose a substantial amount of weight as a result of treatment side effects, these decisions carry much more significance and risk for the teenagers on-going care.

Place of Care

Teenagers, parents and health care professionals face decisions relating to where the teenager receives care and treatment. This can be a decision between inpatient and outpatient care, as well as a decision about where specifically the young person receives care and treatment in the hospital (i.e. intensive care ward, specialist ward, day care), and outside the tertiary hospital (i.e. at home, in a hospice or district general hospital).

Though planning for such decisions is possible, these decisions are accompanied with a degree of uncertainty in that the teenager's clinical condition can change overnight and a new place of care is made available or essential. Decisions can generally be reversed and changed with ease, providing beds are available and clinical condition permits.

Participation in a Clinical Trial

Teenagers, parents and health care professionals face decisions relating to participation in a clinical trial. Typically for this patient group this includes a decision at diagnosis of whether or not to participate in a Phase III clinical trial. Occasionally, in instances where curative treatment is no longer working teenagers, parents and health care professionals will face a decision relating to the participation in a Phase I trial.

These decisions are reversible and teenagers are advised that they are able to withdraw from trial at any point and return to standard treatment. Teenagers are also assured that there is minimal risk entering Phase III trials, though many worry that they are receiving an experimental treatment. The innate uncertainty regarding receiving a treatment that is still being 'tested' is a cause of concern for some teenagers and parents.

Stem Cell Transplant

Teenagers, parents and health care professionals occasionally face the decision of whether or not to proceed with a stem cell transplant. This decision is only encountered in instances where initial chemotherapy treatment has not successfully treated the leukaemia.

There is a degree of uncertainty associated with the decision to undergo a high-risk procedure such as a stem cell transplant. Alongside the uncertainty of success there are uncertainties related to finding a suitable donor and responding well enough to initial work up to receive the stem cells. There is therefore also risk associated with deciding to have a stem cell transplant, as well as significant risk of death should the decision to not undergo a stem cell transplant be taken.

Symptom Control

Teenagers, parents and health care professionals face decisions relating to the type, quantity and combination of medication given to teenagers to control symptoms of pain, nausea and vomiting. In addition, teenagers, parents and health care professionals face decisions about the method of intake for these medications. These decisions are encountered throughout the disease trajectory, becoming more prominent when side effects worsen or when the teenager's disease recurs, or condition deteriorates.

Symptom control decisions are made routinely in conversation with the teenager, parents and other HCP. Decisions are generally reversible and medications can be withdrawn or administered, stopped and started in response to the individual need. These decisions are not void of risk or uncertainty as medications each have their own side effects unique to the recipient.

End of Life Care and Treatment

Teenagers, parents and health care professionals sometimes face decisions relating to the teenagers end of life care, treatment and death. Such decisions include for example, making and discussing a 'do not attempt cardiopulmonary resuscitation' (DNAR) decision and other decisions related to the extent of invasive treatment and stopping curative or disease-directed treatment. These decisions are met towards the end of the disease trajectory when cure is no longer possible.

These decisions are often made in advance of a situation occurring, as such a degree of uncertainty regarding their implementation or necessity exists. There is also often uncertainty surrounding whether the decision is right for the teenager and the family at the time it is made. Decisions can generally be reversed and changed if discussions are had in advance. However, once a DNAR order has been recorded in the teenagers notes this decision would be respected and should it be implemented would not be reversible.

2.8 Summary

This chapter aimed to situate the thesis within the social, academic, and clinical settings from which the research and the researcher originates. This overview highlights how a comprehensive examination of multiple sources contributed to the formation of this research project. Initially, this chapter reflected on the positioning of teenagers over the years and how these teenagers have been conceptualized in the academic literature on medical decision-making. I then moved to a discussion of current UK policy and clinical guidance, as it stands for the involvement of teenagers in medical decision-making. Finally, I presented an overview of current leukaemia treatment, trajectory and prognosis, highlighting the six specific decisions (Feeding, Place of Care, Participation in a Clinical Trial, Stem Cell Transplant, Symptom Control and End of Life Care and Treatment) this thesis focuses on. In the following chapter I present the methodological basis on which this work originates.

Table I Descriptive Characteristics of Included Studies (Day et al, 2016)

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Baker. J et al.	2013/ USA	57 parents and 20 patients (mean age 17)	Multisite, prospective descriptive interviews	Content analysis	6/10	Patient and parents want additional information about trials in different formats, they want more time to prepare and make decisions, they want straightforward and honest communication from a regularly available clinician.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Broome, M. & Richards, D.	2003/ USA	34 Children (8-22 years) with a diagnosis of diabetes or a haematological malignancy	Semi-structured interviews	Narrative analysis	10/10	Chronically ill children are willing to talk about involvement in trials and describe how relationships with others influence their decisions. They have faith in their parents to listen to them and make decisions for them. Cancer patients were markedly different as the physician approached child and parent together rather than parent first. They had a greater level of involvement in research decisions.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Crawshaw. M, Glaser. A. et al.	2009/ UK	38 Young adults diagnosed with cancer between 13 and 20 years old, aware of fertility affects and not currently on treatment	In-depth single interviews	Informed by grounded theory	8/10	Addressing fertility issues is important regardless of the options available, teenagers express clear wish to have a choice in who is involved in discussions. Girls are less likely to have issues raised than boys. Argue that assumptions about how much information on fertility the YP wants can be made based on the age of the child.
De Vries. M, Bresters. C.D. et al.	2009/ Netherlands	14 Physicians and 15 parents of male adolescents undergoing cancer treatment	In-depth semi-structured interviews		7.5/10	Physicians did not accept parents' strategic control around decisions relating to fertility preservation. Unlike other treatments physicians spoke to child first regardless of parents position on the matter.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
De Vries. M. Wit, J. et al.	2010/ Netherlands	15 paediatric haematologists /oncologists	In-depth semi- structured interviews		7/10	Clinicians regard most adolescents as not capable of meaningfully participating in discussions about research. Clinician's don't always provide YP with all the information. Proxy consent is obtained and deemed sufficient. Clinicians judge treatment protocols as not harmful and in best interest of adolescent.
De Vries 2013. C.D et al.	2013/ Netherlands	Parents, paediatric oncologists and 8- 18 (mean 13) year old cancer patients	One-to-one semi- structured in depth interviews		8/10	All felt it is in the best interest to defer to medical judgement/protocols in beginning. There was recognition that as the disease progresses there is more choice and differences in what 'best interest' means. Parents reported little choice at diagnosis and the shock

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
						<p>when they do have to make a decision about things like fertility preservation. Parents recognised that as the YPs disease progresses they become 'layman-experts' and make more decisions. However physicians regard parents/children as having little influence on treatment protocols, claiming their influence starts with minor decisions.</p>

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Hinds. P., Drew. D. et al.	2005/ USA and Australia	20 Patients age 10 to 20 years	Interviews		8.10	These CYP realized they were involved in an end-of-life decision, understood the consequences and were capable of participating in a complex decision process that involved risk to them and others. Decision factors most reported were relationship based, contradictory to existing development theories.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Hokkanen, H., Eriksson,E. et al.	2004/ Finland	20 13-18 year olds currently living with cancer and attending a cancer adjustment camp	Focus groups		7/10	YP stated that they felt HCP asked them unnecessary questions and presented them with fake decisions and the illusion of control. They stated that information received in the early stages was irrelevant and they only needed it when treatment was over. They wanted practical advice on what they were allowed to do and how to cope with the disease, as well as more future orientated information. YP felt improvements were needed in staff, privacy, and physical care facilities.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Holm. K Patterson. J. et al.	2003/ USA	25 parents of 26 children who had completed treatment for cancer at least one year prior to the focus group	Focus groups (5-9 people)		7/10	Parents see themselves as advocates for their children, informing HCP and keeping themselves informed during both diagnostic and treatment phases. They have a role in limiting actions of medical professionals and supporting them.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Inglin. S. Hornung. R. et al.	2011/ Switzerland	15 parents whose child died or was receiving palliative treatment in one of 3 diagnostic groups – cancer, neurological disorders, non- cancer/neurology	Qualitative interviews		7/10	Honesty and openness from HCP considered essential by all parents when delivering difficult news. Parents appreciated when HCP respected them as experts in taking care of their child and actively involved them in decision-making. Parents highly valued supportive home care and long-term bereavement care

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Kars. M., Grypdonck. M.	2011/ Netherlands	44 parents of 23 children (6mnths – 18 year) with advanced and incurable cancer	One time and repeated open interviews Multi-centre study		7/10	Parents don't accept death they deal with the loss, parents who made the transition to letting go had increased receptiveness to child's real situation and needs. Parents stated it is not a linear process from preservation to letting go. Feelings of loss begin in the EOL phase not post death. Parents delay recognising treatment has failed. Dominant perspective of parents influences the child's situation. Best-interest for who, argue that parents can act in ways that have negative consequences for the child. Professional focus should shift from decision-making to guiding process of relinquishing –from the

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
						preservation of the child to letting go.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Kelly. P. Ganong. L.	2011/ USA	15 custodial parents, non- residential parents and step parents who had previously made major treatment decisions for their child with cancer	Minimally structured interviews	Grounded theory	8/10	Parents focus on ill child until the crisis has passed. Biological parents 'step up' to responsibility, while their partners step back or are pushed away. Step-parents play a supportive role to their spouse if they are allowed to.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Matsuoka, M. and M. Narama	2012/ Japan	23 parents bereaved 1-3 years previously	Semi-structured open-ended retrospective interviews	Constant comparison analysis	5.5/10	How parents understand impending death is complex and impacts on decision- making. The key thought of parents is to protect and support their child. Parents argued that HCP need to participate in EOL decision- making, and they needed to feel like they were parents. HCP can help this to happen.
Miller, V., Luce, M. et al.	2011/ USA	219 parents who made a decision about research or treatment for a child	Questionnaires - Completed measures for external influence, distress, decision- making preference and coping		6.5/11	More external influence was associated with more hostility, uncertainty and confusion. Decision-making preference and coping style moderated the influence between external influence and distress

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Miller, V. and Nelson. R.	2012/ USA	184 parents of children with cancer who made a decision about enrolling child in treatment protocol within previous 10 days	Questionnaires assessing voluntariness, external influence, concern of negative effects on care if disagreed, time pressure, information adequacy and demographics		6/11	Several groups of parents appear to be at risk for decreased voluntariness when making research or treatment decisions for their seriously ill children, including fathers, non-white parents, and those with less education. Parental voluntariness may be enhanced by helping parents to mitigate the effects of unhelpful or unwanted influences by others and ensuring that their information needs are met.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Miller. V, et al.	2014/ USA	61 patients aged 7- 21 who were offered participation in a phase 1 trial	Audio-recorded consent conferences	Statistically coded	5/5	Mean proportion of Informed Consent Conferences for trials in which the patient was involved was 43%. Proportion was greater with older patients. After controlling for age the more patient to doctor communication the more patients reported understanding.
Olechnowicz, J. Eder. M, et al.	2002/ USA	14 Informed consent conferences involving children with leukaemia over age 7 parents and clinicians	Audio recorded ICC conferences and follow up interviews with parents, clinicians completed a self- administered questionnaire		4.5/5	Who the clinician identified as the primary decision maker was not related to the age of the patient. Older patients asked more questions than young patients. HCP interaction with patients based on a number of factors; patient age, disease status, training style and preferences. Parents asked significantly fewer questions

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
						if child was present
Pousset, G., Bilsen, J. et al.	2011/ Belgium	165 Physicians who signed death certificates for 1– 17 year olds	Anonymous population based post mortem survey		8/11	Minor patients commonly kept in continuous deep sedation until death (21% non-sudden deaths, 53% sudden deaths). Indications that this is sometimes used with life-shortening intention without involving the patient.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Simon, C., Zyzanski, S. et al.	2003/ USA	108 parents of children with leukaemia 21 – non-English speaking 27 – English speaking minority group 60 – English speaking majority	Audio-recorded observations and interviews		4/5	Clinicians were more likely to omit certain information from discussions with non-English speaking parents, relating to randomisation, right to withdraw and consent documentation. Significantly more non-English speaking parents failed to grasp key aspects of informed consent. Parents in non-English group asked fewer questions. Consultations took on average the same amount of time, despite the added time normally required to speak through interpreters.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Stenmarker, M., Hallberg, U. et al.	2010/ Sweden	10 Paediatric oncology physicians with more than 10 years' experience	Interviews	Grounded Theory	6.5/10	HCP reported the decision burden for adolescents as they are at a stage calling for independence. They speak of the significance of seeking knowledge and information. They avoid identification with families and keep empathetic distance, dealing with their own attitudes to central life issues.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Stevens, P. and Pletsch. P.	2002/ USA	12 mothers whose children had undergone BMT	Qualitative semi- structured Interviews		6/10	Findings suggest that BMT is often a non-decision for mothers, as a life or death situation the voluntary nature of the decision is altered. Emotional trauma decreases mothers' ability to absorb information. Urgency further constricts mothers' time to understand and be informed. Mothers have the burden of responsibility, experiencing regret and recrimination once treatment begins.
Talati, E., Lang, C.et al.	2010/ USA	421 randomly selected general paediatricians and subspecialists from web-based directory	Online or mailed cross-sectional survey		8/11	Paediatricians' decisions to respect refusal from minors are multi-factorial. When prognosis is good, best interest dominates, when prognosis is bad parental authority (younger children) and minor autonomy (older

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Vrakking, A., Van Der Heide, A.et al	2005/ Netherlands	63 Paediatricians 125 GPs 208 clinical specialists	Structured interviews about hypothetical cases – all questions answered on a Likert scale		6/11	children) dominates A substantial proportion of Dutch physicians are willing to use lethal or potentially life- shortening drugs in children. Paediatricians are more willing than GPs to grant request from parent for ending life of unconscious child. Female and religious physicians are less likely. When parents disagree physicians are less likely to grant request of child.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Wicks, L. and Mitchell. A.	2010/ New Zealand	Ten 16-22 year olds diagnosed with cancer during adolescence	In-depth semi- structured interviews		6.5/10	Support for fostering involvement of young people. They reported experiencing a loss of control as the Drs took over, which lead to rebellion and non-adherence. Many factors could be implemented to enhance sense of control, eg. benefit finding, maintaining positive outlook, confidence, motivation, remaining focused.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Woodgate, R. and Yanofsky. R	2010/ Canada	31 parents of children with cancer (6 months post-diagnosis – 5 years after treatment completion)	In-depth, open- ended, semi- structured interviews		8/10	The suffering of parents is complicated by not only making decisions but by having to come to terms with them afterwards. This is made bearable by relationship with child/others/HCP. Parents experience is a relational process shaped by evolving intrapersonal, interpersonal and transpersonal relationships and communication. As such HCP can help parents achieve sense of being a good parent.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Yap, T., Yamokoski, A. et al.	2010/ USA	103 physicians	Cross-sectional questionnaire survey		7/11	Physicians believe providing information about phase 1 study entry to families is most important goal of informed consent process. 64% report providing an unbiased description. Females more likely than males to report influencing.

Author	Publication year/ Country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Young. A., Kim, L. et al.	2010/ USA	3 patients (13-22) 6 mothers (children U18) 6 physicians 8 nurses	Focus groups		7.5/10	All agree autonomy is paramount to conducting ethical research. Young people didn't talk about decision-making, but physicians did. Difference in status, role definition, and information exchange were identified as important in the information consent process. Teenage patients described a loss of agency during IC process

Zwaanswijk, M., Tates, K. et al.	2007/ Netherlands	Seven patients age 8-17, eleven parents and eighteen survivors age 8-17 at diagnosis	Online Focus groups - 3 separate groups for patients, survivors and parents of current patients	7/10	All three highly valued open and honest communication, but not all YP wanted to know prognostic and survival rate information. Adolescents emphasized lack of information specifically for their age group. Majority of participants wanted decisions about treatment to be made in collaboration with HCP and families. Survivors and patients believed they should be the ones to make the final decision. Parents and young people recognised the prescriptive protocols constrained their choice, as did lack of sufficient knowledge, lack of trust in physicians expertise, practical circumstances and feeling too ill or depressed to decide.
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Chapter

3

Methodology

As highlighted in the previous chapter, in order to fulfil the objectives of the research project a particular methodological design was required. To understand the complex process of decision-making between teenagers, parents and health care professionals it was necessary, amongst other things, to observe that process as it happened.

3.1 Ethnographic Research

As with any social science method the definitions and characteristic of ethnographic research are the topic of much debate. While some stipulate rigid categories, designate strict criteria and assume a single 'disciplinary alliance' (Atkinson 2008), this thesis adopts a broad understanding of ethnographic research as,

'The study of people in naturally occurring settings or 'fields' by means of methods which capture their social meanings and ordinary activities, involving the researcher participating directly in the setting, if not also the activities, in order to collect data in a systematic manner but without meaning being imposed on them externally.' (Brewer 2000, pg 10)

Traditionally rooted in anthropology, seminal ethnographic research studies have provided insight into a range of fields, including emerging adulthood in Samoa (Mead, 1928), the experiences of dying children in America (Bluebond-Langner 1978), and the virtual worlds of Second-Life (Boellstorff 2008) to name but a few. The employ of ethnographic research methods in other disciplines has also produced fascinating insight for business, retail and advertising, increasingly used in market research to gain an in-depth understanding of the consumer (Sunderland 2007, Mariampolski 2005).

Fundamentally ethnographic research advocates the 'first-hand experience and exploration of a particular social or cultural setting' (Atkinson 2008). This can be achieved through the employ of a range of methods, most notably (though rarely exclusively) participant-observation. Hitchcock and Hughes (1995) offer a simple summary of what participant-observation involves,

'Look, listen, ask questions, take part, learn the language, learn and record any specialised kind of language or argot, make inferences from what people say, local informants, develop relationships, become friend and experience different ways of life.' (1995, p120)

In essence the participant observer must immerse themselves in a community, be it a family, a village, a clinical team or a school class. By doing so they have privileged access to information usually reserved for these communities, simultaneously acting as both a participant in the setting and an observer of it. Carnevale and colleagues (2008) recognise the relevance of this method in paediatric health care settings. They suggest that participant-observation rejects the traditional structured interviews that children and teenagers can often find 'socially awkward and intrusive', in favour of multi-method observations, the flexibility of which allow for a relationship to develop and the children and teenagers capacities as social actors to emerge (Carnevale et al 2008). To understand how teenagers, parents and health care professionals understand involvement I needed to maintain an effective and trusting relationship with these parties as they experienced involvement through different decisions at different times.

These relationships took time and consideration to maintain, the regularity of visits aided initial relationship building with teenagers and families. I visited initially for short 5-10 minute periods two or three times a week to check in and say hello. Over time these periods naturally extended as I was asked to sit down, watch a show, or have a cup of tea. I attempted to make myself as

available as possible, while never overstaying my welcome or appearing too overzealous. I considered the mood of each room I entered and reflected that back; I never attempted to engage a happy room in a discussion that was likely to dampen the atmosphere. I was conscious to balance heavy discussions with lighter ones so I was not solely associated with intense conversation. I spoke with teenagers about everything they were willing to discuss, never belittling or patronising a concern or problem, be it to do with treatment, school or relationships.

My relationships with HCP were built largely through a genuine respect for the work they did. I was open to learning from them and being taught by them, they responded well to this and a natural relationship developed with those around me. I was cautious to not engage in the gossip and relationship politics that naturally occur in any workplace. However, I was also very conscious not to completely disengage or cut off these discussions if they occurred around me, as they were integral to being seen as part of a group. A balance was maintained and over time a place for me was forged in the team.

3.1a Use of Multiple Data Sources

This work is thus defined by full time participant-observation, embedding in the clinical team, extensive audio recording and analysis of verbatim transcripts (including nonverbal behaviour recorded during observations), as well open-ended semi-structured interviews, and informal conversations. Fundamental to the research is the use of multiple data sources to provide a comprehensive account of teenagers' involvement. The culmination of these data sources provides access to involvement as it is professed and enacted by all parties involved. While interviews would have provided an account of the views held by participants, they alone would not have been able to capture the interaction that occurred in practice. Similarly, recorded consultations alone would not have been able to record how each party viewed the interaction or decision made. To provide a full account of decision-making both the principles and practices must be uncovered. Throughout this chapter I present the methodological, procedural

and ethical elements of the research project. I will now discuss the stages of this data collection in greater detail followed by closer consideration of the methods employed throughout the research.

3.2 Stages of Data Collection

3.2a Setting

All stages of data collection took place with one teenage and young adult multi-disciplinary care team at one metropolitan, tertiary referral specialist treatment centre. Teenagers received care and treatment across a specialist inpatient ward and a specialist outpatient service. Some HCP worked across these services, while others were exclusively designated to either inpatient or outpatient wards. A community palliative care team from a designated paediatric hospital was also available to those teenagers, between 13-16 years old, recognised as palliative by their health care team. Data were collected from members of this team, at MDTs and on home visits for one teenager who fell in their remit.

In addition, each teenager was designated a local hospital where they were directed if they required medical assistance (blood tests, query temperature) while at home, receiving outpatient treatment. Hospices were also available to teenagers where cure was less likely, only one teenager accessed this service utilising the social activities they provided (trips out, celebrity visits, swimming, cinema). Data was not collected at these local sites or hospices, as decisions of interest to this research were not routinely made at these sites. Further, the teenagers and families in this study spent minimal time at these sites.

3.2b Stage 1 – Health Care Professionals

The data set included (i) 8 in-depth interviews with HCP working with teenagers with cancer and (ii) field notes from observations of 12 meetings held by over a one month period by the Teenage and Young Adult multi-disciplinary care team

at one tertiary referral specialist treatment centre (Day et al 2014, Day et al 2015). Data collection for Stage 1 informed the direction of Stage 2.

3.2c Stage 2 – Decision-Making in Principle and Practice

Phase 1: Embedding of researcher – 2 weeks

Data collection for Stage 2 commenced with an initial period focusing on the health care team, prior to the recruitment of any teenagers and families. I attended multidisciplinary team meetings; pre and post ward round meetings, ward rounds themselves and day care meetings of the teenage and young adult haematology team and the palliative care team serving the research site. This initial period enabled me to embed myself in the clinical team, immerse myself in the care environment, and becoming familiar with the daily running of the inpatient and outpatient wards. Allowing time to embed in the clinical team and familiarise myself with the research setting also reduced the impact my presence had on the delivery of care. Consultants and nursing staff quickly came to ignore my presence during consultations. As with most ethnographic research I experienced this setting as an outsider, gradually learning the rules, order and language of the clinical world. Over this initial period, and throughout the research, a place was forged for me within the team and within the lives of the teenagers and families. Managing these relationships and maintaining a non-interventionist stance became increasingly challenging the longer I remained in the field, something I discuss in more detail later.

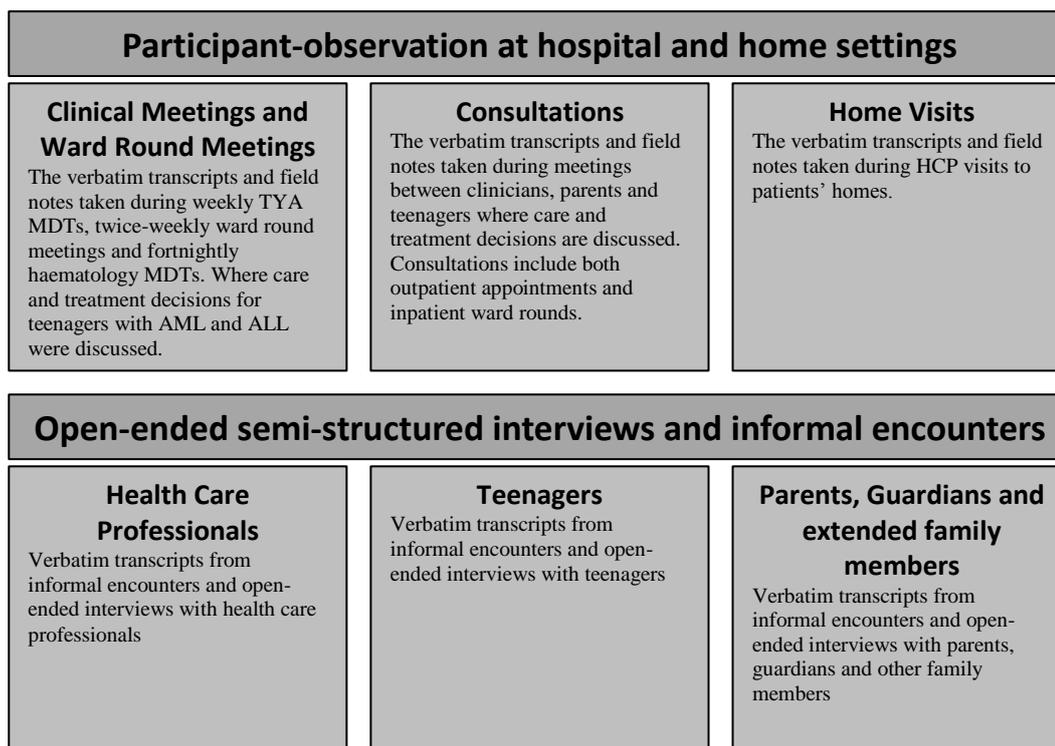
Phase 2: Teenager and parent recruitment – Month 1-8

During phase 2, I began to recruit teenagers and their families to participate in the study in accordance with the eligibility criteria outlined below. This phase commenced after 2 weeks in the field and ran alongside phase 3 (see below). I discuss the procedural aspects of recruitment in more detail in a later section.

**Phase 3: Participant-observation, informal discussions and interviews–
Month 1-9**

Following the recruitment of teenagers and parents I regularly attended consultations between the health care professionals, teenagers and parents where care and treatment decisions were discussed. I also continued to attend pre-ward round meetings, psychosocial MDTs and clinical MDTs [See Appendix II Glossary for Medical Terminology and Clinical Meetings]. In addition, I met with families, teenagers and health care professionals before and after consultations to discuss care and treatment options and their views of what had transpired. I also conducted more formalised interviews with participants to discuss the decisions they were making and their view on their role in those decisions.

Figure VI. Overview of the Dataset



The complete data set is therefore comprised of several elements observational field notes, verbatim transcripts of conversations between teenagers, parents and health care professionals, semi-structured interviews, and informal discussions pre/post consultations. These elements combine to offer accounts from parents, health care professionals and teenagers regarding involvement in principle and prospective accounts of the interaction of these three parties in practice.

3.3 The Methods of Data Collection

3.3a Participant-observation

Participant-observation took place in different settings including: MDT meetings, consultations between parent, teenagers and clinicians, ward rounds, and pre and post consultation discussions. These observations occurred in teenagers' rooms, meeting rooms, the ward kitchen, staff rooms, patients' homes, in the lift and in the corridors. Table III details these observations of team meetings and consultations.

Table III. Observations Over 9 Months of Data Collection

a. Team meeting observations

Type of MDT	Number of meetings attended	Number of patient specific discussions recorded
<i>Teenage and young adult MDT</i>	21	9
<i>Paediatric and young adult haematology MDT</i>	3	5

Type of MDT	Number of meetings attended	Number of patient specific discussions recorded
<i>Day care MDT</i>	22	30
<i>Palliative care MDT</i>	6	6
<i>Ward round meeting</i>	52	107
Total	98	157

b. Consultations

Type of Consultation Observed	Total number of consultations recorded
<i>Inpatient ward round consultation</i>	128
<i>Outpatient consultations</i>	12
<i>Clinical home visits</i>	7
Total	147

At times all three parties (teenagers, HCP and parents) were present together, at others discussions occurred independently with parents and teenagers away from HCP, or between HCP away from teenagers and families.

The aim of observation is to provide meticulous documentation of an interaction: those who are present and the words, actions (including non-verbal signals) and behaviours of all present. Observational focus was placed on the contributions teenagers, health care professionals and parents made in

discussions. I initially set out with a host of open questions about what was happening during these interactions. If, when and how was the teenager invited to speak? What were the differences in topics of discussion? If, when and how did the teenager volunteer a contribution independently? If the teenager was not present did the other parties make reference to what the teenager wanted? How was this done? What was different and similar about the consultations where teenagers were present and vocal and those where they were not? Did the teenager rely on verbal or non-verbal communication? Did parents and health care professionals interrupt the teenager? Did they explicitly ask for the teenager's involvement? Did the teenager comply? These questions guided my initial observations, helping me build a picture of what was happening between and within these groups in practice.

Participant-observation is marked by a researcher's immersion in the setting they are observing. Immersion in the clinical setting in which I conducted the study served a dual purpose. Firstly, it allowed me to learn the structure and routines of the research site, specifically the haematology and palliative care services. Secondly, immersion in the setting allowed the health care team to become familiar with what I, as an ethnographer, would do, adjusting to my presence in meetings and consultations. Both helped reduce the potential disruption of an 'outsider' in the field, allowing me to obtain realistic and true-to-life accounts of practice while health care professionals simultaneously continued to provide their clinical service.

During the course of my field work my initial role as an 'outsider' within the clinical team developed. At points I was cautious that I had become embedded to the extent that I was increasingly viewed as an active member of the clinical team. After several months I was gradually recognised as a potentially useful source of information on teenagers, families, and psychological treatment. I was called on in meetings to provide information or for my opinion on a course of action, a request that I denied each time explaining my non-interventionist role. Similarly, over time I was given minor jobs to assist the team, from turning on

the projector in meetings, carrying folders, collecting medicines to relaying messages from HCP to HCP. I took these requests as an acknowledgement of my acceptance into the setting, I was recognised as a useful, reliable and perhaps more importantly, constant member of an ever rotating team. Managing these roles as they were shaped and developed through interaction was paramount to my success as an ethnographer.

3.3b Open-Ended Semi-Structured Interviews and Informal Discussions

A crucial element of this research that makes it distinct from existing research was the prospective and on-going nature of data collection. Informal conversations and more structured conversations were had with all participants throughout the data collection period. Table IV separates these informal encounters by participant group.

Table IV Informal encounters and interviews over 9 months data collection

Participant Group	Total Number of Informal Encounters Recorded
<i>Teenager</i>	86
<i>Parent/ Guardian</i>	67
<i>Extended family</i>	6
<i>HCP</i>	94
Total	253

Participants were asked about decisions before making them, as they were making them and after making them. It is through these audio-recorded interviews and the informal encounters before and after observations, that I was able to uncover how each party understood participation in principle.

3.3d Review of Policy Statements and Guidelines

The data set also includes a review of the local policy documents and guidelines for health care professionals about involving teenagers in decision-making regarding care and treatment as discussed in the previous chapter.

3.4 Conducting participant-observation, informal encounters and semi-structured interviews

To successfully carry out participant-observation in such a busy and transient setting I was required to be present on the wards as much as possible. Learning the routine of the ward and the team was central to the success of the project. This team conducted twice-weekly ward rounds on Tuesday and Friday, had MDT meetings on Wednesdays and day care clinics on Thursdays. It was this routine that structured my days and weeks during data collection. Monday was the only day where nothing was routinely scheduled and I attempted to keep this day as an 'office day', invariably though this day was taken up by home visits and impromptu meetings. Outside of scheduled meetings and ward rounds additional meetings and consultations were held. I was reliant on participants informing me of these impromptu or 'unscheduled' meetings, HCP, teenagers and family members would send a text or let me know at an earlier meeting that a consultation was due to take place. Where possible the team would avoid big discussions or decisions out of hours (approx. 8am-6pm) when the multidisciplinary team were unavailable. Occasionally however, consultations would be held late at night or over the weekend; often these were due to deterioration in condition or emergency. In such emergency situations I was, rightly, not informed as the on-call team had other priorities, alongside the rest of the MDT I was informed of these consultations retrospectively at the next meeting.

Where possible I went to see teenagers and their families before the ward round entered and stayed after they had left. This became a routine that teenagers and parents expected over the course of the study. On occasion it

was not possible to attend before or stay after as the pace of ward round meant I would miss other consultations to do so. In these cases I would return later in the day to talk with the teenager and/or family about what had been discussed and generally how they were feeling about treatment and decisions that had been made. I had informal conversations with HCP before and after meetings, in the doctors' mess and walking between hospital sites and patient rooms. The structure of MDTs and ward rounds also meant there were often periods where conversations broke off or HCP were waiting for notes to be located or other members to arrive. I took advantage of these brief lulls and engaged HCP in discussions during these periods.

For the more formalised semi-structured interviews an interview guide was used, shaped by the findings that emerged throughout the observational component of the research, as well as the findings of the first stage study and from existing literature. The guide included questions that encouraged participants to reflect on the decisions they were making and the roles each individual plays in the process [See Appendix III Interview Guides].

This guide was used throughout the research and broadly directed discussion in many of the informal encounters with teenagers, parents and health care professionals. Conversations ranged from free flow chats about anything the participant wanted to share to more directed conversations that covered topics in the interview guide. Due to the regularity and frequency of these informal discussions for many participants the questions from the interview guide were asked as and when they became relevant over the course of 9 months of informal visits. It was quickly apparent that for some teenagers, families and HCP a sit down formal interview away from their parent/ child/ work commitments was not feasible. Therefore special effort was made in these instances to cover interview topics during informal discussions.

I entered every interaction with an audio-recorder, a notebook and a pen. For informal conversations and interviews I would rely on the audio-recorder alone, to enable a more fluid conversation notes were not taken during these encounters. Immediately after these interactions I would write a summary of the discussion, any key points and any questions the discussion raised for exploration later. For consultations, I would take notes during the interaction, beginning each with a list of those present and a brief illustration of their position in the room. As the interaction unfolded I would pay attention to the non-verbal signals, the eye contact and facial expressions of those present. As with the informal conversations, following each interaction I would note any key points or questions raised by the consultation.

These field notes would amass over the day. At the end of each day I would return to the office, upload the audio-files and transfer my notes to a detailed case log. It was from this log that I was able to see how the data set was growing and keep track of each and every encounter over the 9-month period.

3.5 The Participants

This project focused on several inter-related groups of participants, teenagers themselves, parents and guardians of teenagers and health care professionals working with teenagers. Table V details the recruitment figures by group.

Table V. Study Recruitment Figures

<i>Participants</i>	<i>Total Number recruited</i>
Health Care Professionals	60
Parents	10
Teenagers	7
Other family members	4

Table VI. details the pseudonymised names, ages, diagnoses of teenagers and their family members.

Table VI. Overview of Recruited Teenagers and Families

Teenager	Age (years)	Diagnosis	Family	
Anwar Passi	14/15	Relapsed ALL	Mum	Saanvi Passi
Poppy Conteh	17	AML subtype	Mum	Nadia Conteh
			Dad	Adam Conteh
Masood Farran	16	Relapsed ALL	Mum	Samina Haider
			Dad	Abdi Farran
			Sister	Taalial Rossi
			Brother-in-law	Jac Rossi
			Family Friend	Anna Awzi
Tom Stephens	19/20	Relapsed AML	Mum	Jane Stephens
Harry Bukoski	15/16	Relapsed ALL	Mum	Karina Bukoski
			Dad	Adrian Bukoski
Becky Aldea	17/18	ALL	Mum	Dana Aldea
			Dad	Raul Aldea
George Mirzaei	17	ALL	Mum	Jasmine Mirzaei

Table VII details the names and profession of all HCP referenced in this thesis. As with teenagers and families pseudonyms have been used.

Table VII. Overview of Health Care Professionals Referenced in this Thesis

Name	Job title	Speciality
Dr Joanna Clark	Consultant	Haematology
Dr Claire Talbot	Consultant	Haematology
Dr Adam New	Consultant	Haematology
Dr Lindsey Philips	Consultant	Palliative Care/ Symptom Control
Dr Mark Charwood	Consultant	Haematology
Dr Evelyn Carter	Consultant	Oncology
Sophia Wright	Clinical Nurse Specialist	Haematology
Julie Taylor	Clinical Nurse Specialist	Haematology
Charlotte May	Clinical Nurse Specialist	Palliative Care/ Symptom Control
Ava Darby	Clinical Nurse Specialist	Palliative Care/ Symptom Control
Olivia Curtis	Clinical Nurse Specialist	Haematology
Megan Jones	Clinical Nurse Specialist	Palliative Care/ Symptom Control
Josie Page	Ward Nurse	TYA Oncology
Ella Fairburn	Ward Nurse	TYA Oncology
Mia Garner	Research Nurse	TYA Oncology
Dr Dora Kamdar	Senior House Officer (SHO)	Haematology
Dr Scott Cowel	Senior House Officer (SHO)	Haematology
Dr Anup Moore	Senior House Officer (SHO)	Haematology

NB: Pseudonyms used for all participants.

The names presented here are not an exhaustive list of those HCP recruited, nor does Table VI reflect the teenagers complete family unit, just those regularly present on the ward and included in this study. Table VIII outlines the contribution of each family to the overall data set.

Table VIII. Contribution of Each Family to the Overall Data Set

a) Consultations

Family	Number of inpatient consultations observed.	Number of outpatient consultations observed.	Number of consultants where teenager was present	Total number of all consultations observed.
Anwar Passi and family	23	8	25	31
Poppy Conteh and family	3	5	8	8
Masood Farran and family	16	N/A	11	16
Tom Stephens and family	17	5	22	22
Harry Bukoski and family	33	N/A	33	33
Becky Aldea and family	12	2	14	14
George Mirzaei and family	26	N/A	24	26

b) Interviews and Informal Conversations

Family	Types of decisions faced by the family over the course of the study	Number of informal discussions family participated in.	Number of interviews family participated in.
Anwar Passi and family	Feeding Place of Care Symptom Control	20	0

Family	Types of decisions faced by the family over the course of the study	Number of informal discussions family participated in.	Number of interviews family participated in.
	End of Life Care and Treatment		
Poppy Conteh and family	Place of Care Participation in a Clinical Trial Symptom Control	24	1 teenager 1 parent
Masood Farran and family	Feeding Place of Care Participation in a Clinical Trial Symptom Control End of Life Care and Treatment	21	1 family interview
Tom Stephens and family	Feeding Place of Care Stem Cell Transplant Symptom Control	27	1 teenager
Harry Bukoski and family	Feeding Place of Care Stem Cell Transplant Symptom Control	33	1 teenager
Becky Aldea and family	Feeding Place of Care Participation in a Clinical Trial	7	0
George Mirzaei and family	Feeding Place of Care Participation in a Clinical Trial Symptom Control	15	1 teenager 1 parent

As is evident some teenagers and families contributed more to the dataset than others, for reasons relating to their availability, accessibility, English language comprehension and general engagement with the study. Below I outline the characteristics that determined inclusion for each group of participants. Summaries have been kept brief and intentionally vague to protect the anonymity of participants.

3.5a Teenagers

As detailed earlier [Teenagers with a Leukemic Diagnosis. Chapter 2], the patient population for this study was teenagers diagnosed with either Acute Myeloid Leukaemia (AML) or Acute Lymphoblastic Leukaemia (ALL). Teenagers were between the age of 13 years and 19 years at the point of recruitment and were able to provide consent (over 16) or assent (under 16) to participate in the research study. Teenagers were eligible for inclusion at any point in their disease trajectory, as I was interested in decisions across the trajectory relating to, feeding, symptom directed care, disease directed care, transplant, clinical trials, end of life, and place of care.

Initially recruitment of ALL patients was focused exclusively on those who had relapsed, however several months into data collection eligibility was extended to include teenagers from point of diagnosis. By including teenagers who were recently diagnosed I was able to increase participant numbers, as well as gather information relating to phase III trial decisions which often happened prior to relapse. All teenagers who were eligible were approached, and all who were approached agreed to participate in the study. No teenager chose to withdraw from the study.

3.5b Parents and Family Members

Parents and guardians were eligible for inclusion if they had a child between the age of 13 years and 19 years at the point of recruitment who was receiving care and treatment at the research site. I was responsive to the realities of family systems and networks, recognising that other adults were often involved in the teenagers care and thus engaged with the decision-making process. This included extended family members, such as, stepparents, older siblings or close family friends with a prominent care-giving or supportive role. These individuals were therefore also offered the opportunity to participate in the research project.

All parents and family members that were eligible and present over the course of the study were approached. Three fathers were not approached for participation due to lack of presence on the ward and opportunity to discuss the research. One father declined signing the consent form for the study stating he would not be present as much as his partner would be. I was conscious of respecting family dynamics, cultural practices and each participant's unique situation; consequently I did not push for participation in instances where such a delegation was made. No parents or family members chose to withdraw from the study.

3.5c Health Care Professionals

All health care professionals at the primary research site who were engaged in discussions related to decision-making for 13 to 19 year olds with leukaemia were considered eligible. Members of the community palliative care team who began caring for a teenager already in the study or eligible for inclusion in the study were also deemed eligible. The realities of clinical practice often made the process of formally consenting health care professionals in the field a challenge, as I discuss in the next section in more detail. No health care professionals refused to consent to participate and no health care professionals chose to withdraw from the study.

3.6 Recruiting the Participants

3.6a Consenting to Participate

In line with ethical guidance, formal written consent was sought from all participants in the study. Detailed guidance was drawn up to address the situation of a teenager, parent or HCP losing capacity to consent, wishing to withdraw from the study, or there was a disagreement between a teenager and their family with regard to participation. As no participant lost capacity or withdrew from the study this guidance is not presented here but can be found in Appendix V. Below I present my recruitment practices for each of the three groups of participants alongside reflections of specific challenges relating to each group.

Health Care Professionals

Many health care professionals were recruited initially during Stage 1 research. During this first stage HCP signed a register at each MDT to consent to participation. Since Stage 2 followed almost a year later, HCP were again consented to participate in this second stage. Clinicians' consent was largely sought prior to the recruitment of teenagers and families so as to minimise the disruption once the study had begun recruiting these participants.

Before the commencement of fieldwork I presented the research at several key meetings attended by members of the wider clinical team. Following these presentations, health care professionals received written information about the study, including notably the aims and objectives of the study, the fact MDTs and consultations would be audio-recorded, and recruitment procedures for teenagers and families [See Appendix VI Participant Information Sheets]. In addition staff received this information via a weekly email that was circulated to the MDT. Consent forms were returned at weekly MDTs and twice weekly ward round meetings.

However, due to the nature of shift work, staff rotation, annual leave and sick leave it was recognised that recruitment of HCP would be on going throughout the study. Information sheets were distributed to any new staff that joined the team or rotated in after this initial period of information giving. For those that were not consented at the outset, written consent was sought as soon as possible.

When a HCP Did Not Give Consent

There were instances where written consent was not obtained from health care professionals to participate in the study. Although I always strived to make my presence and intentions known to the room, invariably there were those who were unfamiliar with the specifics of my role and those who had not provided 'formal consent'. To interrupt a consultation or MDT and explain my study or request written consent would be inconsistent with the fundamental conditions of my presence—not to disrupt on-going routines of practice.

Obtaining consent is a familiar challenge for researchers employing ethnographic methods in busy and transient settings (Mulhall 2003, Moore and Savage 2002, Dewalt and Dewalt 2002), with many recognising that rigorous and pre-determined consenting can damage rapport between researcher and participant and ultimately affect the quality of data collected. I took the position that in order to build successful and informative relationships with the health care professionals in this study I could not fixate on whether or not I had a signature, supposedly recognising their full informed consent to participate. For the exhausted registrar who had to apologise for a third time for misplacing her consent form I did not continue to press her. Similarly, for the consultants and nurses who 'popped in' to MDTs and ward rounds I did not follow them each out to inform them of the study and the fact they had been 'caught' on my audio-recorder. The majority of health care professionals I encountered were aware I was a researcher and that I was audio-recording MDTs and consultations, no objections were made and verbal consent was often given. As with any

ethnographic work a balance was struck between obtaining 'formal consent' and maintaining a non-intrusive relationship with the field and those in it.

Teenagers, Parents and Family Members

Consultants and clinical nurse specialists (CNS) identified eligible families as they were admitted to the hospital or at twice weekly ward rounds. I attended these meetings throughout the data collection period, taking notes and audio-recording discussions within the team of eligible patients. Since data collection for some families began prior to these patients and families giving their consent approval was sought from the Health Research Authority Confidentiality Advisory Group (HRA-CAG) for this temporary holding of personal information prior to consent.

Once a family was identified as suitable for inclusion, with the permission of the health care professional leading the consultation, I attended the next consultation or informal bedside visit with the family. At this meeting the health care professional introduced me as a researcher working as part of the team, they would explain that I was working on a project about decision-making and as part of this would like to sit in on the consultation, audio record the meeting and will explain the study later. The clinician asked the parent/ guardian/ teenager if they were happy for me to stay, take notes and audio record. All families and teenagers were happy with me staying for this initial consultation. Following this consultation teenagers were provided with information sheets and given 2-3 days to read through them before I returned [See Appendix VI]

On occasion, my role and the fact I was audio recording was not fully explained during this first meeting. Becoming embedded in the team meant health care professionals often took my presence for granted and did not introduce me at the outset. In such instances I would stay behind, when appropriate, either alone or with a CNS and introduce myself, provide information verbally and information sheets [Appendix VI] and later return for written consent.

Previous research investigating recruitment bias in research with very sick children found evidence of selective invitation practices by clinicians (Crocker et al 2015). Therefore, I was conscious that more traditional methods of recruitment where clinicians participated in sample selection could have biased my sample. Consenting teenagers and parents was the responsibility of the researcher alone, HCP were not responsible for providing information about the project or for obtaining consent. Approaching parents, family members and teenagers the way this research did ensured that all eligible families were given the opportunity to participate in the study.

General Medical Council guidance on assessing capacity to consent 0-18 year olds (GMC, 2007) was referred to, to incorporate procedures supported at a national level. The procedures we adopted for research participation complied with policy in place at the research site.

3.7 Ethical and Institutional Approval

Here I present some of the ethical considerations for the research project. Due to the nature of the research and the age and health status of the teenagers, the study required an extensive amount of consideration to ensure multiple advisory bodies were satisfied that the research could commence without 'harm' to any participant.

To conduct any form of research with clinical populations in England a number of criteria must be met to ensure researchers have considered the safety and wellbeing of their participants as well as the utility of their research. A research project that proposed an iterative process of data collection, employing participant-observation with very sick children and teenagers had to be well planned and articulated to gain approval.

3.7a Approval for Stage 1

Deemed a more straightforward interview and observations study including HCP exclusively only basic approvals were required. The University Ethics Board, the relevant Research and Development departments and a local hospital research group reviewed Stage 1 of the research.

3.7b Approval for Stage 2

Stage 2 underwent review with NHS Ethics Committee, Confidentiality Advisory Group (CAG), the site specific Caldicott Guardians, the relevant Research and Development departments and a local hospital research group.

Whilst the majority of these review bodies are familiar to those conducting research within the NHS, the confidentiality advisory group is less widely used. Section 251 of the NHS Act 2006 stipulates that common law duty of confidentiality can be temporarily lifted to allow the transfer of confidential information to an applicant. The CAG is an advisory body that considers applications from researchers to ensure that research has an interest in improving patient care and complies with the Data Protection Act 1998. CAG allowed this project to access confidential patient information prior to receiving consent. As a result, I was able to attend MDTs and consultations prior to receiving consent from teenagers and parents.

Applications to each body required extensive consideration and several problems were encountered through the process.

3.7c Problems Encountered and Solutions Found

From the outset I was aware that this methodological design would not align with the pre-defined template for research within the NHS. I was tasked with

formulating a prospective, participant-observation study in an environment where retrospective interview studies or questionnaire-based research is the norm. Discussion with the ethics committee as well as with individuals who had received ethical approval for such research highlighted some of the difficulties designing and implementing this kind of research with seriously ill teenagers.

Unlike interview or survey research, this project could not offer a pre-determined plan of what exactly would be discussed with participants over the course of the study. Fundamentally, those involved would lead the research, through the experiences they had and their engagement with me as a researcher. Although the practicalities of the work were clearly designed and an interview guide was formulated, nothing could anticipate the day-to-day conversations and encounters I would have with participants.

Similarly, though the decisions I was interested in could be clearly articulated to a committee, they could not be disclosed to teenagers and families. I could not foresee with certainty which decisions teenagers and families would be presented with, nor was I willing to pre-emptively inform teenagers of the fact they may be facing transplant or end of life decisions down the road. As a result, the project carried with it an unavoidable degree of uncertainty and ambiguity, something that is not favoured for work with 'vulnerable' populations within the NHS.

Input and advice from teenagers diagnosed with cancer and parents with a child with a cancer diagnosis helped reiterate the need and acceptability of the research.

3.7d Role of PPI in Research Design and Documentation

It was important that the research was reviewed and approved by teenagers and young people with a cancer diagnosis and parents of a child with a cancer

diagnosis. Obtaining feedback from these groups was crucial to ensure that the research was relevant and acceptable to the populations the research intended to serve.

Information sheets and consent forms for both parents and teenagers were sent to an advisory group of parents with a child diagnosed with cancer. This group was a pre-formed advisory group that welcomed information sheets via email and provided feedback via email. Information sheets for teenagers were distributed to a group of 15 teenagers and young people diagnosed with cancer, at various stages in their trajectory. These teenagers and young people were attending a workshop for young people with a cancer diagnosis and welcomed the chance to review the documents; they provided feedback via feedback sheets.

Feedback from both groups was positive, with the majority of parents and young people supporting the need of a project investigating the role of teenagers in decision-making. The parent group felt that all information sheets were 'well written and presented in a good clean style' they stated that 'there was enough information without it being too much to take in and no jargon terms'. As a group they concluded that they would 'be happy to be involved if approached'. They suggested that the original short title on all information be changed from 'Medical Decision-Making with Teenagers' to something less clinical; therefore the term 'Medical' was dropped on all information sheets.

Parents suggested that a paragraph on who I was and what my research interests were would be desirable, so parents know a little about the researcher who will be conducting the project. As a result, such a paragraph was added to the parents' information sheet.

Parents felt there needed to be more explanation for teenagers about the materials that would be produced from the project. This was difficult to fully illicit

it was unclear prior to data collection what kind of specific recommendations and documentation the project would produce. Secondly they felt that both documents ended abruptly and a summary or closing paragraph was required. This was added into both documents.

Initially there were two information sheets for teenagers, one for 13-15 year olds and one for 16-19 year olds. Following feedback from both the parent group and the teenage and young adult group it was decided that only one information sheet would be developed. The information on each was very similar; therefore the two information sheets were combined creating one sheet, which was suitable for all teenagers.

The feedback from the teenage and young adult group was also positive, with majority stating they were happy with the way teenagers would be identified and approached, and would be willing to participate. Minor changes were made to the design of the information sheet, including the addition of colour, emphasis of information in bold font and the removal of underling.

Teenagers also identified some changes they would like to see in the content of the information sheets. For example, the wording of one section was changed from 'I would like to sit in on your meetings' to 'If it's ok with you and your parents I would like to sit in on your meetings...' to make it sound less intrusive. On request of both young people and parents, 'young people' was placed first in the list of all involved, to emphasis their importance [the term teenager was not used on the information sheets, the decision to utilize this term was made after information sheets were produced].

There were some changes and additions that could not be incorporated. For example, the request to add a section on eligibility or on the possible decisions that could be made with this patient group could not be included. This is because it was considered essential that information about the diagnosis or any

potential future decisions should come from the medical team alone, it would not be appropriate to list a series of decisions (sperm banking, transplant, stopping curative treatment etc.) that the teenager may or may not face over the course of their treatment.

Finally, since the majority of teenagers and parents would be happy to participate and believed others would be too, no major changes to the study were made. However, in line with recommendations from teenagers, attention was paid to ensure that no one felt pressured to be involved in the study, and enough time was given to discuss and consider participation.

Through a carefully considered protocol, informed discussion with the reviewing ethics committee and an overriding commitment to avoid burden or distress for teenagers and their families, the project was approved.

3.8 Analysis

Just as the research had to be designed in a way to answer the question, so too was the analytical framework chosen to best meet the aims and objectives of the research. Here I present the principles on which analysis is based, before moving on in the following chapters to discuss my research findings.

3.8a Use of Grounded Theory

The principles of grounded theory form the basis for analysis of this data and have been adopted throughout the research project not exclusively the analysis phase, (Kennedy & Lingard, 2006). There are a number of variants of the “grounded theory” model, however all models encourage reflection on both the conditions of a situation and the ‘actors’ within the situation, as well as the interaction between these ‘actors’ (Corbin and Strauss 1990). Consequently, grounded theory is often called upon in research such as this where focus is

placed on the interaction between individuals in specific environments (Grbich, 2013). Grounded theory has developed since the traditional model proposed by Glaser and Strauss, and several variants now exist in the literature (Charmaz, 2007).

This research project aligns more closely to the Glaserian model of grounded theory, or 'Classic Grounded Theory', than those proposed by Strauss, Corbin or Charmaz. As such, focus is placed on the discovery of emergent directions in the data rather than the verification or hypothesis testing associated with Strauss and Charmaz (Grbich 2013). In line with Glaser two types of coding are called on namely substantive (I-codes) and theoretical coding (A-codes), I discuss this in more detail in the following section. In short, openness and creativity rather than a rigorous and prescriptive analytic process was favoured (Cho and Lee, 2014).

The role of the researcher is an important consideration in grounded theory. Whilst I acknowledge my 'inevitably biased' (Grbich 2013) role as a researcher in the research process, in line with Glaser I view the researcher's role as that of a receiver of information (Glaser 2002), 'one where there is minimal intrusion of their own predilections' (Grbich 2013: 82) during both the analytic and data collection process. Participant-observation based ethnographic data collection methods require the careful balancing of observing interactions and participating in the setting as an embedded researcher. I made a great effort to embed myself in the setting so as to reduce this intrusion from the offset, and as I go on to discuss great effort was made to minimise the intrusion of my own predilections throughout data collection and analysis.

The timing of a review of the literature is a key difference that many cite between the variants of grounded theory (Evans, 2013). Many suppose that Glaser rejected examination of the literature prior to data collection (Evans, 2013) suggesting the review of literature should be delayed until after an

emergent theory is sufficiently developed. However, careful reading of his work highlights his recognition of the importance of early reading of the literature to develop the researchers' theoretical sensitivity (Glaser, 1978). The aforementioned systematic review guided my focus, highlighting the need for prospective research that included the teenagers' perspective over time. Data collection and analysis was consequently seen as an iterative process, pre-existing literature, first stage research and findings throughout the study guided theoretical sampling at recruitment, data collection and analysis. I discuss the extent to which theoretical sampling was possible in Chapter 8, in a reflection of the study's strengths and limitations.

Glaser and Strauss's original text paid 'little attention to the process of coding' (Berks and Mills 2000), however recent texts have afforded more detail to the methods of coding. These processes vary across scholar, time, and text; below I present the process of data handling for this research project.

3.8b Handling of Data

Glaser writes, the researcher 'should simply code and analyse categories and properties with theoretical codes which will emerge and generate their complex theory of a complex world' (Glaser 1992: 71). Aiming to stay true to the sentiment whilst recognising the requirement for a description of analytic method I present here the process of data handling.

All data including audio-recorded transcripts from MDTs, consultations and semi-structured interviews, field journals from participant-observations and notes from medical record review were entered into NVivo (Version 10.1). NVivo is qualitative analysis software that allows the researcher to input, index, code and analyse qualitative data from a variety of sources. Data were initially indexed and later coded to identify preliminary concepts within the data. It is important to note that a decision was made to analyse HCP' data together rather than by distinct professional group, similarly, data from family members

and parents were analysed together. HCP in this study worked as part of a close knit and united team. Consultants, ward nurses and CNSs demonstrated a particularly close working relationship; it therefore seemed inappropriate to separate a team in analysis that presented such a united front in practice. Parents and family members also presented as a united and close-knit unit; additionally there was not sufficient numbers of parents and family members recruited independently to justify analysis by distinct groups. The impact of this decision is discussed in strengths and limitations in Chapter 9.

Importantly, in line with the fundamental tenants of grounded theory, analysis began while I was still in the field, prior to the more formally recognised analysis period (after all data has been collected). Ideas, questions and early codes were noted and logged throughout data collection. This inductive approach allowed for concepts and ideas to emerge without any a priori assumptions regarding involvement of teenagers or what involvement should look like in principle or practice. Crucially, understandings of involvement were not restricted at the outset to any one specific ideal (amount of speech during consultations, for example). In line with Glaser's definition of grounded theory as an inductive-deductive mix (Glaser 1992), deduction occurred later in the process on emerging questions and patterns, I offer an example of the process towards the end of this section.

Once I had left the field I began with indexing (I-coding the dataset). Each transcript was read and, using the features in NVIVO for marking off and "tagging" portions of text, "I-codes" from the codebook were applied. I-codes included the disease, the time point in the trajectory and the decision discussed. The I-codes that were developed for this data set allowed navigation through the data set in a systematic manner, retrieving the text needed to answer the research questions. It also allowed for the scope and depth of the data on any given issue and any given decision to be immediately identified (place of care decisions for teenagers with ALL, for example). It allowed for the retrieval of all data (including consultations, informal encounters, and interviews) where

decisions regarding care and treatment were discussed for each disease group, at each point in the trajectory. This method of data reduction was essential to par down the vast data set for further analytic coding (Ritchie and Lewis, 2003).

Once the I-codes were applied the information relevant to each decision was read for the development of interpretative codes (referred to here as “A-codes”). Line-by-line coding was carried out, with these codes focused on more analytical tagging of the data to develop key ideas that were initially flagged through notes and memos in the field. These codes were refined and categorised as analysis continued. A codebook (see Appendix IV Analysis Codebook) was kept detailing these codes and categories, this allowed for the codes grouped under each category heading to be clearly visualised for other researchers. Definitions are also outlined, and transcript extracts exemplifying each code are recorded so codes are transparent to other researchers and any subjective assumptions can be highlighted. Codes and ideas were constantly compared with one another identifying similarities, differences and relationships allowing for continued development and refinement of ideas.

Here I illustrate the process using one example from analysis. Early memos suggested that “doing what the teenager wanted” was integral to many individual’s understanding of involvement in decision-making. This idea emerged more explicitly from interview and informal conversation data; coding highlighted that this (among others) was a central principle of involvement for HCP, parents and teenagers. The understandings held by HCP, parents and teenagers regarding this principle were compared and contrasted; similarities and differences were identified (see Chapter 4 – 6). This was repeated for all other emergent principles.

With a foundational understanding of each party’s principles of involvement analysis took a more deductive turn. As stated, principles from each party were compared, contrasted and classified into four core groups. This classification

was necessary to deal with the enormity of data that was collected; it was not feasible to consider each individual principle from each party separately in practice. By grouping principles under four key principle categories we were able to take the central ideas forward and focus on the enactment of these categories in practice. Table XVI demonstrates how these principles were grouped, this table is presented in Chapter 7 at the point where principles meet practice. It has not been reproduced here in full, but an extract relating to one principle is presented below. Analysis of consultation observations began with these categorised principles of involvement; focus was placed on how these principles, which emerged through analysis of interviews and informal conversations, were enacted in practice.

Extract from Table XVI. Teenagers, HCP and Parents Principles of Involvement as Identified in Chapters 4-6 Categorised into Four Distinct Groups – Acting on the care and treatment preferences of the teenager.

Group	Principles of involvement as reported in earlier chapters.		
	Teenagers (See chapter 6)	Parents (See chapter 5)	HCP (See chapter 4)
1. Acting on the care and treatment preferences of the teenager	Acting on the care and treatment preferences of the teenager	Acting on the care and treatment preferences of the teenager	Acting on the care and treatment preferences of the teenager
	The significance of chronological age	Recognising the Family Unit	

The table above highlights how one group was formed from principles and factors articulated in earlier chapters. This idea of involvement as ‘acting on the care and treatment preferences of the teenager’ was refined as questions were

asked of the consultation data such as, when was preference sought, why was it sought, what was the teenagers' response, what was the HCP' response, and what was the outcome. Further codes emerged demonstrating the communication practices used by each party to enact, facilitate or reject this idea (and others as they emerged) of involvement. This process of identifying relationships and questioning assumptions led to the development of understanding regarding this and several other aspects of involvement. The result was a collection of codes (i.e. seeking a preference for care or treatment, stating a preference for care and treatment, bargaining) that grouped to form several categories (i.e. HCP communication practices: acting on the care and treatment preferences of the teenager, teenagers' communication practices: acting on the care and treatment preferences of the teenager) under a core concept of involvement (i.e. acting on the care and treatment preferences of the teenager).

This concept of involvement and the codes and categories that underpin it were compared with others that emerged in a similar fashion. Relationships between each emerged allowing for the development of a conceptual model demonstrating how principles come together, immutable factors act on these principles, and communication practices are employed. The process of constantly comparing and verifying each relationship and interpretation, grounds resulting theory (presented in the following chapters) directly in the data with clear evidence as to how the voices and perceptions of those researched link and contribute to the final conclusions drawn.

3.9 Personal Reflections

Alongside the formal ethical guidelines and boundaries I too bought my own notions of what was acceptable for me in the field. While I was there to conduct participant-observation and engage participants in informal discussions about teenagers' involvement in decision-making, for participants I was viewed in many roles. For parents and family members I was a shoulder to cry on, and

someone to voice their frustrations or worries. For teenagers I was someone to talk to about anything from treatment options to the latest school crush, a friend to watch films with and help with revision. For health care professionals I was a silent sounding board, a colleague to accompany them to consultations and often a mentee.

Interestingly, while HCP occasionally requested information from me about teenagers and families, teenagers and families themselves never requested any information from me about what was discussed in their absence. Despite teenagers' and families' awareness that I was present at HCP meetings I was never called on to relay information, nor was I considered to know any more than the teenagers themselves. Negotiating these roles and maintaining the trust and confidentiality of all parties over the course of data collection was paramount to the success of the project.

There were instances when my role as an observational researcher was disrupted and I was pulled into the foreground of MDTs or bedside visits. For example, occasions where HCP would call on me for advice or comment on a teenager's care, or where a mother would call on me to support her during a consultation. Though they demonstrated my growing relationships with the participants, I found these instances uncomfortable and difficult to negotiate.

It would be naive to assume that my relationships with participants did not influence the ideas they were each willing to share. Though I worked hard to build relationships with all participants equally, the reality that some relationships were stronger than others was inescapable. This was in large part due to the regularity with which I encountered certain teenagers and HCP. These relationships influenced my reactions and responses to certain interactions, though never publically or directly to participants themselves, my internal interpretations were not void of bias. Importantly however, these biases

were kept in check through discussions with my supervisory team; they were flagged at all stages reducing their impact on data collection and analysis.

Finally, on occasion I made the decision to not record an encounter, most notably following the death of one young person when I visited the family who remained with their son on the ward for several hours after his death. I made the decision to not audio-record the family in this acute state of grief. This was a situation that I had not envisaged myself in when I was formulating the project and applying for ethical approval. As at many points during the research, common sense, compassion and my personal ethical benchmarks were what determined action in practice, rather than relying on protocols and guidelines to cover every eventuality.

I draw this experience to a close with profound respect for the health care professionals who care for these teenagers and their families every day. They are able to switch seamlessly between delivering good news and bad news, moving from room to room and responding to whatever they encounter. The ability to maintain a positive outlook and a unique sense of humour in the face of such emotionally and practically demanding work is to be commended. Whilst this thesis presents recommendations for improving clinical practice, it has been written following extensive reflection, analysis, objectivity and distance. My intention is to take nothing away from the responsive care and treatment provided by health care professionals in the moment.

See Appendix VII for further personal reflections on this research and my role in the research process.

3.10 Summary

In this chapter I have presented the methodological foundations of the research, outlining the key methods of data collection and the analytical stance underpinning the study. Secondly, I have laid out some of the procedural elements of the study including recruitment and consenting procedures. Finally, I have offered some reflections on the ethical considerations, both formal and personal, that have contributed to the early formation and day-to-day running of the research. I have highlighted the detailed procedures that were stipulated prior to data collection and how these protocols were enacted in practice, as well as some of the unforeseen challenges that occurred whilst interacting with these three parties. In the following chapters I will present the key findings of the research, demonstrating how these methods have produced a robust and coherent data set that develops understanding of the complex process of decision-making that takes place among teenagers, health care professionals, and families.

Chapter

4

Health Care Professionals Principles of Involvement – The roles and responsibilities of HCP, parents and teenagers

In this chapter I focus exclusively on the principles HCP hold regarding teenagers' involvement in decision-making. Drawing on data from several sources I present four principles held by HCP with regard to the involvement of teenagers in decision-making, namely, (1) Doing the right thing as determined by clinical consensus (2) Acting on the care and treatment preferences of the teenager, (3) Giving the teenager a voice and (4) Communicating information. Through these principles of involvement we are able to identify roles HCP assign themselves, the teenager, the parents and family. Following this I present the role HCP assigned the disease itself as one of several immutable factors that impact on teenagers' involvement across the trajectory. Table IX presents an overview of these principles and immutable factors and their occurrence across the data set.

Table IX. Overview of Health Care Professionals Principles and Occurrences Across the Data Set

Principle	Definition	Number of times principle appeared across the data set	Number of individuals that made reference to the principle
Following prescribed clinical consensus	HCP following the clinical consensus of a clinical body	29	22
Acting on the care and treatment preferences of the teenager	HCP acting in accordance with the preference of the teenager, with regard to care and treatment.	55	37

Principle	Definition	Number of times principle appeared across the data set	Number of individuals that made reference to the principle
<i>Family and relational structures</i>	The influence of family members on the way in which HCP understand, view and enact involvement of teenager.	41	35
Giving the teenager a voice	HCP allowing the teenager the opportunity to verbalise a preference or opinion on the care and treatment they receive.	3	3
Provision of information	HCP providing teenagers with information regarding their care, treatment and prognosis.	39	26
<i>Individualised Information</i>	HCP discussing the necessity of individualised information.	3	3
Immutable factors			
Uncertainty of disease course	The influence the uncertainty of the disease course has on how HCP view the involvement of teenagers.	24	26
Stage in the trajectory	The influence the stage in the teenager's illness trajectory has on HCP views regarding their involvement at different decision points.	9	9

This thesis acknowledges that the four central principles HCP hold about teenagers involvement are weighed, balanced and prioritised in every situation,

coming in and out of prominence in the face of each teenager, individual decision, the stage in the disease trajectory and the relationships between HCP, parents and teenagers.

4.1 Data

The findings presented in this chapter are drawn from data collected from semi-structured, open-ended interviews and informal conversations with health care professionals as well as observations of conversations and discussions had between HCP at multidisciplinary team meetings. Table X outlines the data sources called on for this chapter.

Table X. Data Source Table Health Care Professionals

Data source	Number of encounters
Semi-Structured, Open-ended interviews	11
Informal conversations	83
MDT meetings	98
Total Number of Encounters	192

4.2 Doing the Right Thing as Determined by Clinical Consensus

Much behaviour is motivated by a desire to do what is right as prescribed by a clinical body of individuals. Health care professionals made reference to this with regard to making decisions about care and treatment and involving teenagers in decision-making. As one consultant summarised, doing the right thing is central to their role in the decision-making process,

Dr Claire Talbot: Our job is to do the right thing, not be loved isn't it...as much as we might want to be

This suggests that doing the right thing as determined by the clinical consensus may not always align with doing what the teenager or family want, resulting in HCP being seen in a less than positive light by some. The statement is made that it is the HCP role to determine what is 'right', with no mention of the teenagers or parents contribution. Conviction in the medical care provided allowed some HCP in this team to feel confident in determining the right thing to do; it was something that this consultant in particular did not question;

Dr Claire Talbot: I mean you know I really think the patients get the best haematological medical care they could anywhere in the world here, I think the quality of care is really good so I don't worry on the 'did we do the right thing or not'?

This confidence was expressed principally by one of the consultants suggesting belief in the care they provide and an apparent lack of doubt in their clinical practice, something a consultant needs if they are to successfully take responsibility for a final call. However, other health care professionals seemed to express more concern, doubting whether or not they 'did the right thing'. This was most notable when disease directed treatment has not worked and end of life issues come in to play, for example, place of care decisions, or the decision to stop disease directed treatment. This could be attributed to the fact that these issues do not have a right and a wrong answer, but in the face of a life or death decision, resolution must be reached one way or another. The quote below demonstrates the HCP difficulty in identifying the right thing from a clinical perspective,

Dr Joanna Clark: Actually I don't think we could've done it any better but we just you know if you make a decision to treat or to wait, whatever the

decision is if you treated and there was some discussion about whether that treatment needed to be done and they died of treatment related toxicity you'd always be discussing why did we go ahead and in this individual why are we waiting? Well we're waiting because we're not sure but obviously so then of course because he relapsed and died the discussions we're always well we should have treated earlier but actually had it been, had we done that had we transplanted him and he died of TRM [treatment related mortality] the discussion would always be why did we do that then why didn't we wait, so to some extent probably whatever we had done would've been the wrong thing

Here Dr Clark noted the difficulty in determining when to treat teenagers with high dose chemotherapy. The final statement suggests that HCP recognised that the right and wrong thing is largely determined by the outcome; in this case the teenager's death in either scenario would have resulted in HCP questioning whether what they did was right. This also suggests that HCP carry the burden of responsibility for decisions in situations where there is very limited possibility of long-term cure, rather than the teenager and their families. This is an important point when reflecting on how HCP understand the role of teenagers in decision-making.

HCP make judgements on what is the right thing for a teenager, based on a combination of factors including medical judgement, previous experience and relationships with the family concerned, as the following statement suggests with regard to not escalating care to ITU for one teenager,

Sophia Wright: We said if we needed to get advice then we would but, you know, so if he became acutely really sicker, we'll just up the morphine then things like that rather than yeah, so I think we kind of said that it wouldn't be in his (teenager) best interests, it's not the right thing to

do and it's not nice down there [in ITU] and we would just manage the symptoms really

The decision at hand is considered the responsibility of the HCP; the resulting outcome that the teenager's care would not be escalated to ITU is based on the clinical assessment that ITU care would not be in the teenager's best interest. In this instance HCP report telling the teenager what course of action is in his best interest as opposed to asking him. Whilst in this instance the CNS is discussing relaying the decision to the teenager once it had been made, one nurse suggested how involving teenagers earlier when making these decisions HCP burdens can be eased;

Josie Page: I think the more we include families and patients in that the easier those things become so actually if the doctors are agonising over, actually you could have all health professionals in the room agonising over 'should we stop this, carry on with this, should we introduce a different type of drug or should we do whatever' and they can't decide between them often if you include the family or the patient in that they'll have an opinion and it makes it much easier then for that.

This nurse suggested that involving teenagers in decisions by giving them a voice and potentially acting in line with their wishes could have a positive impact not only for the teenager or the family but also for the health care professionals themselves. It is suggested that by involving teenagers and their families the responsibility of decisions and uncertainties about doing the right thing can be alleviated by directly asking those for whom the decisions will ultimately effect. Decisions about stopping disease directed treatment were interlinked with the words 'failure' and 'giving up' for several of the health care professionals. By asking teenagers to get involved and state a care and treatment preference at this stage they are able to help the health care professionals, and offer reassurance that this decision is the right thing, for them. However, we must

then question who is benefiting from following the prescribed clinical consensus? Who is the decision right for and what happens when what is right for one party is not the right thing for another? This is observed in discussion about a decision to attempt a second course of curative treatment after initial treatment failed,

Sophia Wright: And you know what in hindsight it was the best thing to do because his mum and dad really felt that they had done the right thing that they had done everything and their grieving I think was so much better whereas it would have always been 'if only' but I don't think it was right for him [teenager], but hindsight looking back at his family they would've, they had to do that.

This demonstrates the fragility of doing the right thing as determined by the prescribed clinical consensus. In this instance doing the right thing for this family meant doing something that wasn't necessarily right for the teenager. With the benefit of hindsight the CNS is able to conclude that the decision to attempt another round of treatment was the right thing. Whether or not this same conclusion would have been reached by all HCP at the time is unknown.

Multidisciplinary team meetings are places where the 'right thing' is often discussed and debated between HCP in real time. In most instances discussions focused on the decision to stop curative treatment and palliate teenagers or to continue to offer Phase I trials as observed in this discussion,

Dr Claire Talbot: Do you think it's wrong to offer [the Phase I trial]?

Sophia Wright: No, I just – cause you've got to get your data [trial data to improve care and treatment] so no, because I'm not even against him [teenager] having a bit of hope. That's what we was just saying. I don't know if it's good for him to have that hope or good to be enjoying your

last bit of time. For some families they could, they just need that hope to get through it, don't they?

Dr Claire Talbot: It's really difficult [to decide] though, it is.

Sophia Wright: Yeah, it's really difficult. And there's no right answer, is there?

Often, as this excerpt suggests HCP found it difficult to establish what the right thing to do was with regard to offering Phase I trials or stopping disease directed treatment. These discussions occurred over multiple meetings and informal HCP to HCP discussions. However, this debate was not taken up with the teenager or family in question, instead, as discussed in Chapter 7, the options presented to the family centred on the various disease directed trials available. Stopping disease directed treatment was presented to the family when all trial options were exhausted, shortly before this teenager died.

HCP identified the challenges associated with following the principle of doing the right thing as determined by clinical consensus. Not only in determining what the right thing is, but also in judging when to take responsibility for a decision based on the clinical assessment that it is the right thing to do. It is clear that the right thing does not always align with what the teenager, parents or HCP want. Moving on I look at a second principle HCP identified when discussing the involvement of teenagers in decision-making; acting on the care and treatment preferences of the teenager.

4.3 Acting on the care and treatment preferences of the Teenager

Decisions relating to place of care were most commonly associated with the HCP principle of acting on the care and treatment preferences of the teenager. For example, HCP often verbalised the teenager's desire to go home, as soon

as discharge became a clinical possibility. As one HCP stated, teenagers have a choice and thus are able to state a preference,

Josie Page: We just follow the patients lead really, so if they wanna be here they get to be here, if they wanna do, if they want all their treatment through Bentley Hospital and under the Bentley hospital team then that's how it works, if they want to be at home if they've got good community support then great they'll go there if they want to be in their local hospital then we'll try and sort that out for them so they get a choice.

This quote suggests that whatever the teenager wants the HCP would attempt to facilitate. The notion of following 'the patients lead' positions teenagers as the central decision maker, whose active involvement as the central decision-maker is paramount. However, it is suggested that the quality of community support is important in this situation. It is doubtful that any teenager would or could make this assessment of 'good community support'. If community support is not deemed suitable by whoever decides, is the option of returning home taken away? Is decision-making power thus restricted and the principle of acting on the care and treatment preferences of the teenager replaced by that of doing what is 'right', or what is possible? Further reference to these types of decisions suggest that HCP prioritise one view of involvement over another, as one health care professional remarked,

Sophia Wright: Um I think somehow we should've aimed to have got him home and I think the consultant does in retrospect, should've aimed to get him home more than because that's all he wanted to do was go home here

In this example, it is apparent that what the teenager wanted was not the course of action taken. For a reason that is unclear for this particular scenario, HCP had access to the teenager's preference for care but did not act upon it.

This suggests that whilst the principle of acting on the care and treatment preferences of the teenager can be prioritised for some decisions and at some time points, HCP acknowledge this is not always possible. However, failure to do what the teenager wanted with regard to care does not mark a failure to involve the teenager in the decision; we cannot equate the involvement of teenagers in medical decision-making to teenagers getting their most desired treatment outcome at every decision point.

Importantly, what the teenager wants with regard to care and treatment does not necessarily remain consistent over time nor does the HCP response to the teenager's care and treatment preference, as the following examples demonstrate. The decision not to escalate the care of one teenager to ITU identifies how HCP view the notion of acting on the care and treatment preferences of the teenager over time. Initially the preference of the teenager was central to the decision,

Ella Fairburn: Wednesday he kind of, he [Masood Farran] was really good wasn't he, when we spoke about ITU. It's just basically the decision that he thinks, saying, I don't want to go back [to ITU].

Sophia Wright: it wouldn't be fair on him [Masood Farran], he hates it down there [in ITU] and it would be very invasive

This teenager had previously been treated in ITU and had not liked the ward, when questioned by HCP about ITU he had stated a desire to not return. As indicated in Chapter 7, this preference was initially based on the environment of ITU in comparison to the teenage cancer ward. Following deterioration in his physical condition this care preference was carried forward by HCP, and translated into a preference about resuscitation status. This statement was the focus of much talk between HCP when making the decision several weeks later

to not escalate his care to ITU. However, shortly after these conversations when mum begins to query the decision, the following discussion is had,

Dr Joanna Clark: But they [Masood's family] know we're not going to ITU?

Sophia Wright: Yes, but mum wanted that readdressed with him [Masood], as if to say he could change it, cus she's [mum's] saying that he doesn't understand what that means – but actually it doesn't matter what he understands, she's not getting it's a medical decision so we kind of – she [mum] spoke to him [Masood] but he wouldn't say anything firm. It was fine but I think she thinks we can change that decision [to not escalate care to ITU], and we're not.

This discussion above suggests that what the teenager or family wanted was not in the foreground of discussions, instead doing what was deemed clinically the right thing to do takes precedence. This remained the case when the teenager appears to voice a change of preference for his care the following week,

Sophia Wright: She [ward nurse] said he [Masood] was asking to go downstairs [to ITU]. He said he couldn't breathe.

Dr Joanna Clark: oh to the ITU?

Again, what the teenager wanted was not deemed to be in his best interests and care was not escalated. This example demonstrates the teenagers changing preferences for care and treatment and the HCP response to those preferences. Initially, the teenager's preference and the course of action deemed best by HCP align and a decision was made. However, in this instance, when HCP recognised a shift in the treatment preference of the family the principle of doing the right thing as determined by clinical consensus

superseded the view of acting on the care and treatment preferences of the teenager. Once again, the fact this teenager did not get his desired outcome does not necessarily mean he was not involved, but that how the HCP viewed his involvement changed.

HCP weigh and balance the teenager's preference for care and treatment against their clinical responsibility to provide the most suitable care. When the two do not align HCP ultimately must prioritise one view of involvement, depending on the decision faced, the stage in the trajectory and the influence of family. This is discussed in greater depth in Chapter 7 where findings from practice are presented.

4.3a The influence of the Family

The involvement of the family is an expected and accepted component of most hospital care across the spectrum of age. HCP recognised that regardless of the teenagers age, parents, siblings, grandparents, children and partners are commonly included in discussions and decision-making surrounding an individual's care and treatment. One HCP recognised extensive family involvement as the key difference between decision-making with teenagers and older adults,

Charlotte May: I think, I think the obvious thing would be the considerable involvement of family. I think, and sort of, friends, watching them engage with the patient and sort of seeing that decision-making process, that sort of planning for treatment, planning for the care, watching sort of mum or dad or whoever the parental figure is, just trying to allow their teenager who is kind of at the age where they should be making some decisions for themselves but also, that kind of is still a child in their eyes as well.

Health care professionals acknowledged the importance of respecting family dynamics and allowing parents and teenagers the space to establish their roles in the decision-making process. HCP understood that there often existed a tension between the growing independence of teenagers and the necessary dependence of a teenager diagnosed with cancer, which sometimes led to confusion about the influence parents and families have on a teenager's choices,

Dr Mark Charwood: You just don't, you really don't know what the influences of parents are in both directions, as in often there is not appropriate levels of guidance given because either no-one wants to speak about it or, parents are not involved as much as we would perceive the should be.

HCP could never be present for all discussions parents and teenagers had about their care and treatment. Teenagers and their families have a long established relationship and a unique communication style that as Dr Charwood suggests, the HCP cannot always access. Separating the views of teenagers and their families is therefore something HCP struggled to do, often leading HCP to involve the family as a unit, accepting that the teenager's preference for care and treatment and parents preferences for care and treatment are interlinked.

Health care professionals spoke frequently of teenagers doing what their parents wanted with regard to care and treatment, stating that teenagers rarely go against their parents' wishes, even if they differ from their own,

Sophia Wright: - The family are going to go for absolutely anything [curative treatment or trials that are available], and he [teenager] will just do whatever he's told by his family, so he's happy.

This CNS recognised that the teenager's preference was to follow his parents' lead, consequently affording the parents a role. However, as suggested below HCP sometimes felt that this focus on the family was detrimental to the teenager themselves,

Sophia Wright: At the end of the day if that family think that's the best thing to for their child it might be wrong in every aspect, but for them and for their grieving then, but I'm not sure sometimes we lose focus of where the patient sits in all that because we're so righteous and doing everything for the family and sometimes I think we may lose focus of not putting that patient first.

Dr Joanna Clark: 'It's been tricky because we weren't 100% sure that the patient wanted more [disease directed] treatment but the family absolutely did. But in the end he tolerated a [disease directed] treatment, he didn't respond, he was happy with them being able to stop [disease directed treatment]'

In these scenarios the HCP acknowledged that the teenagers' care and treatment preferences got lost in those of the family. What it means to 'put the patient first' in practice is something I attend to in Chapter 7. Despite HCP suggestions that on occasion the family preference for care and treatment overrules that of the teenager, it is entirely possible that the teenager has allowed for this or even encouraged it. To involve the teenager is not to disregard the influence of those around them. The possibility that teenagers themselves may put their care and treatment preferences to one side and prioritise the wishes of the parents and extended family members should not be ignored.

HCP suggested that it was important to try and identify from the beginning the role of the family, though they acknowledged that this role is unclear and can differ family to family. One CNS offered an example of how differences of opinion within a family can play out in practice. In this example, following relapse the teenager did not want the trial drug offered by one hospital,

Sophia Wright: But he [teenager] absolutely didn't want it [trial drug] and his mum and dad were so, so, just couldn't let him go and he was quite clear he didn't want it he asked how long he had left [to live] all the things, he was only 15 and he went home and his mum and dad said 'we'll talk to him' and I thought, if you can make 48 hours [without changing his mind] he'll be alright he won't go for this [trial drug], but the next morning she [mum] rang and said 'we're on our way up, he's agreed [to have the trial drug]'. But it's that usual thing whereas they do what their parents want in the end in that conflict, they could try but. Actually he had the [trial drug] treatment stayed [in hospital] a month, luckily it didn't make him that sick but it did nothing. And we went in to tell him his disease was still there and he smiled. It was like, I've never seen that reaction he was just so pleased to be going home and for it to be over.

This is a prime example of how family intervention can direct the course of action and the care and treatment wishes of the teenager themselves in the decision-making process. The HCP recognised that the teenager did what their parents wanted in this situation, despite it going against what he initially wanted. This could be as a result of his parents convincing him of the benefits of the trial drug and him changing his mind, or him simply agreeing to try the drug for his parents. As Dr Charwood suggested earlier, this is an example of a decision being reached following a private discussion between parent and child, where the influence of each is unknown. HCP acknowledged that this type of family involvement was most notable with the decisions surrounding end of life care. As recognised below, HCP viewed the role of the family as integral to these decisions,

Dr Claire Talbot: You've clearly got to involve the family and they're very important and it's them that are going to grieve and so if you're kind of thinking well how can I minimise their grief at the same time it's very important

This idea that it is the family that will be left behind if the teenager dies brings a new perspective to the central view of involving teenagers by 'doing what they want'. This introduces the possibility that when cure is not likely, the principle of doing what the family want with regard to care and treatment is viewed as more pressing than perhaps it is in the early stages of a diagnosis. It also raises the possibility that teenagers themselves acknowledge this to some extent and prioritise their parent's wishes, as the HCP do. Consequently, to view the involvement of the teenager in isolation is to belie the complexity of relational structures within families.

4.4 Giving the Teenager a Voice

The third principle expressed by HCP was that of giving the teenager a voice, enabling teenagers to verbalise their wishes and preferences for care and treatment. As shown above, HCP spoke of the importance of disentangling the voice of the teenager from that of the parents and the family,

Julie Taylor: I think there is a real effort amongst the team to make sure the teenager has a voice and if parents start talking over them there is a real effort to come back to them

This suggests that the whole haematology team make a concerted effort to distinguish between the family's (often the parents, but also grandparents and older siblings) voice and the teenager's voice. By giving the teenager a platform

for sharing their perspective it is assumed that the teenager is involved in the conversation and subsequently the decision. However, just as failing to do what the teenager wants with regard to care and treatment is not reflective of a failure to involve, giving the teenager the chance to voice their opinion or treatment preference is not necessarily reflective of successful involvement either. Letting the teenager speak does not mean that they have been heard in a constructive and non-tokenistic sense. As discussed above the idea of distinguishing the teenagers voice independent of the voice of the family is a challenge faced by HCP, as one consultant stated,

Dr Lindsey Phillips: So ideally, the patient makes all decisions and we utterly respect them but, we know even in an eighty-five year old [patient] there may be a very strong daughter or a very strong wife who is making those decisions and influencing so, if that is the family norm it's very important that we respect that and not put pressure –

Recognition of the family as a unit is seemingly crucial for this consultant, who suggested that giving the teenager a voice does not necessarily equate to giving the teenager an independent voice, devoid of family input. On occasion the teenager may nominate a family member to be his spokesperson as Dr Phillips recounted to her colleagues,

Dr Lindsey Phillips: I talked to him [teenager], [I said] do you want to talk? It became clear quite quickly that he didn't want to talk and so I said – do you want to, do you want to talk, and he said no, talk to my sister.

This consultant respected the teenager's decision to entrust his voice to his sister, demonstrating how family, other than parents, can assist in allowing the teenager to have a voice in a way that the teenager is comfortable with.

Further statements from HCP highlight some additional challenges associated with the principle of giving the teenager a voice. HCP discussed the variation in teenagers' apparent willingness to voice a preference for care and treatment, for some teenagers this was easier than for others as one nurse suggested,

Josie Page: That is how we work anyway we try to encourage them to be as much as a part of what we're doing but for some patients that's it just takes a bit more work so some patients are like totally want to be involved they want to sign their own consent forms they want to know what's going on with their treatment and just do the whole thing and for those patients who don't, you kind of have to eek it out of them

For this nurse, the teenagers' involvement was equated with their willingness to be an active participant, signing forms and asking questions. The idea of 'eking' out involvement raises questions about the benefit of giving teenagers a voice, even if they do not want one. For many teenagers, involvement as vocalisation of wishes regarding decisions about their care and treatment may be last on their list of priorities, taking great comfort in the ability to delegate to parents or health care professionals. In these instances should the principle of involvement as giving the teenager a voice still be prioritised? As I discuss in chapter 7, often HCP are encouraging of this delegation when cure is not likely. Similarly, chapter 7 also highlights how the involvement of teenagers in practice includes their ability to delegate and remain silent as a way of demonstrating agency.

As one HCP suggested, after turning 18 years old teenagers are legally adults and therefore bound to some level of involvement through vocalisation of a care and treatment preference,

Josie Page: Yeah and just sort of say you know this is up to you to make a decision on this and I know it's hard but you know you're an adult now and you need to tell us what you think about this and if you've got

questions then we need to know about it, like don't just sign things just because your mum tells you that you should, or your dad tells you that you should

There appears to be instances where HCP believed that the teenager should be encouraged to have an independent voice and others where delegation to a family member was equally acceptable. This once again was something HCP weighed up in relation to the communication style of the teenager, the relational structures and pre-existing family dynamics and the decision to be made. Whether or not HCP assessments equate to how the teenagers themselves view their involvement is yet to be uncovered, equally, whether or not the drive towards involving teenagers in decision-making by encouraging them to be vocal is a positive one in their view will be discussed in Chapter 6.

4.5 Communication of Information

HCP held the principle that the provision of information was central to the involvement of teenagers in decision-making. However, as shown throughout this section, HCP report the control teenagers and their families had over how this principle of involvement was enacted. Several of the health care professionals discussed the necessity of being upfront with teenagers about their prognosis,

Dr Claire Talbot: It's a disaster when the parents are told first because they will always say 'well don't tell so and so' and then they know something is going on, massively increases their anxiety, the young patient, teenagers often want to do like videos, or make books or do things to leave for their family members and stuff well they can't do that if they've not been told and what you don't want is suddenly for there to be a big gulf because of a lie between parents and child at that sort of time of life so I feel really strongly about it

This highlights the HCP view that communication about prognosis is necessary to allow teenagers time to prepare in situations where cure is no longer likely. By ensuring teenagers are aware of their potentially poor prognosis they are able to engage in the process and in instances where cure is not likely, produce something for their friends and family to leave behind when they have gone. Dr Talbot suggests that a 'lie' between parent and child can cause a 'gulf' in their relationship. It is unclear whether teenagers and parents feel this way, or if the 'gulf' provides protection for both parties.

Dr Talbot also alludes to the fact that the open disclosure has value beyond the teenager and family, suggesting that it is 'a disaster' when the parents are told first. This gives the impression that the teenagers engagement, awareness and contribution at this stage is considered to be a benefit not only to the teenager, but also to the health care team who feel comfort in the fact that everyone is on the same page.

HCP reported an added complication when the family believe that honesty is not the best policy and attempt to prevent the health care team from being upfront with their child. Several health care professionals identified this as a common issue they had to try to overcome, often upsetting the family by answering the teenager's questions,

Dr Joanna Clark: There was one of my patients he relapsed after a transplant and god it was so difficult because her father was furious with me for telling her, although I didn't actually tell her, I said I'm going to put you on this treatment which is tablets, she said 'oh well what happens when these don't work' and I just said 'well then it's difficult' that's all I said and the father went mad and really wrote me the most awful letter

Dr Clark highlights how she did not explicitly tell this teenager that she would die, instead implying so with the statement 'then it's difficult'. This suggests that HCP do not necessarily provide explicit information about death, even when asked. Similarly, as the following quote suggests teenagers often sought information from their parents rather than their HCP, the outcome of which HCP cannot control resulting in less than honest information exchange,

Sophia Wright: He [Anwar Passi] asked her [Saanvi Passi] if he was going to die on Friday. [Anwar was asking] Is that why we spoke to him – all the doctors – for so long and she said no. Which I can understand, but I kind of dug deep and chatted about, why did you say that? What do you think he's thinking but... she thinks he's got no idea what going home and maintenance means. She thinks, he thinks he's going to get better like he did before.

Here Saanvi tells her son he is not going to die. This links in with the issues discussed above with regard to the role of the family in involvement and how HCP must balance this with the role of the teenager. However, as suggested by several members of the team, the provision of information is largely dependent on the teenager asking the questions and demonstrating a willingness to know,

Sophia Wright: How many times can you say 'is there anything you want to ask us? Are you worrying about anything? Are you worried about the future...?' (Laughs) you know there's only a certain amount you can do of that as well

Julie Taylor: I suppose if he asks you questions directly [about his prognosis] it's a bit easier to answer.

Sophia Wright: Yeah, but he never will. They never do.

As these statements suggest, HCP felt they were reliant on the teenagers asking the right questions. If the teenager isn't asking the questions it puts the health care professionals in a 'very difficult situation' (Sophia Wright). As a result direct and complete information exchange regarding prognosis is not a communication practice that can be used with all teenagers to help elicit their involvement; some teenagers may not want to know and the health care team must respect this. There was an understanding echoed by all team members interviewed, that each teenager is individual and a prescriptive model of communication cannot be readily applied to all of them. HCP suggest that the teenager is able to determine how and when they receive information regarding their care and treatment, which is not to say, that the information that is provided answers the teenagers' questions directly;

Dr Adam New: If you've been doing this for a long time and you've built up a relationship with someone and you're saying 'well you know you're having this treatment' but you know you wouldn't keep it a secret let's say for instance if the treatment isn't working you'd say you know 'you've had a scan, you've had a bone marrow the results not what we hoped for it's shown that your disease has come back' and that kind of thing 'the treatment that you were on that was the plan but we're not following that anymore because we're concerned that that's not working' and you would say all those things but you might not actually completely verbalise 'and the outcome of that is you're going to die.

As demonstrated by an earlier quote, this consultant explicitly acknowledged that communication does not always equate to explicit verbalisation. This is particularly evident with questions relating to end of life. Whether or not the teenager and parents understand the implication, largely determines whether or not information has been withheld or a teenager has been fully informed. In line with this, HCP discussed the necessity of establishing how much information each individual teenager requires about each stage of treatment and each decision point,

Dr Lindsey Phillips: But, I think if the patient is not allowing words to be used then it is wrong to use them, to associate our desire for them to know – so we have to, my key is to not be selfish but to try to understand what the patient, what words does the patient want to have.

Dr Mark Charwood: I think it's important, making an assessment of the level at which they want information but, not circumventing them with important information and that to different degrees that they need to have all of it but perhaps you can argue about the, I don't know, volume.

As these statements highlight, HCP acknowledge that communication does not always extend to an explicit verbalisation of the inevitable outcome, which is not to say that communication is dishonest. HCP focus on establishing what the teenager wants and needs to know at different times across the trajectory and balance this with the clinical necessity of obtaining informed consent. Greater work needs to be done to understand the concept of honesty in practice, to uncover why it is idealised in an environment where it's not always welcomed, something I return to in later chapters. Health care professionals made reference to the fact that in many instances the possible or probable death of a teenager was not discussed with the teenager in clear, unambiguous terms,

Sophia Wright: I would say that, generally patients don't ask if they're going to die, so it doesn't come up and there is often palliative care but especially with inpatient who we haven't actually said 'you are dying' to because there's no need to they haven't asked us and we can pretty much guarantee they know.

Dr Adam New: How do you know that [teenagers know a prognosis]? How do you know that, yeah I think that, I think that you again it's because you're

having conversations with someone over a period of time and you know and it's as you know a lot of communications non-verbal you just know, you feel it you just feel it.

Sophia Wright: But I think acutely, if he was gonna die, I think we need to – it would be really nice to have a strategic plan to get him home, even if it be for a day to die. I think it would be really –

Dr Claire Talbot: If that's what he wants to do.

Sophia Wright: Well he's not gonna have that question but I know – we all know that's all he wants.

Sophia did not clarify how she knew that this was what this teenager wanted. However, as Dr New stated, over time HCP have conversations, learn about the teenagers and their families and ultimately get a feeling about their preferences. It was acknowledged that verbalising how one came to know that they knew what a teenager knew and wanted was difficult, as it was based on this almost inexplicable feeling. This view was reflected by several of the health care professionals, and suggests that teenagers' preferences can be heard in decision-making without the explicit verbalisation of the eventual outcome. It also reinforces the earlier statement that certain information is only provided if a teenager sought it. What is essential however is a strong relationship between teenagers and health care professionals so that this 'guarantee that they know' is based on a genuine understanding of the teenager rather than a generic assumption,

Sophia Wright: I just think there's rare occasions when we think they've heard something but actually they haven't asked you outright anyway so you don't know definitely they've heard that and we presume they know it but actually we don't clarify that enough maybe

This lack of clarification Sophia referred to may result in a teenager not fully understanding the severity of their situation; consequently, their involvement in subsequent decisions may be limited, or based on a limited understanding of their long-term prognosis. Either way this is something that requires investigation of real time practice to identify how this non-verbalised honesty plays out and how the teenager themselves views the interaction and their role within in it. This is something attended to in Chapter 7.

Health care professionals viewed trust between teenagers and the health care team as one of the key consequences of open communication. As one consultant noted;

Dr Claire Talbot: I have quite strong views on this because for the patients, you know you've gone through this whole journey together with some of them we've known for months or years and you know they've had rough times and good times you've kind of gone along that together and I think when you're looking after teenagers their ability to know you and trust you is really key

Importance was placed on developing a strong and trusting relationship with teenagers. What happens in practice when there is an apparent break down in trust is something I discuss in the following chapters. It is evident that the provision of information is a complex principle of involvement, influenced by the decision at hand and the information preferences, both assumed and verbalised, of the teenager. The degree to which HCP discuss the provision of information is dependent on the decision to be made, the stage in the illness trajectory, and the communication style within families.

4.5a Individualised provision of information

Ultimately, what is evident is that HCP believe in the provision of individualised provision of information when it comes to involving teenagers in decision-making. Statements were made that acknowledged the involvement of teenagers is not a universal concept that could be applied with ease to every individual that entered their ward. As two HCP suggested;

Dr Adam New: So I think that there isn't a one size fits all even though we have a common philosophy that patients should know what's going on and we shouldn't keep secrets and that kind of thing but within that framework you would sort of treat all of them as individuals.

Sophia Wright: The ethos here is that we would never lie, so we would never lie to a patient we would never talk to a patient's family without asking them first, or talking to them first. We have a very strong ethos whatever their age but obviously you have the very young end of the spectrum where it may be slightly different but still that ethos stands very much

Both Dr New and Sophia acknowledged a central 'ethos' that supported a view of teenagers' involvement as the provision of information. However, they both recognised that this principle of involvement is open to interpretation in the face of each teenager. As shown throughout this section, HCP acknowledged a role for both teenagers and their parents in the control and management of information. The questions and information preferences of teenagers, alongside the information disclosure preferences of their parents impact on how the HCP can enact principles of involvement. That is not to say that teenagers are not involved, instead that the teenager's involvement goes beyond the explicit communication of information.

4.6 Immutable factors relating to the diagnosis

4.6a *Uncertainty of the Disease Course*

The uncertainty of the disease course was referenced by 25 HCP during discussions of the teenagers' involvement. Several health care professionals discussed the specific problems associated with haematological cancers, some of which are outlined below,

Julie Taylor: 'I don't think there is a high chance of cure, although one consultant told me 70% and one told me 30% but when you get into 3rd stage relapse as you say there's not the same research data, there's not the same body of information so it's more guess work'

Josie Page: It's all just so confusing I think and we could look at you know, look at the previous weeks' worth of I don't know electrolytes and say we can see from this that you know things are tailing off and it's not looking good so in a week we would predict that it would be so bad that you could die from that, but who knows what the next week might look like so you're sort of taking this gamble...I think it's, it's much harder to sit down and tell someone this is what's going to happen because you just don't know

These statements highlight a degree of uncertainty within the team with regard to the disease prognosis. The first statement above recalls a significant disparity between two consultants estimates of cure rate, one stating 70% and another 30%. The uncertainty of the outcome influences the extent to which HCP can provide information, this central principle of involvement can therefore not be prioritised in every instance. In the case reported, the teenager was made aware of just one of these estimates. Arguably, to make an informed decision the teenager would have to be aware of all the different opinions regarding the possible success of the treatment; how realistic this is in practice, and the

influence of this type of withholding is discussed in chapter 7. Uncertainty became an increasing challenge for HCP when decisions around palliation and withdrawal of curative treatment began to emerge,

Josie Page: I think with the haematology patients it all gets a bit blurred in with symptom control because you can be giving them blood transfusions to try and control their symptoms rather than to try and prolong their life so it's not a treatment but it all feels a bit messy, I think it's much, much harder I think one of the most complex end of life conversations I've been a part of are to do with haematology patients because it's not clear cut at all.'

Dr Evelyn Carter: So – actually we are essentially doing end of life care but that end of life care might be quite prolonged?

Dr Claire Talbot: So what we're saying, we don't know. This is the problem with leukaemia -

Dr Adam New: I was thinking it's a really difficult thing here because on one level we almost need to just palliate him –

Sophia Wright: Yeah, yeah definitely

Dr Adam New: - and get him home, but on the other level there is a potential drug that could get him into remission to enable us to transplant him –

Dr Claire Talbot: So we're totally conflicted in the – it's hard isn't it?

These statements suggest that for those teenagers for whom disease directed treatment was not working, decision-making processes were much more complex due to the nature of the condition. As Josie explained, transfusions were still given, just with different intent. How teenagers view this complexity,

and how this view influences how they view their role and prioritise their preference in decision-making is discussed in chapters to follow. It is suggested that there is not as clear a distinction as with solid tumour patients, due to the systemic nature of the disease a variety of treatments are available and consequently stopping disease directed treatment is not as clear-cut. This uncertainty influences how when and to what extent HCP feel able to involve teenagers in decisions about their care and treatment.

4.6b Stage in the Trajectory

As mentioned at the outset, this thesis specifically focuses on six key decisions HCP, teenagers, and their families may face during their disease course. HCP spoke of the how the nature of these decisions and the point in the teenager's disease trajectory influenced different ways involvement of teenagers was understood in principle. Throughout this chapter reference has been made to how the stage in the trajectory and the decision at hand has influenced the view at the forefront of HCP understanding of involvement. Here I present further evidence from HCP that they do not view the involvement of teenagers as constant over time and across decisions.

At diagnosis, HCP identified the teenagers' role as listening to information and asking any questions they had. The specific diagnosis and treatment protocols largely determined the next steps; therefore the principle of providing information dominated HCP view of the teenagers' involvement. As Dr New suggested,

Dr Adam New: The second aspect of it is meeting the patient and the family and giving them information and seeing what questions they've got so that's always the really critical you know, so they're really two things straight away and to see what initial questions they have but obviously there's a lot to take on board if your child is diagnosed with some sort of

cancer so it's really addressing their [parents and teenagers] immediate questions and concerns.

He acknowledged the initial role of parents and teenagers is to ask questions. If treatment is unsuccessful or the teenager runs into complications with care, the HCP recognised a more active role for teenagers and families,

Julie Taylor: I think the decisions start coming in when it doesn't work so for the patients which is a minority in haematology, when they relapse so when the first line chemo doesn't work.

It is at this point HCP reported further treatment options were discussed and additional rounds of chemotherapy or transplant were presented as options. However, once again these decisions are often made for the teenager and the family as a result of the biological response to certain drugs and the effectiveness of certain treatments. As one consultant summarised, whilst discussing the presentation of transplant as a treatment option;

Dr Mark Charwood: The problem is, the necessary other catch is that they are there because [transplant] that's the only sensible alternative. And that's, I think that's particularly mean to say all these terrible things [side effects] could happen to you but if you don't [have the transplant] you will almost certainly relapse. I mean again, what do you do with that information?

Dr Charwood suggests that when transplant is the only viable alternative for treatment, HCP must weigh up how much information about the transplant they provide with the knowledge that the teenager has no choice but to accept transplant if they want a chance at survival. If this treatment is unsuccessful and an assessment is made that cure is no longer likely, the involvement of

teenagers becomes less clear-cut for HCP. As shown throughout this chapter, it is at this stage that HCP expressed the most doubt and engaged in the most discussions regarding teenagers' involvement and the principles that should be prioritised.

It is evident that HCP recognised several immutable factors relating to the disease course that influence how they view the involvement of teenagers in decision-making about their care and treatment. The medical model is inherently prescriptive, with protocols and treatment plans to follow. HCP acknowledge that this restricts teenagers' involvement at certain points to listening and understanding, rather than voicing opinions and deciding on a course of action. However, HCP recognise a shift when disease directed treatment stops working and suggest that at this point families and teenagers are pulled into the decision-making process, able to voice opinions and preferences. However, as shown earlier these preferences are not always attended to and many decisions towards end of life are classified as clinical and thus the responsibility of the HCP to make. Whether these shifts are welcomed or recognised by teenagers and families is something I discuss in the following chapters.

4.7 Summary

This chapter reveals the depth and breadth of perspectives held by HCP regarding the nature of involving teenagers in decision-making. The main principles reported as central to this understanding were communicating information to the teenager, acting on the care and treatment preferences of the teenager, giving the teenager a voice and doing the right thing as determined by clinical consensus. As shown in earlier chapters, these principles of involvement have been echoed elsewhere in the literature with regard to the involvement of teenagers in certain decisions. Reflection on HCP principles over time and across decisions suggests that these views and understandings are weighed up, balanced and prioritised in each situation. While acting on the

care and treatment preferences of the teenager was sometimes considered integral to involvement, on other occasions doing the right thing as determined by clinical consensus was prioritised. The principle of involvement that HCP prioritised changed in relation to several immutable factors that they recognised; uncertainty of the disease course, stage in the trajectory and the unalterable protocol.

HCP reported the importance of doing the right thing as determined by clinical consensus when making decisions about a teenager's care and treatment. The right thing was largely considered the role of HCP to determine, though some acknowledged the benefit of involving teenagers and parents when decisions of serious consequence needed to be made. This influenced how HCP viewed the role of teenagers across decisions and time points.

HCP spoke of their understanding of involvement as acting on the care and treatment preferences of the teenager. While they advocated this for certain decisions, for others the notion of acting on the care and treatment preferences of the teenager was not possible, feasible or desirable due to immutable factors such as the unalterable protocol or the possibility of death. HCP reported the influence that parents treatment preferences have on the teenagers treatment preference. They acknowledged that teenagers would often follow the lead of their parents, whether this is through a true change in preference, agreement to parents' wishes or coercion was unclear. Consequently, to do what the teenager wants HCP recognised that what the family wants must also be considered.

HCP principles of involvement included the notion of giving the teenager a voice, space to verbalise their opinions and preferences. Again, HCP acknowledged that this was dependent on the teenager themselves, and their willingness or ability to verbalise their wishes. This suggests that HCP view involvement of teenagers largely by how actively they are able to participate, assuming that

without a voice teenagers cannot be involved. Whether this is the case in practice or even how teenagers themselves understand their involvement is discussed in the later chapters.

HCP viewed open communication as paramount to involving teenagers in decision-making regarding their care and treatment. However, they recognised that communication in their view is not always equated to explicit verbalisation of every outcome; instead sensitive information is often implied or suggested. What is apparent is that HCP often view information provision as an indication that a teenager has been involved in decision-making, despite certain information being with-held and other information merely implied. Whether or not this conceptualisation of communication enables teenagers to be fully involved in the way they wish to be is yet to be uncovered.

Finally, HCP noted that immutable factors relating to the course of the disease trajectory influenced how they were able to view and enact involvement. The uncertainty of the trajectory and the eventual outcome prevented them from providing teenagers with completely accurate accounts; similarly they suggested that the stages in the trajectory impacted on which principle of involvement they were able to prioritise in practice. The nature of a leukaemia diagnosis meant many protocols were in place, and many decisions were made in response to the teenager's physical condition. As a result HCP acknowledged that teenager's role as decision-maker was often curtailed by clinical necessity or determined by these immutable factors.

The following chapter focuses on the principles held by parents and families with regard to the involvement of their children/ siblings in decision-making. I detail these principles before turning attention to the principles held by teenagers themselves, and the enactment of involvement when these three parties come together in practice.

Chapter

5

Parents and Family Members Principles of Involvement – The roles and responsibilities of HCP, parents and teenagers

In this chapter I focus exclusively on the understandings held by parents and family members regarding the involvement of teenagers in decision-making. Drawing on data from informal discussions and interviews with parents and close family members I present the professed roles and responsibilities parents and family members assign to themselves, their teenager and their teenager's HCP in the decision-making process. I reflect on how these views relate to those expressed by HCP, before focusing on the views of teenagers themselves in the following chapter. Table XI presents an overview of these understandings and their occurrence across the dataset.

Table XI. Overview of Parents and Family Members Principles and Occurrences Across the Data Set

Principle	Definition	Number of times principle appeared in the data set	Number of individuals that made reference to the principle
Recognizing the Family Unit	Parent and FM views about the involvement of the family unit alongside that of the teenager.	5	3

Principle		Definition	Number of times principle appeared in the data set	Number of individuals that made reference to the principle
Parents and Family Members (FM) Role	Responsibility for acquiring information	Parents and FM views about their responsibility to acquire information about their child and their child's condition, treatment and prognosis.	13	6
Teenagers Role	Acting on the care and treatment preferences of the teenager	Parent and FM views of HCP doing what teenagers want with regard to decision-making about their care and treatment.	7	4

Principle		Definition	Number of times principle appeared in the data set	Number of individuals that made reference to the principle
	Distributing responsibility to teenagers	Parents and FM views about the responsibilities teenagers have in the involvement and decision-making process.	2	2
HCP Role	Following the advice of HCP	Parent and FM views about acting in accordance with the recommendations of HCP.	5	4

5.1 Data

The findings presented in this chapter are drawn from data collected from semi-structured, open-ended interviews and informal conversations with the parents and family members of teenagers diagnosed with leukemia. Close family members included siblings (1), in-laws (1), grandparents (1), and a close family friend (1). Table XII presents an outline of the data sources called on for this chapter.

Table XII. Data Source Table Parents and Family Members

Data source	Number of encounters	Number of individuals	Number of families
Semi-Structured, Open-Ended Interviews – Parents and Researcher	2	2	2
Informal Conversations – Parents and Researcher	67	8	7
Informal Conversations – Close Family Members and Researcher	6	3	1
Total Number of Encounters	75	11	7

First we draw focus to a central principle of involvement reported by parents and family members, before moving to a discussion of principles relating specifically to the roles and responsibilities of the three parties as articulated by parents and family members.

5.2 Recognising the Family Unit

Parents were strong advocates of the principle of involving teenagers together with their families, seeing their role as central to the decision-making process. Often parents expressed this by recognising the family as a decision-making unit, regardless of the age of their child. For these two mothers with children over the age of 16, the legal age of consent was recognised but the importance of their child discussing decisions with family remained,

Jane Stephens: Although Tom was at the age of consent we still discussed as a family any decisions to be made over the course of his

treatment – we discussed as a family taking into consideration what the doctors advised.

Nadia Conteh: So I think most of the decisions being made will be her now because she [Poppy] is in that age of consent but at the same time I know she is making the right decision – and when she makes that decision she will tell me. If I felt that what you have done might not be right, okay, let me see how it is so, I have to accept this other options.

As this mum went on to state, although HCP were legally permitted to seek consent from Poppy alone, Nadia felt her presence was important to the consent process,

Nadia Conteh: The first week I needed to go back home to pick up a few things and I was on my way and Dr Charwood needed to ask her to take consent, ask her to see if they would go for the treatment and they have to wait for me to come back, because I wanted to hear more about what support that would give her, what help it would be which [is] really important it's not just like 'don't care, don't worry, I can take that decision myself' no, because she knows that we will see that we will try and evaluate what is the decision she needs to make and ask how it is going to affect her and take that decision together.

Nadia saw her role as an interrogator of HCP proposed treatment plans, stating that she was able to assess the risks and benefits in a way that would help her daughter reach an informed decision. Nadia also suggests that her daughter understood the importance of the decision to be made and as a result welcomed her involvement. Occasionally, parents saw their role as more directly shaping how teenagers interact with HCP and how their involvement is enacted. As one mother recounted,

Samina Haider: He's hearing everything, even today, now, in the morning when the doctors came in I told them, I said don't ask him nothing, leave everything to me. If he says I'm in pain, I'll come and say he's in pain – whatever, whatever, whatever, but Masood this week said was awful for him.

Samina's attempts to prevent HCP from communicating with her son were based on a desire to protect her son from hearing any more bad news about his prognosis. Whilst he himself voiced no objection to his mum's decision, the HCP were only able to respect mum's wishes for the morning – the indisputable necessity of clinically assessing the patient himself intervening. However, following this HCP delivered all information regarding prognosis, death and EOL decisions to Masood's family, without Masood present. The assertion of her role as protector shaped the enactment of Masood's involvement in decision-making during the final weeks of his life.

Another mother, who spoke of the responsibility she had for the treatment her son received, echoed the suggestion that parents were responsible for intervening to protect their child. Jasmine discussed how, knowing the side effects heavy dose chemotherapy had on her son, she would refuse another round of the same heavy dose chemotherapy,

Jasmine Mirzaei: It happened but in case he [George] has that chemo again, that would be my fault – you know.

Emma Day: why would it be your fault?

Jasmine Mirzaei: Because if they wanna do it, us, we have to sign it and I have to agree on it. – It was, it was too much on him, he, he can't take it – his body can't take it.

When asked if she would consent if HCP offered the treatment, Jasmine said 'No'. She spoke about taking responsibility for this decision, despite her son being of consenting age, and him being the one who would have the legal responsibility to consent. This highlights the fundamental fact that parents often feel responsible for their child, regardless of age and regardless of whose signature is inked on the consent. This is crucial to recognise when discussing the involvement of teenagers in decision-making, particularly involvement in decisions for life-threatening diagnoses. To focus exclusively on the teenager is to overlook parents' intrinsic responsibility as a parent, to deny the parents this role when their child faces life and death decisions is tactless. This relationship must be acknowledged in the enactment of teenagers' involvement.

5.3 Parents and Family Members Roles and Responsibilities

Parents and family members outlined the key roles and responsibilities they believed they held in the decision-making process. These centered on their advisory and supportive role, their responsibility for acquiring information.

5.3a Responsibility for Acquiring Information

As discussed in the previous chapter, the provision of information from HCP to parents and teenagers was key to HCP understanding of involvement. The acquisition of information was equally important for parents and family members; with many reporting that information regarding their child's diagnosis and treatment helped them establish themselves in the medical setting and was thus integral to enacting their role. One family expressed their desire for clear and coherent information for their family as a whole, as Masood's brother-in-law stated,

Jac Rossi: I think it's the same principle – you end up calling up, I don't know Virgin Media over a problem and they put you through so many different departments in the end you're just thinking oh well, I can't be fucking bothered and you put the phone down, That's how I felt. I felt so frustrated that no one was taking charge of the situation and just being, you know what, we are the one person, this is the one person who's gonna take responsibility and explain everything to the family and do this.

This desire for a single point of contact to take responsibility for providing consistent information across the trajectory is not unreasonable and is recognized by HCP as integral to the clinical nurse specialist (CNS) role. However, despite the allocation of a CNS to this family, they still felt 'no one was taking charge of the situation', and taking responsibility for information provision. I argue that this has little to do with the capabilities of the CNS, or the organizational structure of the unit and more to do with the uncertainty surrounding treatment options. For Masood, HCP were consulting various departments, hospitals and specialists to identify the best course of action following his relapse. The lack of understanding and direction felt by this family reflected that felt within the health care team as they worked to determine if, when, and where Masood would be eligible for Phase I trials. Family members identified the difficulties associated with maintaining their perceived role and responsibility to stay informed, when cure is no longer likely, and HCP themselves are negotiating information on various options.

For a family who never faced decisions regarding Phase I trials, and whose treatment plan was comparatively straightforward, HCP delivery of information was praised by one mother,

Nadia Conteh: They [HCP] have been very, very good in terms of relationship, communication with them, which means they encourage

them, they let them understand what they are going to encounter, what they can get out of it, not making them feel dejected in terms of what they are going through.

This mother felt that the HCP approach helped her daughter not only understand information but also encouraged her to complete treatment and feel supported. Her reference to 'them' suggests she believed HCP approached all teenagers in a similar manner. Positively involving teenagers in this way is seemingly straightforward when cure is likely and treatment is successful. Information acquisition and upfront communication serves a purpose, to encourage teenagers to adhere to treatment and boost morale following a serious diagnosis. When the treatment goal is no longer for cure, and the information provided is no longer positive the purpose and utility of teenagers' involvement changes. The influence this change has on the enactment of involvement in practice is something I return to in Chapter 7.

Of note, no parents or family members expressed a desire or expectation for their child to receive information directly from HCP independent of the family. Whilst, HCP were recognised as a source of information for parents they were rarely the only source accessed. The acquisition of information from multiple sources was deemed central to their perceived role as information seeker.

Acquiring Information by Overhearing

Several parents made reference to instances where information was acquired by overhearing conversations between HCP. One mum deduced that her son was getting discharged from hospital based on information she heard while going to the loo,

Jane Stephens: I went to the loo out there and I said [to Tom] oh, they're talking about you. I said we're – you might be able to go home, and he's going oh you're being too positive. I'm saying no, you've got to be

positive thinking. Cause I heard 'em say something about “well if his temperature just staying like that’ and that’s all I heard.

Jane reported that HCP were discussing her son outside of his room, and from the statement ‘if his temperatures are just staying like that’ she inferred that the health care team might be considering sending her son home. This information was confirmed shortly after when the HCP entered Tom’s room on a ward round. Jane was able to inform her son of a discussion that neither was invited to be a part of, accidentally involving both of them in an information exchange. Whilst for this family, the information was positive and quickly reported to them by the HCP, for other parents and teenagers overhearing HCP discussions can cause panic if that information is then not then relayed to them,

Jasmine Mirzaei: He, he feels insecure. I’m trying to tell him – I’m not sure how. He overheard him [doctor] – he says “are they taking me to ICU?” I said no I’m here, no I’m here. I’ll make sure they don’t take you there.

Here one mother recounted how her son overheard a discussion between the doctors regarding his possible transfer back to intensive care. Jasmine was left to reassure her son that she would not let this happen. HCP must be aware that the nature of the hospital ward allows parents and teenagers to access information from HCP without their explicit intent. This suggests that teenager’s and parent’s involvement through the provision of information is not restricted to direct conversations between HCP and families.

Acquiring Information Through Research

Several parents and family members reported doing their own research around their child’s condition and treatment options. Whilst HCP took on the responsibility of providing information, parents and family members took

responsibility of acquiring information to better understand care and treatment. As the following discussions with Masood's sister and Poppy's mother suggested,

Talia Rossi: Cause I've been doing a lot of research that whatever they (HCP) saying is just completely different, and I'm just thinking why is that?

Nadia Conteh: It's got me in that situation where any treatment, any medicines that are given out I'm asking which one is that, and then I'm looking out what is it for, and I am looking at research on it and I am looking, almost ridiculous.

Emma Day: That must have been exhausting

Nadia Conteh: It was so exhausting. I was having nightmares, books and books beside me, I was like I don't want to do this, I just want to focus on the children I don't like reading anymore. But you know it gets you into a situation you want to help but, at the same time you need to know what is going on around you, it's knowledge.

In order to understand 'what is going on around' her, Nadia, in line with other parents and family members felt she had to do extensive research outside of the consultation. With HCP taking responsibility for delivering information and parents taking responsibility for acquiring information, how teenagers themselves view their responsibilities in this information exchange will be discussed in Chapter 6. No parents encouraged their children to seek information to the extent they were willing to, begging the question as to how much teenagers are able to understand 'what is going on around them'. Whether teenagers are seeking similar levels of information, or relying on the information provided from parents and HCP alone is something I discuss later, the influence this may have on involvement in interaction is something I turn to Chapter 7.

One teenager translating for his mother (influence of language on teenagers role discussed in Chapter 6), described the treatment he would have received had the specific type of ALL he has been recognized earlier by the HCP,

Harry Bukoski: My mum reads up on like –

Karina Bukoski: [Speaks in Polish]

Harry Bukoski: [Translating for Karina] yeah, so there was a case where a girl was diagnosed with the Philadelphia syndrome and all they did was just clean out the bone marrow then transplant.

Interestingly, this is something the HCP felt this family had not fully understood, due to their lack of questioning. With the assistance of Karina's research skills and the open communication between Harry and Karina, both were privy to information that HCP attempted to minimise their exposure to. Though HCP did inform both Harry and his mum of this initial misdiagnosis, the family's subsequent lack of questions to the HCP led them to conclude that the family had not understood the information they had been given. HCP made an assumption about this families understanding based on their verbal engagement with the health care team, however, this family sought information from other sources and thus reached an understanding through different means. This notion that information can be obtained from other sources is something HCP must acknowledge.

Acquiring Information From Other Families

Parents were also able to access information from other families on the ward. The communal kitchen and open games room provided plenty of opportunities for families to meet and discuss their child's treatment, as the following examples suggest,

Taalía Rossi: It was the same medication – there was another kid who was 14 years old – he’s dying as well he was on the same medication. Whatever they were giving – so whoever’s dying they give them that medication

Samina Haider: to ease them

Taalía Rossi: to literally slow them down, and it, it kills them slowly basically.

Jasmine Mirzaei: You know I spoke to Becky [Aldea] because they’ve got the same thing, same leukaemia. He’s [George] got B-Cell – everything is same with her [Becky], just she is a girl, her treatment would be two and a half year; he is a boy it would be one year more. But now after eight hours – eight doses of chemo they see just inacey-wincey, not in blood and microscope, they see inacey-wincey of leukaemia after eight doses.

In these scenarios the information acquired from other families provided some sort of confirmation that their family member was dying, as well as hope that other teenagers with the same diagnosis were successfully receiving treatment. The actual information that is delivered in discussions between different families requires examination to determine the impact such discussions have, something not attended to here. Whether teenagers talk as openly together on the ward is something parents did not allude to, though by virtue of their impaired immune systems many are restricted to their rooms and thus unable to physically meet others.

Acquiring Information Through Experience

Finally, a key way in which parents reported acquiring information about their child's diagnosis and treatment was through experience. One mother who had been in and out of hospital with her son since his diagnosis in 2013 spoke of her understanding developing over time,

Samina Haider: When I, when he was diagnosed – when I started – when I came in 2013 I swear to god when doctors are talking I don't understand nothing. I just watched them you know. But time goes on – I started researching... so now it's easy for me.

Samina recognised that she initially found the doctors talk confusing but given time, she found it much easier to understand. The changing levels of parents understanding is something HCP must acknowledge as a family move through the trajectory. Responding to a comment about whether or not her son's response to medication was strange for her to witness one mother stated,

Jasmine Mirzaei: The first time was – but I've got experience now. I know [only] 3 months passed but I still – you know.

This suggests that parents experience can build over a relatively short period of time, experience being less related to actual duration and more related to the events and decisions faced. For this mother, the first three months of her sons' diagnosis was characterised by repeat admissions to intensive care following severe reactions to the medications he was given. Unusually therefore, this family had experience of events, decisions, roles and responsibilities within their first 3 months that many families will never face over the entire trajectory.

Parents and family members reported acquiring information from a number of sources as one of their key roles and responsibilities across the trajectory. While some sources required them to actively seek information, others provided information with little to no effort on the part of parents' and family members.

5.4 Teenagers Roles and Responsibilities

Parents and family members also discussed the roles and responsibilities they attributed to teenagers, though these were less well defined than those they afforded themselves. Focus was largely placed on the roles and responsibilities teenagers could not or should not adopt, rather than outlining a clear role for them to adopt.

5.4a Acting on the Care and treatment preferences of the Teenager

The principle of acting on the care and treatment preferences of the teenager resonated with parents and family members, as it did with HCP. However, unlike HCP who supported the idea of attempting, where possible, to do act on teenagers care and treatment preferences, these family members were less convinced that involvement centered on the enactment of their brother/ brother in law's wishes and preferences,

Jac Rossi: Because they [HCP] had it in their heads – like this was a couple of months ago – they said to us, oh yeah, we know Masood doesn't want to go back to intensive care unit – it's not that he doesn't want to go – the way he sees it, if he's well enough to be upstairs, he's happy to be upstairs... That's the issue. Because in intensive care he was bored. He was in a room with no TV or anything, just sitting there – so obviously he didn't want to go back there. But they have the tendency

of trying to dictate and trying to use certain mind games, like oh yeah, Masood doesn't wanna go down there, Masood doesn't want this.

Jac took issue with the way in which HCP established what his brother-in-law wanted with regard to readmission to ITU. The return to ITU seemingly has different connotations for HCP and teenagers and their families. In this instance the teenager's preference not to return to ITU was based on his previous experiences of being bored on the comparatively dull ward, rather than a deeper acknowledgement that not returning to ITU would impact on the degree of resuscitation he could receive. Jac made reference to the 'mind-games' HCP play to make a decision seem like it had been conceived in line with what the patient wants. As Masood's sister went on to state, this became increasingly evident for the family when Masood voiced a preference that was not enacted,

Talia Rossi: But then he [Masood] asked to go downstairs [to ITU] – why didn't you [HCP] take it seriously?

Emma Day: Who did he ask?

Talia Rossi: The nurses... Why didn't you go to the doctors if Masood – you guys were looking out for Masood and whatever Masood wants – we will do –

The family continued,

Jac Rossi: We knew him better than anyone else –

Samina Haider: Um hum

Jac Rossi: - and he said he didn't want to go back into intensive care –

Talia Rossi: but then he was asking –

Jac Rossi: - but he asked to go.

Taalía Rossi: – with two days to go – yeah

Jac Rossi: Two days before he passed away –

Taalía Rossi: he was begging.

Jac Rossi: – he begged to go downstairs [to ITU].

This family noted inconsistency with the way in which HCP framed the teenager's role and responsibility in the decision-making process. By implying that HCP will 'do whatever the patient wants' the family are left questioning why Masood's preference was ignored when he requested transfer to ITU. Taalia Rossi goes on to rhetorically question the HCP involved in her brother's care, asking 'is it you that's suffering? No, it's him. So let him go downstairs', suggesting that this is decision she felt should have been made with the family and teenagers preference at the forefront. They are left with a memory of their son and brother 'begging' for the chance to be transferred to intensive care to receive 'more oxygen' [Taalía Rossi], and this request being overlooked by the HCP. As I shall discuss in Chapter 7, the way this decision was framed in consultation with the family and Masood arguably set unachievable expectations for the role and subsequent involvement of Masood as the central decision-maker.

Taalía acknowledged that HCP directed the majority of their talk towards the teenager during consultations, something I return to in Chapter 7. However, like her husband she argued this was not the most effective way of eliciting what the teenager wanted,

Taalía Rossi: ... Cause sometimes when the doctors were talking, they don't even look at us they look at him [Masood]. He's unwell, he can't

even understand what the hell you're saying – that's why sometimes he looks at me, for them to, to talk to me.

Masood's sister explained that her brother often looked to her to communicate with HCP when he was not feeling well and did not understand what was being discussed. She suggested that HCP afford teenagers a role in communicating that they do not always welcome. Saanvi Passi echoed the notion that seeking a preference from the teenager alone is ineffective due to a lack of understanding. Speaking after a consultation where, despite efforts by Dr Talbot to convince her son, in line with her sons' wishes he was not re-fitted with an NG tube,

Saanvi Passi: No I'm not happy with what she [Dr Talbot] said because I know he's not eating that much. He needs it [the NG tube]. Especially with all his medicines, if he is feeling sick, because he's – I'm giving him early in the morning, he was sleeping so he doesn't know; he doesn't know the value of having the tube.

Saanvi spoke about benefits of the NG tube that her son was not aware of. This idea that the teenager does not have care agency, that he is not responsible for the daily management of symptoms and thus not fully able to comprehend the value of the options available is a notable one. Whilst, talk of teenagers capabilities often focus on age and comprehension of information this introduces the idea that teenagers are simply not the individuals responsible for providing care and thus are relegated to less active role in treatment decisions than parents. In some instances this may be welcomed by the teenager, encouraged by the parent or decided by the immutable practicalities and physical limitations imposed by the disease and/or treatment. In line with this, one family reported that medication and treatment side effects reduced Masood's capability to effectively report symptoms,

Taalía Rossi: Because all of these painkillers they're [HCP] giving him [Masood], I know they were easing up the pain – but I'm telling them [HCP], there is no pain. He is not in pain. But whatever you say to him he goes like that [nods] even if I say to him “are you ok?” and he's not, but he'll go “yeah”. If I say to him “are you hungry?” he will say yes. He was high babe.

Retrospectively discussing the weeks and days before the death of her brother, Taalia Rossi suggested that the medication her brother received made him less competent in his role as a decision-maker. She suggests that he was 'high' and simply nodded in response to any question he was asked; consequently, she believed she was in a better position to determine her brothers' level of pain than he was. Therefore, in this scenario doing what the teenager wanted was not considered central to the decision-making process for this family member. This highlights a potentially important role family members assign themselves in pain reporting as their son/ brother progresses through the trajectory.

One mother did acknowledge her daughters capabilities as a decision-maker and championed her ability to make a choice. However, this was with regard to a decision about continuing academic study while receiving treatment as an inpatient,

Nadia Conteh: It's not about us, it's about what she wants to do because, from our point of view she is capable, she is brilliant.

This mother praised her daughters' capabilities and stated that for this decision, to continue A Level study, it was what her daughter wanted that was important. This suggests that parents are able to make the distinction between decisions that they are comfortable with teenagers leading on and those that they are not.

In this case the decision is not a medical one, but an academic one and thus the parent believes lies in the teenagers remit. Importantly too perhaps, this decision allows both parent and teenager hope for a future.

5.4b Distributing Responsibility to Teenagers

Parents and family members rarely spoke, without prompt, about the responsibilities of their child. The roles they assigned themselves were evident; as were those they assigned HCP. The roles and responsibilities they assigned to teenagers however were less clear. The two parents who did allude to their child having or taking some responsibility for decision-making were the parents of two of the older teenagers. One mother speaking of a decision not to re-admit her son as an inpatient stated,

Jane Stephens: The thing is, he's not silly and if he does feel sick – or his temperature goes, he would ring and he would come straight up anyway.

Here Jane afforded her son Tom the responsibility of returning to hospital should he feel unwell. This is one of the few comments by all parents and family members where the teenager has been referenced independently of them. Jane acknowledged Tom's exclusive responsibility to verbalise his symptoms and act upon them, positioning his involvement, co-operation and common sense as integral to the decision.

A second mother spoke of the trust she had in her parenting and the values her and her husband had instilled in their children. This offered comfort when discussing the responsibility all her children have to take initiative and make decisions,

Nadia Conteh: I know that the initiative that they are going to take is to help; it's going to be a good one, it not going to be one that is going to be stupid because they have the moral upbringing and understanding of what they need to be doing.

This further supports previous sections and chapters that recognize the intertwined nature of parent and child. As Nadia stated, she was comfortable with her child's role in stating a preference and coming to a decision because she was confident that her child will reflect the same values and come to the same decisions as she would. As mentioned earlier however, this mother revealed how she would encourage further discussion, should her daughter come to a decision that she did not agree with. Finally, both these mothers discussed their child taking responsibility for relatively minor decisions, no parents or family members facing end of life decisions with their child discussed the teenager's responsibility in the decision.

5.5 HCP Roles and Responsibilities

Parents and family members saw the roles and responsibilities of HCP as central to how decisions got made and consequently central to their principles of involvement. As demonstrated below parents and family members afforded HCP the role and responsibility of ultimate decision-maker, whose advice and guidance should be followed.

5.5a Following the advice of HCP

Parents and family members stated that for them, the principle of following HCP recommendations was often integral to their decision-making process. A belief that HCP act in the best interest of teenagers was central to the willingness of parents to follow their lead, and encourage their teenage family member to do so too. Acting on the advice of HCP was often seen as the right thing to do, the

best course of action regardless of the teenagers preference. One parent elevated the doctors' word as the ultimate authority to convince their child to follow a course of action,

Saanvi Passi: If Dr Talbot says yes then he'll put up with it [NG tube] – if not

Anwar Passi: No

Saanvi Passi: You will

Anwar Passi: No

This parent positioned the consultant as an authority figure for her son, whose advice should be heeded. Her son, however, placed less significance on HCP advice and ultimately, despite attempts to convince him; he did not have the NG tube. Unfortunately for the mother in this case HCP advice does not guarantee the outcome. Despite policy attempts to move away from a more paternalistic model, there remains an ingrained acknowledgement amongst parents that doctors often have decisional authority over them or their child. When asked 'Who makes the decisions?' one mother responded

Jasmine Mirzaei: I think all together... Mostly I think doctors, because I'm not a scientist, or I'm not familiar with these sorts of things – they know his physical and body situation. They do their best to make a best situation – a best decision.

This was a common response from parents, who recognised there was a role for everyone [parents, family, teenager and HCP] together, but that ultimately HCP, specifically doctors, make the decisions and the responsibility lies with

them. This parental view is reinforced from the outset when their child is first diagnosed, as one mother recounted,

Nadia Conteh: We know the kind of cancer she has is rapid growing one, so we didn't have any opportunity to start thinking about options, trying to guess what options we need, we went straight for what the doctors think is right.

This idea that parents and teenagers go with 'what the doctors think is right' continued as the treatment progressed,

Jasmine Mirzaei: It [MRD test] show[ed] low-risk of cancer – like, hopefully – so I'm going to continue [with the treatment], because they [HCP] say we have to, it's logical.

Jasmine made reference to doing what the HCP advise because it is logical. Reflected in much previous literature (Zwaanswijk et al 2007, Stevens et al 2002, Woodgate et al 2010, De Vries et al 2010), is the idea that the degree and extent of teenagers and families involvement is constrained from the outset by immutable factors such as treatment urgency and rigid protocols. This early concession to go 'straight for what the doctors think' sets the scene for how parents, inexperienced in the hospital setting, position themselves and their child in decisional involvement across the trajectory. For some parents this positioning holds true throughout their child's disease trajectory, while for others this early bewilderment, and perceived roles and responsibilities inspires a quest for knowledge so they can better involve themselves and their child.

There was a sense amongst some parents and families that doctors were not always right, advice should not always be followed without question and the

protocols and plans HCP offer have a degree of flexibility. Parents and guardians seemed to take responsibility for identifying these points at which advice could be questioned. As shown by this discussion between a mother and son relating to the insertion of NG tube,

Jane Stephens: Why don't you just refuse then? "I don't wanna" – Can you refuse it?

Tom Stephens: No – I dunno. I don't think it's best to refuse what the doctors say. Let's be honest.

Here, despite not wanting the tube, Tom rejected his mothers' suggestion that he should go against the advice of the doctors. Tom's previous negative experiences of having the NG tube were the topic of much discussion between him and his mum. Jane was keenly aware of how much Tom disliked the NG tube previously and how much it dampened his mood, Jane was keen for Tom to not go through this again and wanted to protect her son from the discomfort of having the NG tube. This knowledge led her to question whether the doctors' advice was right for her son, at that moment in time.

The belief that doctors are not always right seemed to serve an important purpose for one family, who recounted an anecdotal story of another family's experience in hospital,

Anna Awzi: Doctors are not always right to be honest

Samina Haider: This [is] her opinion

Taalía Rossi: That's my opinion as well.

Anna Awzi: They're not always right

Taalía Rossi: Because I've seen, this lady they told her – her daughter was that small they told her that it's 15% [chance] that her daughter would live. They refused to believe that and her daughter now is 12 years old.

Holding a belief that the doctors do not always get it right allowed the family hope. By maintaining this belief they afforded themselves a layer of protection from any bad news the doctors gave them. For this family, this belief led them to ask many questions of the HCP and the treatment they provided, doing their own research alongside as discussed earlier.

Previous negative experiences with hospitals influenced some parents' trust in HCP. One father explained how his mother had recently died at the same hospital and spoke of his belief that the hospital was in some way responsible, reflecting on how this influenced his involvement in his daughter's care, Raul said the following,

Raul Aldea: – I tell him [Dr New] please believe me because you understand me, why I tell the doctor to tell me exactly what's happening for my daughter. [...] I leave my job, please believe me, I come here every day cause [in case they are] doing something wrong for my daughter, I love my daughter too much, I [want to] know when they are doing something.

His fear that the doctors would do something to his daughter without his knowledge, that would harm his daughter, led him to try and actively involve himself in every decision HCP made. As a result, this family as a whole found it difficult to follow HCP advice and trust in the diagnosis they were given and the treatment they were provided. He recognised that his English was 'no good' and often relied on his daughter to relay information he was unable to understand to

and from HCP. Nonetheless he acknowledged his responsibility to obtain information from the doctors, whilst affording the doctors the role of decision-maker, the individuals doing the things that, because of the limitations of language, he is trying to understand.

5.6 Summary

In this chapter I have presented the principles expressed by parents and family members, highlighting the roles and responsibilities that shape their involvement, and that of teenagers and HCP in the decision-making process.

The principle of acting on the care and treatment preferences of the teenager was criticised by parents and family members as an effective way to involve teenagers in medical decision-making. Parents expressed issue with HCP relying on the teenager's preference when the teenager does not fully understand the choices to be made, due to the practicalities and physical limitations imposed by the disease and/or treatment. Similarly, parents and family members identified inconsistencies in how HCP assess the preferences of teenagers and when these preferences are acknowledged and enacted. By propagating a narrative of patient choice and involvement based on the principle of acting on the care and treatment preferences of the teenager, the HCP set an unrealistic expectation for teenagers' involvement. Consequently, leaving families confused and frustrated when the teenager's preference is seemingly overridden by the HCP clinical assessment of best interest. The two families who expressed dissatisfaction with the HCP approach to involving teenagers by 'acting on the care and treatment preferences of the teenager' were the families of the two teenagers who died during or shortly after the study. Suggesting that involving teenagers by centralising their preferences may be less acceptable for parents and family members and less achievable for HCP when a teenager's treatment is unsuccessful and cure unlikely.

Rather than enacting the preferences of the teenager, parents and family members expressed the importance, and often the necessity, of doing what the HCP advise. Assigning HCP the role and responsibility of ultimate decision-maker. Parents held the advice of HCP in high regard and often opted for the choice advocated by the HCP. Parents' alignment with HCP influences how the involvement of the teenager can be enacted. For teenagers under 16 years of age, parental consent is legally required before treatment commences, for teenagers up to 18 years of age parents are still able to override their refusal – therefore due to immutable factors relating to legal status the alliance between HCP and parents preference has the potential to side-line the preferences of teenagers.

However, parents and families do not always align closely with HCP, with some suggesting that the choices they advocated were nothing more than rehearsed protocol. In these instances parents and family members questioned HCP expertise and the paternalistic view that doctors are always right. Here, parents and families asserted their role as protector and voiced their preferences and encouraged their child to do the same. Notably, these preferences were rarely asserted for decisions of serious consequence (i.e. initiating treatment at diagnosis, instating a DNAR), and when they were, they were often over-ruled by the medical assessment of best interest.

Parents and family members recognised the imbalance of knowledge between them and HCP. As is apparent, parents and family members accepted that seeking information from a variety of sources, including HCP to gain knowledge about their child's treatment and side effects, was integral to their role. In each family, at least one member seemed to take responsibility for actively acquiring information through research and conversations with others. Inevitably, all gained experiential knowledge as decisions were faced and treatment progressed. Whilst parents and family members often reported extensive searches for relevant information, there was no mention of the teenagers doing the same, nor any expectation for them to do so. If, as findings suggests,

teenagers are privy to substantially less information than their families and HCP, and both parents and HCP champion the importance of information in the decision-making process, what benefit is served by encouraging teenagers to take decisional authority.

What is evident is that parents and family members strongly advocate for the involvement of the family as a whole. No parent or family member expressed the belief that a teenager should be responsible for making decisions independently of them, be it of serious consequence or not. Few parents outlined the responsibilities of teenagers themselves. Only the mother of the oldest teenager in the study, acknowledged her sons responsibility to respond to his physical symptoms.

Consequently, the role and responsibilities of the teenager are underrepresented and largely unknown. In an effort to rectify this I now move on to discuss the principles of involvement as expressed by teenagers themselves, before concluding findings with accounts of the involvement of teenagers when all three parties come together in practice.

Chapter

6

Teenagers Principles of Involvement – The roles and responsibilities of HCP, parents and teenagers

A chief aim of this thesis is to provide accounts of the involvement of teenagers as perceived by teenagers themselves. I sought accounts from teenagers who were experiencing a serious leukemic diagnosis, focusing on the decisions they encountered in real time. In this chapter I focus exclusively on the understandings and conceptualisations of the involvement of teenagers in decision-making as expressed by seven 13-19 year olds. I draw on data from informal discussions and interviews with teenagers currently receiving care and treatment for leukaemia. I present principles that illuminate how they understand their involvement in decision-making, as well as the involvement of their families and health care teams. I reflect on how these principles relate to those expressed by health care professionals and parents before moving on in the following chapter to discuss involvement when these three parties come together in practice. Table XIII outlines these principles as they occur across the data set.

Table XIII. Overview of Teenagers Principles and Occurrences Across the Data Set

Principle/ factor		Description	No. of times principle was mentioned in informal discussion / interview	No. of teenagers who made reference to principle /7
Acknowledging Changing Information Preferences	Information seeking	Teenagers' reference to their preference for information acquisition and	19	4

Principle/ factor		Description	No. of times principle was mentioned in informal discussion / interview	No. of teenagers who made reference to principle /7
		information seeking.		
Teenagers Role	Teenagers defining involvement	Teenagers views about their satisfaction with their role in decision-making	8	5
	Acting on the care and treatment preferences of the teenager	Teenagers' views about HCP doing what teenagers want with regard to decision-making about their care and treatment.	25	6
HCP Role	Following the guidance provided by the HCP	Teenagers views about acting in accordance with the recommendations of HCP.	29	6
	Recognising HCP distinct roles in decision-making	Teenagers views about the distinct roles different HCP have in the decision-making process	9	5
Parents Role	Recognising parents as Information holders	Teenagers views about parents as holders of information about their illness and treatment	5	3
	Accepting advise from parents	Teenagers views about parents as advisors in the decision-making process	5	3

Principle/ factor		Description	No. of times principle was mentioned in informal discussion / interview	No. of teenagers who made reference to principle /7
Influence of a language barrier		Teenagers views about the influence of the language barrier between their parents and their HCP.	2	1
Immutable Factors	Diagnosis restricting choice	Teenagers views about their diagnosis and the limited treatment options restricting their ability to choose.	16	5
	The significance of chronological age	Teenagers views about the significance of their chronological age with regard to their role in decision-making	15	4

6.1 Data

The findings presented in this chapter are drawn from data collected from semi-structured, open-ended interviews and informal conversations with teenagers diagnosed with leukaemia. Table XIV outlines the data sources called on for this chapter.

Table XIV. Data Source Table - Teenagers

Data source	Number of encounters	Number of teenagers /7
Semi-Structured, Open-Ended Interviews with Researcher	4	4
Informal Conversations with Researcher	104	7
Total Number of Encounters	108	7

Informal discussions occurred over a period of 9 months and were had with teenagers alone or while parents and family members were present but occupied with other things. Informal discussions, were exactly that, they had no pre-determined structure. Conversations naturally unfolded and a range a topics were covered, including those pertinent to this research (decisions about treatment, thoughts about decisions that had been made, how they viewed HCP and themselves at different points), as well as those less so (who was dating who in their class, the plot line to the Fast and Furious movie series and what dresses were going to be in fashion that summer). As regular visits were made, relationships were built and discussions about what was happening with their care and treatment unfolded naturally.

Structured interviews were had to elicit more specific views about involvement (see Appendix III interview guide for teenagers), for some teenagers this was not necessary, as the guided topics had been covered naturally over the course of informal discussions. Through the informal discussions it was also apparent which teenagers would respond and engage with the more formalised interview and those who would not (due to physical wellbeing or those who became increasingly withdrawn). Table XV outlines the informal conversations and interviews held with each teenager over the 9-month period.

Table XV. Informal Conversations by Teenager

Teenager name	by	Number of informal conversations	Semi-structured Interview conducted
Anwar Passi		15	No
Poppy Conteh		16	Yes
Masood Farran		4	No
Tom Stephens		26	Yes
Harry Bukoski		32	Yes
Becky Aldea		6	No
George Mirzaei		5	Yes
Total		104	4
Range	4 – 32	Average	15

The number of informal conversations with each teenager ranged from just four to 32. A number of factors contributed to this including, the teenager’s physical wellbeing, length of inpatient admissions and the length of time in the study (Masood passed away three months into the study).

6.2 Acknowledging Changing Information Preferences

The exchange of information has hereto been recognised as integral to the involvement of both parents and teenagers in the decision-making process. Whilst the role and information preferences of HCP and parents have been clearly documented in this thesis the role and preferences of teenagers currently undergoing treatment have been less clearly articulated. Interestingly, one patient explained his changing preferences as his disease progressed, treatment intensified and his hospital stay extended,

George Mirzaei: I think the psychologically – the psychological side to it is very important, because (pause) I’ve been here for over a hundred days. So at around, you know day 50 – my decision may be different to today. Like with chemotherapy. So I think there are stages sort of to

being – not isolated but being in a confined sp[ace] – you know. Being in a room so long.

He suggested that his psychological state over the course of his hospital admission changed. When asked if he felt HCP should listen to his decisions differently in accordance with the changes in his mental health George responded,

George Mirzaei: Yeah. Because I would say at – you know, someone who's been in the hospital for two days is gonna be more patient and understanding to someone who's been here for 500 days and is mental.

Though he does not elucidate how HCP should respond and deal with the teenagers preferences across the trajectory in practice, he did advocate the principle that the way teenagers preferences are dealt with should be responsive to the changing psychological state of the teenager. George explained how his information preferences were also subject to change across his trajectory,

George Mirzaei: I think that depends on my wellbeing – my health and wellbeing

Emma Day: Can you explain what you mean by that a little bit?

George Mirzaei: I was blind in my left eye in ITU but they didn't tell me. My mum said not to tell- told them [HCP] not to tell me. So I guess that made it easier to – well, I just didn't know until the other day.

Emma Day: How did you feel when you found out?

George Mirzaei: Scared. So... I would've probably had a panic attack if they told me then.

Emma Day: Are you glad they didn't?

George Mirzaei: Well I'm glad they told my mum. But yeah, I mean that was her decision for them to keep that from me.

Emma Day: How do you feel about her making that decision?

George Mirzaei: Not sure, I mean I wouldn't have wanted to know. Only because I can see from both my eyes now – so I, I can say, you know, it was good that she didn't tell me, but if it was permanent then, you know, maybe my answer would be different.

Crucially, George recognised that the outcome, in this case regaining sight in both eyes, influenced how positively he was able to reflect on his mum's decision to keep information from him when he was acutely unwell. He recognised that receiving the news at the time would have caused him to panic, adding to the stress and uncertainty of an ITU admission. He also acknowledged that it was his mum's decision to keep the information from him, rather than the health care professionals. It is these scenarios that reinforce the perceived parental role as protector and information holder, for teenagers, parents and HCP.

For other teenagers, a clear preference was stated for receiving information upfront and directly to them, as shown by this statement made by Poppy,

Poppy Conteh: I like being told straight up. I don't like people - I just like being told it straight, it's easier that way rather than pondering.

Poppy suggested that receiving information upfront was easier than wondering what may or may not be happening. Of note, the decisions faced by Poppy were of less serious consequence than the other teenagers in this study, responding well to treatment she was not faced with information relating to poor prognosis or potential death. There was an acknowledgement that HCP would

give teenagers the information they wanted, when they wanted it as Tom explained,

Tom Stephens: They [HCP] give you the choice, and so it's down to you really they don't put it – because they say 'how much do you want us to tell you, we can tell you percentages of survival rates' I mean, they say like 'oh do you want that or not', and so it is down to you really.

Tom suggested that he was able to make a choice about what information he received, notably regarding survival rates. Another teenager, who, unlike Tom, opted not to hear about survival rates after transplant echoed this. Crucially, teenagers recognised times when they want information and times when they are content with less information, as well as recognising types of information they welcome and types they do not. This suggests that teenagers afford themselves a role in filtering the information they receive. As George suggests, this is also a role some teenagers are happy for parents to adopt when they are critically unwell in ITU.

6.2a Information Seeking

Like their parents, some teenagers suggested that the principle of information seeking was important to them. However, this was reported almost exclusively around diagnosis, with no teenager reporting the continued search for information as his or her treatment and/or disease progressed. Poppy described receiving information from booklets provided to her by HCP and articles provided by parents early in her trajectory,

Poppy Conteh: I read lots of like articles. My mum was reading articles [...] yeah, read this, [mum] threw them at me and I wasn't in the mood to read and I was like oh.

Emma Day: Was that good for you?

Poppy Conteh: Yeah, I knew quite a lot about it and because when I got home they gave me like a big booklet on just my specific type of leukaemia. Because there are in fact two types – there is AML and then APML, which is like the rarer one. So I read a lot about that one. In detail.

Poppy states that with the encouragement of her mum and HCP, who provided her with articles and booklets, she read about her cancer. She also acknowledged that there were times when she was 'not in the mood' to read information, content with her mum continuing to search for and absorb information independently. On the whole, teenagers trusted in HCP to provide them with information as and when they needed and wanted it, seeing little use in researching around their disease or treatment, as Harry recounted,

Harry Bukoski: I just don't really get into that sort of thing [searching for information online]. I just let them [HCP] do their thing and get on with it. [...] And also, like I mean it's like, my mum can read on the Internet as well but information could be like ten years old and out-dated. And then she'll read about it and she'll be like 'oh no' – she'll get all worried about it and then the doctors are like 'no, just don't, don't worry about it, that's like ten years old, we did that with different patients and stuff, we've got like a medicine that will do it in one day instead of two years'.

Again Harry acknowledged differences between how he and his mum sought information, and the disadvantages of doing research outside of his health care team. Unlike parents, teenagers did not report seeking information from multiple sources, instead relying on that provided by HCP and occasionally parents. These comments suggest that teenagers are confident in the HCP provision of information above and beyond anything that they would be able to find through other means.

Teenagers regarded asking questions of the HCP as part of their role in decision-making, as Poppy suggested,

Poppy Conteh: You can ask them [HCP] questions, asking questions is probably the key thing of the whole thing, it's better to ask question that just to go right okay.

Emma Day: Who did you ask the questions to?

Poppy Conteh: I would to the doctors, or maybe just the nurses – they always told me, or they ask the doctor and come back to me.

While Poppy suggested that asking questions is the 'key thing', an examination of the types of questions she asked in practice would offer further insight into the purpose of asking questions of the HCP. For example, Poppy suggested that asking questions was better than just agreeing outright to a course of action. Whether in practice, teenagers ask questions as a way of challenging a course of action or to better understand a pre-determined course of action is unclear and something to be discussed in Chapter 8.

6.3 Role of Teenagers

Teenagers verbalised various principles about the role they played in decision-making. These principles focused on their preferences, the impact of their diagnosis and the significance of their chronological age. Initially it is important to acknowledge how teenagers themselves defined involvement and how they reported their satisfaction with their current level of involvement. Before moving to a discussion of principles relating more specifically to the roles teenagers assign each individual in the process.

6.3a Teenagers defining involvement

Importantly, teenagers in this study reported they were satisfied with their role in decision-making regarding their care and treatment. Regardless of the role reported, no teenager expressed dissatisfaction, as indicated by the following statement from Poppy,

Poppy Conteh: Involvement means me being the main orchestra – As in make sure my points are being heard. Just what involvement means.”

Emma Day: “And do you feel you were involved?”

Poppy Conteh: Yes. Yeah, which is great. Nice being in charge of a life, it’s my life.

Of note, Poppy went on to mention how she did not feel she made many decisions and the HCP did not really give her many options. She did however recognise that she had a degree of control over her treatment timetable once she became an outpatient, often changing treatment times to fit around her exam schedule and other academic events. These were important choices for Poppy and afforded her a sense of ‘being in charge’, allowing her to maintain her school commitments despite her diagnosis. For Poppy her definition of involvement did not include her preferences being acted on, but simply her ‘points being heard’, beyond listening, what HCP or parents do with her points in practice is unknown and seemingly unimportant. Tom and George focused on information exchanges when discussing their inclusion,

Tom Stephens: I’d say I was very included, so like with the information given, they always give it to you, they always give you the choice (pause)

George Mirzaei: Yeah [I’m happy with my level of involvement]. It’s more, it’s more about being informed about what’s going to happen, rather than saying ‘option A, B or C?’

George and Tom stated that HCP were the main decisional authority, that their parents were often privy to more information than them, and that what they wanted was not always acted upon. These teenagers simultaneously stated that they were involved in decision-making and that they were happy with their role. This perhaps indicates a discrepancy between what constitutes the involvement of teenagers in policy and what teenagers themselves recognise as involvement in principle. As George succinctly summarises, for him the involvement of teenagers should be about information rather than choice.

6.3b Acting on the Care and treatment preferences of the Teenager

Four teenagers in this study raised the principle of acting on the care and treatment preferences of the teenager. For these teenagers the principle that HCP might follow the teenagers' lead and do what they wanted in terms of care and treatment presented a problem. For Anwaar Passi when asked if there were any decisions he wanted to take the lead in making he simply responded 'No'. Others provided more detail on why acting on the care and treatment preferences of the teenager, a principle held by HCP, was not a preferred method of decision-making. For example Harry remarked,

Harry Bukoski: I would – I think I would have made bad decisions anyway. Yeah. Even though, like, they'd tell me what to do and tell me what would happen if I wouldn't do it, I'd still make the wrong decision.

Continuing on,

Harry Bukoski: Cause like I don't think a patient could decide a treatment plan for themselves. Because, like, he does - (laughing) I, I wouldn't know what things to do. I'd be like just – I'm just gonna go home.

Harry suggested that he would make the wrong decisions and ultimately make decisions that allowed him to leave hospital and go home as soon as possible. Discussing a difference of opinion he and his consultant had about restarting his chemotherapy, where George wished to restart treatment as soon as possible and Dr Claire Talbot decided to wait until George was more clinically stable, he stated,

George Mirzaei: I think at that point my mental state was 'I'm sick of here [hospital] now, like I wanna leave', because I wasn't allowed – or I just didn't leave my room for so long. I couldn't really walk and – It was all just – I wanted to do it [get treatment restarted] and go home. But yeah – no, she [Dr Claire Talbot] – [delaying] it was the right thing. She did the right thing.

George acknowledged that his mental state caused him to favour the option that got him out of hospital the quickest, rather than the option that ultimately, with hindsight; he believed to be the right thing. He recognised disparity between what he wanted and what the 'right thing' was. Similarly, Tom recounted an occasion where he was not 'allowed to choose',

Tom Stephens: And one of the big decisions that I am so grateful for, that I wasn't allowed to choose, I wasn't allowed to choose the decision because I was eighteen they automatically sent me to this hospital. Whereas if I was nineteen I would have had the choice to have stayed at {local hospital} or come here. Now, being a young kid I was thinking oh it's close to home, be able to get visitors all the time just stay there but, I'm so grateful that I did not have that choice.

As is evident these teenagers were grateful to the HCP for not encouraging them to lead on decisions, as well as taking away their responsibility to make them. All three expressed a belief that they would not have made the right decision, and ultimately would have taken the option that required less travel, treatment and time in hospital. Crucially, these teenagers relied on the HCP to ensure they made the best choices, clearly appreciative of their input for decisions about place of care and treatment plans, both before and following relapse.

6.4 The Role of HCP

What is evident thus far is that teenagers do not view themselves in isolation, they recognise the importance of their relationships with those around them. Teenagers acknowledged that their relationship with HCP played an integral role in how decisions were made regarding their care and treatment.

6.4a Following the Guidance Provided by HCP

As indicated earlier in this chapter, teenagers reported a preference for the principle of following the lead of HCP with several teenagers suggesting that HCP were the ultimate decision-makers. Tom explained,

Tom Stephens: So at the end of the day they [doctors] have the final decision so, and you may get people who say 'oh no they don't, you have a choice', yes you have a choice but, you don't have the end choice sort of thing, you know what I mean.

Here Tom highlighted an important point about how he understands the nature of teenagers' involvement. As he stated, teenagers 'have a choice' but not the 'end choice', the final call remains with the HCP, specifically the doctors. The teenagers' role in decision-making does not extend to teenagers being the final

decision-maker. Harry echoed these sentiments and when asked if he would want to be more involved in decisions about his care and treatment, he responded,

Harry Bukoski: No. I, I think they, they [HCP] know what they're doing. They don't need the decision – like, opinion of a 16 year old.

Similarly George stated,

George Mirzaei: I, I don't, I don't really have – I'm not saying I don't have much say, but I don't really know enough to have a say. So I would just go with what the doctors say.

Finally, when asked if she felt HCP would respect her decisions if they went against HCP suggestions or advice Poppy stated,

Poppy Conteh: I don't know I think they [HCP] are just kind of glad to take over it, they don't really give me much options. I kind of just like trusted them that what they do is what's best for me, I wouldn't have gone 'oh no I don't like that give me something else'.

All statements suggested that these teenagers did not hold the value of their potential input in particularly high regard. The knowledge and experience of the HCP outweighs the benefit of their opinions or suggestions. For Poppy this was reinforced for her by the fact that HCP didn't really give her many options regarding care and treatment decisions throughout her trajectory. For others, experience had taught them that following the lead of the HCP was necessary even for minor decisions, as Harry recounted,

Harry Bukoski: The decisions I get to make now are like 'do you want this liquid or tablet?' I think that's the, that's the decision I made the most. Or if I want to put cream on, but that wasn't really much of a decision cause I had to do it anyway. I was just like 'I don't wanna do it' but then they're like 'you have to', I'm like 'okay then'.

The general message relayed by teenagers was that HCP were in charge of both decisions of minimal consequence (i.e. those relating to application of creams, fluid intake, NG tube insertion) as well as decisions of serious consequence (i.e. any decision where the outcome has significant impact on the teenagers health or long-term survival - treatment, transplant), and they would be ill advised to attempt to argue or intervene. Teenagers did recognise clear and distinct roles for different HCP that shaped how they interacted with them and crucially, how they obtained information about their treatment and engaged in the decision-making process.

6.4b Recognising HCP Distinct Roles in Decision-Making

Teenagers described how experiencing care and treatment as both inpatients and outpatients changed their preconceptions about the roles of doctors and nurses. When asked who ultimately decides what happens with regard to care and treatment in hospital, Harry commented on the distinct decisional role of the consultants and nurses,

Harry Bukoski: Consult – consultants I think. Cause that's like – like, they're the boss. And then there's the doctors who sign off on medications and stuff [...] and then there's the nurses who just sort of look after me. They – I, I think they [nurses] do most of the work. They deserve the glory mostly I think. Cause like, the doctors, they come around – they just sort of talk of a bit and then they just leave and then the nurses are just there, like 24/7.

Similarly Poppy acknowledged the difference between the roles of doctors and nurses,

Poppy Conteh: I thought nursing would be easy but it's not. Like, it's the nurses who have to deal with the patient. The doctors don't deal with the patients; they just have the knowledge of what's going on. They do quite a lot – it's all scientific.

Both Harry and Poppy made statements about the communication and relationship disconnect between them and the individuals they believe make the decisions and hold the knowledge about their care and treatment. Both spoke of doctors as more illusive and less involved with them as a person, while the relationship and communication style they report with nurses is more connected and reciprocal. Though they believed the nurses were the HCP who did 'most of the work' and the HCP who 'deal with the patient' they did not assign nurses any decisional authority. Nurses are involved in the daily care, engaging in more touch and physical caring activities than eye contact and formal conversation. Despite the large multi-disciplinary team, comprising HCP from a variety of specialities, teenagers exclusively referenced doctors and nurses during discussions about decision-making. While doctors were deemed responsible for making decisions, nurses were often recognised as individuals who would provide information to the teenager. As illustrated here, the doctors were regarded as too busy to provide information,

George Mirzaei: Cause the doctors are quite busy so you can't really just call them and like, you know, what does this do, what does that do – so you need to kind of – I wouldn't say wait until the morning but you do kind of need to wait until the doctors talk to you rather than you talking to the doctor.

Poppy Conteh: I would always ask anyway like the nurses because you could talk to the nurses when you want to get more, what's the word more informal

Again, both teenagers acknowledged a difference in the way they are able to communicate with the doctors and nurses providing their care. Teenagers afford a status to their doctors, suggesting that they have to wait until the doctor is ready to talk to them rather than engaging in informal conversation as they would with the nursing staff. Despite this lack of familiarity and imbalanced information exchange teenagers still recognise doctors as the key decision-makers. This understanding of roles has implications for how teenagers position their own involvement, not as principle decision-maker but as a contributor in the information exchange. George went on to discuss the role his doctors have outside of his immediate health care team,

George Mirzaei: I think that doctors just – doctors on my ward are kind of my voice.

Emma Day: Your voice to the rest of the hospital?

George Mirzaei: Yeah, as in they're my representatives.

George trusted the doctors on 'his' ward to accurately represent his needs to the rest of the hospital, ordering tests and scans, making referrals and escalating his care to ITU when required. Crucially, despite the acknowledgment that communication between doctors and teenagers is relatively formal and restricted to certain times, teenagers do not report a need for doctors' roles to change to be able to act as their voice and decision-maker.

6.5 The Roles of Parents

Teenagers also articulated several roles they assigned to their parents and family members. These roles echo those described by parents themselves and HCP (parents as information seekers, holders and advisors). This suggests that all three parties in principle are in some agreement about the role played by parents and family members in the decision-making process.

6.5a Recognising Parents as Holders of Information

One role several [three] teenagers recognised for parents was to obtain and retain information about their treatment and condition. As well as seeking information through independent research [see information seeking] teenagers acknowledged that parents were privy to more detailed information from HCP than they were. 17-year-old George recounted the following scenario demonstrating this,

George Mirzaei: Cause I know they [HCP] – my mum is usually involved in those conversations outside [my room] cause they have them without me.

Emma Day: Right, why is that?

George Mirzaei: And – I'm not sure. It's usually, my mum's there and they'll explain everything to her and the dilemma, then they'll come in [to the room] and explain the dilemma to, to me as well. But I've realised not in as much detail as to my mum but...

Emma Day: How do you feel about that?

George Mirzaei: Well I wouldn't have the energy to actually sit there and...

Interestingly, George was aware these conversations were happening outside of his room, though he was unable to, or opted not to explain why he was not included. HCP themselves acknowledged that sometimes conversations happen without the teenager present, however, HCP stated that this is always done with the teenagers consent, something this teenagers comments refute. Importantly, despite not being asked at the time George appears to accept that HCP and his parents have these discussions, he does not voice any desire to be part of the conversation.

Teenagers saw their parents as individuals, who would keep track of their treatment, overseeing their physical changes and developments, Poppy commented,

Poppy Conteh: I think I do have my counts like my mum she has like a booklet of all my blood counts, every time he came.

Emma Day: Has she kept a close eye on it for you?

Poppy Conteh: Yeah, that's why she always asks the doctor for the counts. It's just like; I don't think most parents usually ask for that (laughter).

Despite joking that her mum is going beyond what most parents do, Poppy was aware that her mum was keeping a close eye on her physical condition. Teenagers acknowledge that the way they acquire information was different to how their parents acquire information, with parents taking a more active role in seeking and holding knowledge. Just as teenagers reported on parents gathering information from the Internet and articles, they also reported on parents gathering information from HCP directly. Neither is reported as unreasonable or problematic by teenagers, suggesting teenagers themselves recognise that their parents' information needs are distinct from their own.

6.5b Accepting Advice from Parents

A second role these teenagers identified for their parents was that of advisor. Teenagers frequently spoke of seeking advice from parents and making decisions together as a unit, as Becky concluded,

Emma Day: Who do you think makes most of the decisions when you're here?

Becky Aldea: Me.

Emma Day: You?

Becky Aldea: Yeah.

Emma Day: Can you name any or think of any that you've made?

Becky Aldea: Every, every decision.

Emma Day: Everything?

Becky Aldea: Yeah

Emma Day: Is that how you like it?

Becky Aldea: No, I ask my parents as well, they always tell me.

Becky viewed her parents as a source of information and as individuals that she trusted to help her make decisions. Further, Poppy acknowledged that there were times when her mother helped her understand information,

Poppy Conteh: Yeah, sometimes the doctors would be saying all these things and I was in hospital and I was like, not even like with it, I was like 'huh?' I said to mum, 'what are they saying?'

She acknowledged that there were times when she was 'not even with it', continuing on to reference medication side-effects and lack of sleep as possible

causes. This is reflective of Taalia Rossi's comments in the previous chapter regarding the effect medication had on her brother's role. Both Poppy and George recognised their parents' role to help them make decisions and understand information. No teenager reported making any decision without consulting his or her parents.

6.6 Influence of a Language Barrier

Finally, it would be remiss of me to ignore the influence of the language barrier that existed between some families and health care professionals. For five families in this study English was their second language and, by their own admission, two sets of parents had a limited grasp of this language. This changed how teenagers discussed their parents role, though both still acknowledged their parents as advisors and partners in the decision-making process, they recognised that their parents were not able to hold independent discussions with HCP. One teenager in particular, who acted as the translator for his parents stated,

Harry Bukoski: Well I just sort of tell them [parents] what's up and they're like 'okay'.

Emma Day: So if you had to draw a line of how you, the health care team and your parents interact, how would it go?

Harry Bukoski: It goes doctors, through me, to my parents. And then it's sort of if they want to sort of ask about something then it goes parents, me, doctors.

Harry saw his role as integral to information exchange between HCP and his parents. Though a professional translator was brought in on two occasions, to discuss Harry's relapse and transplant, for day-to-day consultations and ward rounds he took on the responsibility to relay information between his parents

and HCP. When asked if he translates information exactly, including that on the English language chemotherapy information sheet, Harry commented that he usually summarised. The accuracy of information exchange in practice is something that needs to be considered and is important to note in hospitals where many languages are spoken.

Despite the language barrier affording Harry greater responsibility in the information exchange, this did not translate to greater responsibility for decision-making. Harry did not voice any suggestion that the language barrier affected his role in the decision-making process. Harry's view of his role in decision-making was not distinct from the other teenagers in this study. As shown from his quotes earlier in the chapter, he saw his role principally as a signatory and as following the advice and suggestion of his health care team. Through observation it was apparent that Harry discussed all decisions made throughout his trajectory with his parents, as any other teenager did.

6.7 Immutable Factors

6.7a Diagnosis Constraining Teenagers Choices

Teenagers were largely aware of the severity of their illness and the constraints that the diagnosis, or relapse placed on their freedom of choice with regard to treatment decisions. This awareness contributed to teenagers devaluing what they wanted in the moment, and valuing the long-term aim of survival. As suggested by the following statements from two teenagers discussing treatment options after their relapse,

Emma Day: Would you ever have not chosen transplant?

Tom Stephens: No.

Emma Day: No. Why was that?

Tom Stephens: Because there was not another option. It was either that or like you're done for (laughs).

Harry Bukoski: I Just – I didn't have a choice. I mean, like who – who wouldn't go through treatment to live instead of go visit a six foot hole early?

Both Harry and Tom recognised that the decision to have a transplant was the only curative treatment option available to them at this point, both making reference to the alternative – death. Here what the teenager ultimately wants, to survive, aligns with the HCP goal of cure, both are united to commence with the only treatment option available to potentially achieve this. This suggests that the principle of acting on the care and treatment preferences of the teenager can be enacted with ease when both the teenager and HCP share a common aim.

It was not just following relapse that teenagers acknowledged a limit to the treatment options available to them. Several months after diagnosis, following the first rounds of chemotherapy Becky voiced a desire to stop the treatment she was receiving because of the nausea and sickness that ensued. When asked why she was continuing with the treatment, despite nausea and sickness, Becky stated,

Becky Aldea: Because I can't stop.

She did not elaborate, and it is unknown whether she felt she could not stop because she was not allowed to stop or because stopping was not a viable option if she wanted to live. Here what Becky initially wanted was not the course of action taken, she continued with treatment following several discussions with HCP where the alternative, death, was explicitly and repeatedly reiterated. During a discussion the following month, when the side effects of treatment had

waned, Becky said she was glad treatment was not stopped. These examples highlight instances where survival and cure is still a possibility, regardless of how small that possibility is, and where on the whole the outcomes were positive. Whether these teenagers would have been grateful their preferences were not acted on if treatment later failed is unknown.

Despite the recognised influence of diagnosis and clinical presentation restricting and determining a course of action, some teenagers acknowledged themselves as the principle decision-maker, as a discussion with Anwar Passi suggested,

Emma Day: Who would you say made that decision for you to go home?

Anwar Passi: I don't know.

Emma Day: Would you say it was you or your mum or the team?

Anwar Passi: Me.

In the weeks leading up to Anwar's discharge from the ward he was repeatedly asked whether he wanted to go home or stay in hospital. Though his discharge was largely determined by his physical health and coordination of community teams to provide the support he required at home, Anwar felt the decision was his. The teenager's preference was sought when discharge home became a viable option, and plans were put in place throughout Anwar's deliberations and changing wishes about his place of care. Despite this, Anwar owned the decision about his place of care, and HCP often attributed the decision to him. This suggests that the principle that decisions are being made in line with what the teenager wants has a value beyond the objective practice. Of note, Anwar only recognised his role as principle decision-maker for minor decisions, such as place of care, and certain minor procedures (insertion of NG tube), he did not assign himself this role in the face of decisions of serious consequence (i.e. continuation of disease directed treatment).

6.7b The Significance of Chronological Age

Teenagers were able to articulate their role most clearly with reference to their chronological age and the responsibilities that they were afforded in accordance with their age. For one teenager when asked about his role in decision-making he first responded,

Harry Bukoski: Like, I didn't really have a role, did I? I mean I just sort of – I was sort of receiving like medicines – but I wasn't really making the decisions about them.

Stating that he did not really have a role beyond receiving medication, Harry continued on to discuss the decision to have a stem cell transplant specifically, a decision he made the day after his sixteenth birthday, he stated,

Harry Bukoski: I think I had - yeah went for one or two meetings, had to sign a consent form – that was the first thing that – that was the first decision I had to make and that was the only real thing I had to sign. Cause I wasn't 16 until I got my cells so I couldn't really make any decisions.

For Harry particularly, who had a milestone birthday during the consent process, the view of his role was directly related to his chronological age. Though he continued on to state he did not think a day made him any more or less competent as a decision-maker, he acknowledged his new role as the signatory. Outside of this role as a signatory he described his role as a passive receiver of medications.

Other teenagers reflected the importance placed on age of consent when making decisions about minor procedures, Tom acknowledged the practical benefits of his role as an older adolescent,

Tom Stephens: Yeah, so I could give consent. Same with the bone marrows as well, I could just sign it and feel like a big man (laughter)

Emma Day: Did that make it easier?

Tom Stephens: Yeah a lot easier, because obviously if my parents aren't around then I can just go away and do it [consent] and they are still like, alright at home on the sofa.

Here Tom speaks to the practical benefits of being able to consent for procedures. Unlike with younger children, the teenagers' parents were not always present, being over 16 allowed Tom to make decisions in such instances. Tom also joked that his role as a signatory made him feel like 'a big man', suggesting the process of being able to consent affords him a status in the decision-making process he did not have prior to turning 16. Similarly, Poppy recognised the benefits of being legally responsible for signing her consent,

Poppy Conteh: Yeah. [I'm] 17. So I have most of my decisions.

Emma Day: What's that like?

Poppy Conteh: Weird. It feels like I'm a parent, not a parent an adult (laughter). It's nice having control. And I always feel that my parents are telling me what to do and this is an aspect of my life that I'd – yeah, I want this and I want that.

Poppy commented on how her parents were 'always telling her what to do', contrasting this with her role as a medical decision-maker, where she was able

to say 'I want this and I want that'. She afforded herself a sense of control, not in making the decision but by stating a preference. She noted that she felt like an adult, similarly to Tom, affording herself a higher status in the process than 'child'. For all three teenagers over 16 years, signing the consent was viewed as integral to their role. This role is not legally afforded to teenagers under the age of 16, leaving those under 16 perhaps less confident with their place in the decision-making process. Of note, in England parents are able to override a teenager's refusal to consent until they are 18 years of age, no teenager made reference to this fact, and no HCP discussed it with a teenager in my presence. Whether chronological age has an impact on teenagers' involvement in practice is yet to be uncovered in this thesis. However, two teenagers made reference to how their experience as a patient diagnosed with a life-threatening illness afforded them knowledge and understanding beyond their years. During a discussion about how Harry relates to people his own age since his diagnosis, he commented,

Harry Bukoski: Yeah, definitely [find it difficult to relate to own age group]. If you took another 16 year old and put him next to me and made him sort of do the same, like, thing that it would be sort of responsible to do – I'd certainly do it a different way. [...] I think they'd sort of go the easy way and not think about what would happen if they did that.

He expressed a belief that the experience he had been through had changed how he approaches decisions and the responsibility he takes for making the right choice. He went on to give examples of his friends' immaturity in hypothetical situations and the irresponsible decisions he believes they would make, compared to the sensible, responsible and mature decisions he would make. However, as stated earlier, Harry doubted his capacity to make decisions about his care and treatment, suggesting perhaps that although he feels more responsible than his peers this does not extend to a belief that he is more responsible than his health care team. George also voiced his belief that

experiencing such a serious, life-threatening diagnosis changed his perceptions and developed his understanding of people,

George Mirzaei: Yeah I mean now I, I, I understand why people – because I was watching this documentary called The Place For The Dead People or – I don't know what it was the translation was awful. But it was in India and it was a place for all the terminally ill patients, and there was this Norwegian guy who was a banker or an accountant and he stopped working to go to India and look after the people and feed them and he was just... I, I understand why someone would do that. I dunno. Before [my illness] I would be like – I can't explain it.

Here George acknowledged that his illness changed the way he perceived other peoples decisions. He appears to have developed an understanding and compassion for other people, including those facing life-limiting conditions.

6.8 Summary

The voices of teenagers themselves highlight how teenagers understand their role and the role of those around them when making decisions about their care and treatment. Teenagers verbalised clearly defined roles for both parents and HCP, acknowledging that teenagers do not act in isolation when decisions need to be made. Teenagers stated a preference for principles relating to the gradual receipt of information from HCP, and regularly checking if they want more information. Unlike parents, teenagers did not report seeking information from multiple sources, relying instead on that provided by HCP and occasionally parents. Consequently, teenagers acknowledged that they received varying degrees of information about their condition, largely through choice. Teenagers recognised that their information needs were distinct from their parents and were content with parents obtaining information through independent research

and discussions with HCP. As a result, teenagers were satisfied that their parents were privy to more information than they were.

Teenagers acknowledged that despite the formal, structured and imbalanced communication style between them, consultants were often responsible for the final decision regarding their care and treatment. Whilst in contrast, teenagers believed that the nurses who provide daily care, information, and answers to their questions had no decisional authority.

Teenagers did not state a preference for decisions being made in line with what they wanted, instead preferring to follow the lead of the HCP who had the experience and forethought to act in their best, long-term interest. Teenagers also recognised the restrictions their serious diagnosis placed on the choices regarding the care and treatment, acknowledging death as a very possible outcome.

What is evident is that these teenagers generally reported feeling listened to and involved despite stating that doctors made the final decisions, they were not fully informed and their preferences were often overruled. This suggests that teenagers are seemingly content with a different kind of involvement than HCP and policy assumes. They do not see the value in HCP acting on their preferences for decisions of consequence. They welcome the choice about what information they receive recognising occasions when information is not desirable. They acknowledge their parents and HCP as integral to decision-making. At no point did teenagers voice a preference to make a decision free from HCP opinion and suggestion, nor did teenagers present a strong desire to make major decisions of consequence (i.e. about treatment/ transplant) independent of their parents and families.

Chronological age was integral to how teenagers perceived their involvement. The legal authority granted when a teenager turns 16 was, for those over 16,

central to how they understood their role in involvement and their status in the interaction. Teenagers also spoke of their developing knowledge, responsibility, understanding and compassion throughout their time as a patient. For some, their experiences over time afford them a maturity that they believed their peers have not yet reached. A teenager who has relapsed at 15, following several years of treatment and a number of major decision points, may be able to contribute to decision-making in a different and perhaps more mature way than a newly diagnosed 18 year old with little experience of the medical setting. Currently, policy does not account for this, and the 18 year old would be afforded a formal role while the 15 year old would not. As shown this legal role in turn changes how teenagers view their role and status in the process. Whether this developed maturity is shown by teenagers and recognised by HCP in practice to the extent teenagers recognise it in principle is unclear at this stage.

One teenager spoke at length about his psychological state and the changes over the course of his hospital admission. He believed that his preference should be attended to differently in accordance with his state of mind. Although none of the teenagers in this study were formally diagnosed with a mental health condition, the anxiety and confinement associated with ward-life caused one teenager in particular to assess the utility of his contribution during decision-making discussions. George was open about the changes he recognised in his psychological wellbeing and his gratitude that his preference was not adhered to during times when he felt he was 'mental'. An understanding of each teenagers psychological wellbeing throughout the trajectory is therefore integral to how involvement of teenagers is enacted, and how confident each teenager feels in his or her contribution. This is a topic afforded greater discussion in Chapter 8, with implications for clinical practice discussed in Chapter 9.

It is apparent that teenagers facing serious and life-threatening diagnoses are able to articulate a preference for involvement that is based on information

exchange rather than choice, collaborative rather than independent decision-making and HCP rather than young person led decisions. Teenagers emphasise times when they do not want all the information about their diagnosis, treatment and prognosis. The extent to which this preference can be accommodated in practice when policy and HCP advocate the open and upfront provision of information is unknown. The following chapter focuses on the interactions between teenagers, parents and HCP when they come together in consultations to exchange information and decide on a course of action.

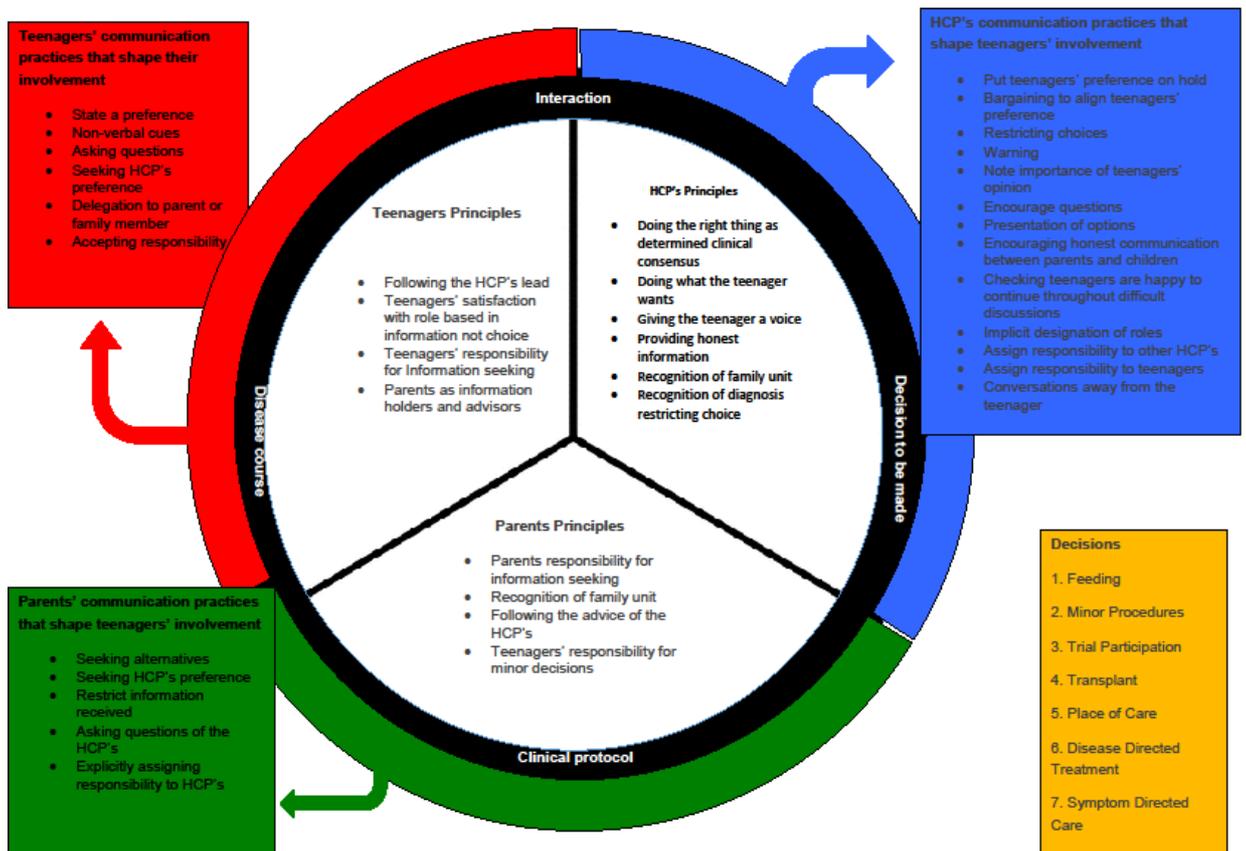
Chapter

7

Involvement in Practice – The Consultations

The last three chapters have focused on the principles expressed by teenagers, HCP and parents for the involvement of teenagers in decision-making. In this chapter I explore what happens to these principles in on the ground interactions among HCP, parents and teenagers. I present the various communication practices each party uses in interactions where options about care and treatment are presented and decisions are made. Figure VII depicts an overview of these principles and communication practices; these are broken down by decision in Appendix VIII. Attention is paid to how the principles each party holds regarding the involvement of teenagers in decision-making actually play out in interactions in practice. This demonstrates just what constitutes teenagers involvement in decisions about their care and treatment.

Figure VII. Principles in Practice



Initially I provide an overview of the consultation data, the actual on the ground audio-recorded interactions among HCP, parents and teenagers. As is evident from Table XVI I have classified the principles expressed by teenagers, parents and HCP regarding teenagers involvement in decision-making into four distinct groups, namely: (1) Acting on the care and treatment preferences of the teenager, (2) Doing what HCP determine is right (3) Provision and exchange of information and (4) Role designation.

Table XVI. Teenagers, HCP and Parents Principles of Involvement as Identified in Preceding Chapters Categorised into Four Distinct Groups

Group	Principles of involvement as reported in earlier chapters.		
	Teenagers (See chapter 6)	Parents (See chapter 5)	HCP (See chapter 4)
1. Acting on the care and treatment preferences of the teenager	Acting on the care and treatment preferences of the teenager	Acting on the care and treatment preferences of the teenager	Acting on the care and treatment preferences of the teenager
	The significance of chronological age	Recognising the Family Unit	
2. Doing the right thing as determined by clinical consensus	Diagnosis constraining teenagers choices	Following the advice of HCP	Doing the right thing as prescribed by clinical consensus
			Uncertainty of the disease course
			Stage in the

Group	Principles of involvement as reported in earlier chapters.		
	Teenagers (See chapter 6)	Parents (See chapter 5)	HCP (See chapter 4)
			trajectory
3. Provision and exchange of information	Acknowledging changing information preferences	Parents and family members responsibility for acquiring information	Provision of information
	Parents as Information holders and advisors		Family and relational structures
4. Role designation	Teenagers defining involvement	Distributing responsibility to teenagers	Giving the teenager a voice
	Following guidance provided by HCP and recognition of distinct roles.		

I proceed to demonstrate how these principles are enacted in interaction with attention to the communication practices each party used, the decisions that emerged and what constituted the teenagers involvement in the decisions. Thus an account of principles in practice is presented.

These groups have originated from the principles expressed by teenagers, parents and HCP in the preceding chapters (see Table XVI). By framing observations of practice around HCP, parents and teenagers' principles we are able to understand these principles in line with the communication practices used by each party to enact involvement.

The findings presented in this chapter are drawn from data collected from observations and transcripts of audio-recorded interactions between HCP, teenagers, their parents and family members across a variety of settings, over a period of nine months. Table XVII outlines the data sources used in this chapter.

Table XVII. Data Source Table – Consultations

Type of consultation	Number of consultation types observed	Number of cases in which the consultation type occurred
Inpatient Consultations	129/ 150	7/7
Outpatient Consultations	21/ 150	5/7
Consultant Led Consultations	108/ 150	7/7
Nurse Led Consultations	42/ 150	7/7
Consultation with teenager present	138/ 150	7/7
Consultations without teenager present	12/ 150	3/3

150 consultations were observed over the course of data collection, these included inpatient and outpatient consultations, consultations where the teenager was present and where they were not, as well as consultant led and nurse specialist led consultations.

7.1 Overview of the Consultation

Throughout this chapter the term consultation is used to describe any meeting of HCP and teenager or parent, in some situations all three are present and in

others the HCP meet with either parent or teenager in isolation [see Table XVII]. On average consultations observed during this study lasted anywhere between five minutes and 50 minutes, with the average consultation lasting approximately 15-20 minutes. Consultations occurred with as few as two individuals, (one HCP and one family member) or as many as thirteen individuals, (nine HCP and four family members). The average number of people present for a consultation was seven (four HCP and three family members, including teenager). Consultations were carried out either in the teenager's side room, in a meeting room on the ward, in outpatient clinic or at the teenager's family home. An extract from Table VIII is reproduced below and highlights the number of consultations observed with each family and the types of decisions they faced over the course of the study.

Table VIII. *Contribution of Each Family to the Overall Data Set*

b) Consultations

Family	Number of inpatient consultations observed.	Number of outpatient consultations observed.	Number of consultants where teenager was present	Total number of all consultations observed.
Anwar Passi and family	23	8	25	31
Poppy Conteh and family	3	5	8	8
Masood Farran and family	16	N/A	11	16
Tom Stephens and family	17	5	22	22
Harry Bukoski and family	33	N/A	33	33
Becky Aldea and	12	2	14	14

Family	Number of inpatient consultations observed.	Number of outpatient consultations observed.	Number of consultants where teenager was present	Total number of all consultations observed.
family				
George Mirzaei and family	26	N/A	24	26

7.1a Speakers

The transcripts produced from audio-record consultations were each coded by speaker, this allowed for percentages of speech from each individual within and across consultations to be counted. Across all* consultations, HCP accounted for 44% to 87% (median average 67%) of speech during consultations. Parents' accounted for 0.5% to 57% (median average 11%), while teenagers accounted for 0.6% to 46% (median average 17%) of speech during consultations. HCP on average accounted for the majority of speech during consultations, followed by teenagers and then their parents.

Table XVIII. Percentage of Speech During Consultations by Age of the Teenager

Teenager	Age (years) NB. Where 2 ages are present a birthday occurred during the course of the study	Average % of speech during consultation
Awar Passi	14 -15	12%
Poppy Conteh	17	14%
Masood Farran	16	6%
Tom Stephens	19-20	27%

Teenager	Age (years) NB. Where 2 ages are present a birthday occurred during the course of the study	Average % of speech during consultation
Harry Bukoski	15-16	23%
Becky Aldea	17-18	15%
George Mirzaei	16-17	17%

Percentages from each consultation have been rounded up to the nearest whole number and the mean calculated.

As is evident from Table XVIII, the age of the teenager was not a key determinate in how much each spoke during consultations. Although Tom Stephens, the oldest participant accounted for the highest percentage of speech, for those 14-18 years old [the other six teenagers in the study] an increase in age did not associate with an increase in speaking in the consultation. The two teenagers (Anwar and Masood) with the lowest average percentage of speech across all their consultations were the two teenagers with the poorest prognosis, suggesting stage in the trajectory may moderate teenagers' speech in consultations. Further, the teenager with the largest number of family members present for consultations (Masood) spoke the least, suggesting family dynamics and cultural factors are likely to have an impact on how much or little teenagers speak in a consultation.

If we were to equate teenagers involvement to a numerical count of verbal contribution during a consultation, it could be concluded that teenagers are less actively involved in decision-making than HCP, and more so than parents. However, to do so would belie the complexity of involvement and the practices teenagers, HCP and parents use to shape the teenagers involvement through interaction. Whether or not the teenager speaks in the interaction cannot be used as an indicator of involvement. In order to better understand how

principles of teenagers' involvement are enacted in practice I turn now to a discussion of these practices.

* Percentages have been calculated from audio-recorded consultation data only – 143 consultations.

7.2 Acting on the Care and treatment preferences of the Teenager

The principle of acting on the care and treatment preferences of the teenager was acknowledged by all three parties, as was the recognition that the utility and practicality of enacting this principle varied in practice (see Chapters 4, 5 and 6). Here we present examples of practices used by each party that influence how involvement through acting on the teenagers care and treatment preferences is enacted when HCP, parents and families and teenagers come together in interaction. Here I separate practices to make the teenager's preference known and responses to the teenager's preference.

Table. XIX Practices Employed by Each Party to Enact Principles of Acting on the Care and treatment preferences of the Teenager

Individual	Communication Practice	Number of occurrences	Number of Individuals adopting communication practice	Profession of HCP adopting practice
HCP	HCP Seeking the Teenagers Preference	48	11	5 Consultants 4 CNS 1 Nurse 1 SHO
	HCP Indirectly Seeking the	2	2	1 Consultant

Individual	Communication Practice	Number of occurrences	Number of Individuals adopting communication practice	Profession of HCP adopting practice
	Teenagers Preference			1 CNS
	HCP Stating the Teenagers Preference	31	6	3 Consultants 1 SHO 2 CNS
	HCP Put Teenagers Preference on Hold	9	5	4 Consultants 1 CNS
	HCP Bargaining with Teenager in Attempt to Change a Preference	25	6	4 Consultants 2 CNS
	HCP Restricting Teenagers Choices	5	6	2 Consultants 4 CNS
	HCP Heed Warning of a Negative Outcome	10	4	2 Consultant 1 CNS 1 SHO
	HCP Acknowledge the importance of the Teenagers opinion	13	6	2 Consultants 2 CNS 2 Nurse
Parents and family	Parent/ Family Member Stating the Teenagers Preference	9	4	

Individual	Communication Practice	Number of occurrences	Number of Individuals adopting communication practice	Profession of HCP adopting practice
Teenagers	Teenagers Stating Their Preference	53	7	

Table XIX identifies the practices employed by each party, as well as the number of instances in which that strategy occurred across the data set, and the number of individuals that employed it. For HCP I also highlight the profession of HCP using the strategy.

7.2a Making the Teenagers Preference Known

HCP Seeking the Teenagers Preference

In order to act (or not) on the care and treatment preferences of teenagers, a preference must be identified. HCP discussed principles relating to acting on care and treatment preference of the teenager and seeking their preference on certain options related to care and treatment (See Chapter 5). While this was the case in some instances, the teenagers' preferences were not sought in every situation. Table XX outlines instances where a discussion was had regarding a particular decision during consultations.

Table XX. Number of Discussions had in Consultations for Each Decision

Decision	Number of discussions about a decision had in	Number of consultations	Number of cases

	consultation		<i>/7</i>
Feeding	38	28	6
Minor procedures	13	11	3
Place of care	45	29	7
Disease direct treatment	16	13	4
Symptom directed treatment	76	50	6
Phase III Trial	4	4	2
Phase I Trial	12	8	1
Transplant	13	12	3
End of Life	10	7	4
Total	227	162	N/A

As is apparent 227 discussions were had regarding these decisions over the course of data collection. However, as Table XXI demonstrates teenagers' preference was only sought on 48 occasions.

Table XXI. Number of Times HCP Sought the Teenagers' Preference for Each Decision

Decision	Number of times HCP sought the teenagers' preference on a decision in a consultation	Number of consultations	Number of cases /7
Feeding	4	3	3
Minor procedures	5	4	2
Place of care	16	11	5
Disease direct treatment	5	5	3
Symptom directed	12	9	5

Decision	Number of times HCP sought the teenagers' preference on a decision in a consultation	Number of consultations	Number of cases /7
treatment			
Phase III Trial	3	3	1
Phase I Trial	1	1	1
Transplant	0	0	0
End of Life	2	2	2
Total	48	38	N/A

Further, Table XXII highlights 53 occasions where teenagers provided a preference either independently or in response to one being sought from HCP.

Table XXII. Number of Times Teenagers Stated a Preference for Each Decision

Decision	Number of times a teenager stated a preference	Number of consultations	Number of cases /7
Feeding	10	4	3
Minor procedures	9	6	1
Place of care	9	7	4
Disease direct treatment	12	8	3
Symptom directed treatment	8	6	3
Phase III	1	1	1
Phase I	1	1	1
Transplant	0	0	0
End of Life	3	1	1
Total	53*	35	N/A

*On occasion teenagers stated a preference without one being sought by HCP

Rather than seek preference, HCP often sought agreement for a pre-determined course of action, something I attend to later.

When the teenagers' preferences were sought, they were sought in several ways and for several reasons. Firstly, observations suggest that for certain decisions the teenager's preference was sought by asking an almost rhetorical question as shown in this interaction,

Dr Mark Charwood: I was just wondering about us letting you go home.

Tom Stephens: Yeah

Dr Mark Charwood: Would you like to do that?

Tom Stephens: Of course I would (laughter)

Here the question asked reiterates what both parties already know; that Tom wants to go home. Tom had wanted to go home for some time, and only when he was clinically able to leave the hospital did Dr Charwood directly ask Tom this question. This was similar to other interactions with teenagers and HCP when facing decisions about place of care. The principle of acting on the care and treatment preferences of the teenager was enacted in practice when clinical assessment coincided with the teenagers assumed or known preference.

Secondly, HCP used open-ended questions to elicit teenagers' views and thoughts on certain options, as observed here with the option of re-starting chemotherapy following a break due to poor nutrition,

Charlotte May: How would you feel about starting chemo?

Becky Aldea: Bad

Charlotte May: Bad. Why do you feel bad Becky?

In this instance, the decision to re-start chemotherapy had already been made; HCP were waiting for Becky's clinical condition to stabilise before deciding the exact date to recommence treatment. Here Charlotte sought Becky's preference not to determine a course of action but to establish ways to help Becky deal with the decision that had been made.

Thirdly, HCP used closed questions, offering a choice between several options. As I go on to discuss later in the chapter the presentation of these options was not without bias. Here Anwar was given a choice between two options with regard to his symptom control,

Ava Darby: Do you want it [oramorph] regularly or do you want it just when – as and when you need it?

Anwar Passi: When I need it.

Ava Darby: Just when you need it – [to mum] is that all right with you?

Saanvi Passi: yeah

Anwar was given a choice between having oramorph regularly or having oramorph when he needed it. Before the decision was finalised Ava checked with Saanvi that the choice Anwar had made was ok with her; suggesting that the preference of the teenager's mother is also important to the HCP in practice. Here seeking a preference allows HCP and teenager to make a decision based on the teenagers reported requirement for pain control. Anwar was given the choice of when, rather than if, he should take Oramorph.

Decisions about participation in a Phase III trial were widely reported by HCP, as an occasion where doing what the teenager wanted was paramount. The following interaction demonstrates this in practice,

Mia Garner: Are you thinking you might like to go on the trial or –

Becky Aldea: Yeah, I think to go on the trial –

Mia Garner: - go on the trial –

Becky Aldea: - But I have to explain to my parents as well so they know

Mia Garner: Yeah. What are they thinking?

Becky Aldea: Cause really I forgot what it was about – (laughter)

The research nurse directly asked the teenager several times throughout the consultation whether or not she wished to join the trial. These decisions were unique in the sense that HCP gave full responsibility to the teenager, with her preference truly paramount to the outcome. As Becky made clear here, although the decision was formally hers to make, she will do so with the support of her parents. Again suggesting that acting on the care and treatment preferences of the teenager is not devoid of parental input in practice.

HCP Indirectly Seeking the Teenagers Preference

With regard to end of life decisions, the lack of an explicit verbalisation that death was imminent or likely made the seeking of a preference more difficult. These were decisions that only two teenagers were approached about in this study. The following interaction depicts how the HCP sought the preference of one teenager,

Ava Darby: And are you worried that if you don't get better? Does that frighten you?

Anwar Passi: [sound of disagreement]

Ava Darby: No? (pause) [Sound of community nurse arriving downstairs]
If you were to get sicker, where would you like to be?

Anwar Passi: I would probably like to be in Bentley Hospital (tertiary referral specialist treatment centre)

Ava Darby: Would you?

Anwar Passi: Cause I was there – like that's the main hospital.

Ava Darby: Yeah

Anwar Passi: They can take proper care of me.

[Community nurse enters and conversation is interrupted]

Whether or not Anwar understood that Ava was asking where he would like to die, rather than where he would like to be treated and cared for if he were to get sicker is unclear. His response suggests that should he get sicker, he wants to return to the main hospital where he had been receiving treatment, because they are able to care for him properly. Due to the interruption by the community nurse, the statement is not unpicked any further and Anwar's preference for place of death is noted as Bentley Hospital.

A further example of indirect preference seeking is seen through an interaction between HCP, Masood and his mum, Samina Haider. Samina asks Dr Talbot to help Masood better understand a discussion he had with Dr Charwood the previous week regarding the decision made to not escalate care to ITU. After Samina claims that Masood did not understand what Dr Charwood meant and Masood says he does not remember the conversation, the following discussion is had,

Dr Claire Talbot: So I think, what Mark was trying to say was that because you are so poorly which, we have to think a little bit about if you

started to become really unwell what thing would we do. Okay? And I think when we know the leukaemia is there and it's being – we are really struggling to control it, it's, it's not fair to you to keep doing more and more and more. Does that make sense?

Masood Farran: [Nods head]

Dr Clarie Talbot: So, I think what, what Mark what talking about was the intensive care unit and those things. I think before you said to Mark that you wouldn't really want to go to ITU if you got poorly again.

Samina Haider: [To Masood] understand this one because, [to HCP] he was, he didn't understand it so, hopefully he need to understand it.

Dr Claire Talbot: [To Masood] Do you remember that?

Masood Farran: (makes sound of understanding)

Dr Claire Talbot: Yeah. And what do, do you still feel like that or, do you feel different?

Masood Farran: I don't know.

The question Dr Talbot actually asked was if Masood would want to go to ITU again if he got really poorly. Masood's response was that he does not know. The fact that escalating care to ITU allows for invasive ventilation, was not explained to Masood. It is unclear whether he understood the actual decision he was making, or that the HCP at this stage believed not escalating care was the right thing to do to avoid potential pain and suffering. Masood's brother-in-law argued he did not understand, and this indirect preference seeking for this crucial decision is something he takes issue with after Masood has passed away. Importantly, through clinical training and MDT discussions HCP understood that the option to not escalate care to ITU was a clinical one. HCP acknowledged their right to instate a DNAR order without the teenager's consent, though they recognised that informing them and allowing them the opportunity to ask questions is considered good practice.

Teenagers Stating Their Preference

In 23 instances three teenagers asserted a preference without being called upon to do so. This most commonly occurred with regard to place of care decisions and decisions about minor procedures. HCP rarely asked for teenagers' preference about place of care until clinical presentation suggested a change to hospitalisation [typically the discharge from hospital to home] was possible. As a result, teenagers often made the following statements unprompted,

Anwar Passi: I want to go home

Poppy Conteh: It would be better to go back home – cause then I can go to the after school lessons. I don't really want to miss school for this.

Becky Aldea: I wanna go home

HCP did not ask for the teenager's preference in these instances because often there was no reasonable alternative to the current place of care. These statements from teenagers reinforced to HCP that home was the preferred alternative to hospital, the idea that a teenager would rather be at home was a taken-for-granted assumption. Similarly, teenagers made the following statements in response to HCP stating a feeding tube, catheter or cannula would be inserted as part of their treatment plan,

Anwar Passi: I don't want it [NG tube] in

Olivia Curtis: Have you seen – it's like a feeding tube.

Harry Bukoski: [Shakes head] I'm alright (laughter)

Olivia Curtis: I know

Harry Bukoski: I'll force feed myself

Anwar Passi: I don't want cannula

Dr Adam New: You don't want cannulas okay. You don't want cannulas ok (laughs a little) so maybe a line will be needed then (laughs a little).

Again, these teenagers expressed a preference for a decision that HCP did not identify as optional. HCP recognised that teenagers would rather not have an NG tube fitted, and would rather not stay in hospital for months at a time but also acknowledged the limited choice they had over this. Only one teenager independently stated a preference for a decision of more serious consequence. Becky expressed her preference to stop disease directed treatment. She was not asked for her preference but offered it freely, several months after her initial diagnosis,

Becky Aldea: If it was for me I would say no, I wouldn't want to do the [disease directed chemotherapy] treatment no, but my parents, they always tell me to. I have to do it but if it was up to me I wouldn't do it cause

Dr Claire Talbot: Just the thing is, the thing is your –

Becky Aldea: Cause its just too much trouble for me. I, I, I'm telling you.

Becky expressed both her preference and her parents' preference for the future of her treatment. Despite recognising her preference did not align with her parents, she acknowledged that it was her parents' preference that she acted in line with. Here the teenager herself rejected the idea of acting on the care and treatment preferences of the teenager, when making decisions of serious consequence in practice. That is not to say she has not been involved.

HCP Stating the Teenagers Preference

During consultations HCP often used leading statements to establish the teenagers preference. HCP used statements about the assumed preference of the teenager [31 instances across 19 consultations with all 7 cases] as a strategy to elicit the teenager's preference. In other words, HCP would seek a preference by stating the preference they anticipated. This is demonstrated by this interaction where the community palliative care team came to introduce themselves to Anwar, who was due for discharge in the days following. While HCP were making moves to discharge Anwar from the hospital his preference on his place of care was regularly sought and often changed depending on how physically well he felt,

Ava Darby: But you're desperate to get home, right Anwar? Is this what you really, really want?

Anwar Passi: No

Ava Darby: No?

Anwar Passi: No.

Ava Darby: What do you want?

Anwar Passi: I'm not desperate to go home.

Ava Darby: Okay

Anwar Passi: I want to wait until it's safe.

Anwar dismissed Ava's assertion that he was desperate to get home and stated that he only wants to return home when it is safe for him, with his limited mobility, to do so. The way this question and others like it are phrased requires the teenager to actively assert themselves if they disagree with the HCP statement. Anwar has spent the majority of his life in and out of hospital and is confident in asking for what he wants, however for those less confident or experienced in the health care setting this may be more of a challenge.

Notably for Anwar and his place of care decisions, HCP statements of preference seemed to be based on the initial preference they obtained from him and the assumption that home is the preferred place of care. When this preference to go home aligned with his clinical readiness to be discharged HCP seized the therapeutic window and moved forward with discharge, despite the teenager's fluctuating preference throughout.

HCP also made statements about teenagers' preferences in situations where preference had not yet been sought. Based on prior encounters with teenagers and the relationships HCP had built, assumptions were made about what the teenager wanted. During the following discussion with Masood's dad, Abdi Farran, Sophia made a statement about Masood's preferred place of death,

Sophia Wright: But, as I said, I believe Masood will probably want to be here [tertiary referral specialist treatment centre] and all your, and if all the family did we would do everything to get him back here.

Sophia encouraged Abdi to find out what the family want with regard to Masood's place of death. For several reasons, socially, emotionally, and practically HCP thought it would be best for Masood to die on the ward. Sophia makes an assumption about Masood's preference aligning with this and does not encourage dad to seek out Masood's preference first hand.

Similarly, Dr Phillips discusses Anwar's preference for his catheter to be removed, something he had requested earlier in his trajectory,

Dr Lindsey Phillips: Yeah that's right – [inaudible]. You hate that catheter, don't you?

Anwar Passi: No

Dr Lindsey Phillips: Oh, now you don't mind it?

Anwar continued on to explain that it was a catheter he had earlier in the year that he disliked. Stating the teenager's preference with the teenager present allowed for this teenager to disagree and correct the consultant.

Parent/ Family Member Stating the Teenagers Preference

In some scenarios teenagers were not called upon to state a preference, nor did they willingly offer one. In such situations HCP turned to parents and family members to establish the teenagers preference [9 discussions across 8 consultations with 4 cases]. This often happened away from the teenager themselves, when HCP and parents/ family members had stepped outside the teenager's side room. As observed in the following interaction one mum stated the teenager's preference to re-start disease directed treatment,

Jasmine Mirzaei: I don't know. He [George] wants to [start chemotherapy] so much, as quickly as possible get on with everything, go home as quickly as possible

Dr Claire Talbot: (sound of approval)

Jasmine Mirzaei: I just want him to be healthy and so, so whatever you, you think.

Here Jasmine stated George's preference but did not reinforce or support his preference, instead stating her ultimate goal for her son to 'be healthy' and then deferring to what Dr Talbot thinks is best. Similarly, Saanvi presented her sons preference for care and treatment to Dr Talbot with her son present,

Saanvi Passi: His NG tube came out today – this morning. According to him, he’s not saying that he needs it. He needs it.

Dr Claire Talbot: [to Anwar] so, look at that – cheeky. You’ve got such a gorgeous smile.

Again, the mother did not support the teenager’s care preference but informed the HCP of it. In both instances the parent turns to the consultant to determine the course of action leaving the responsibility to respond to the teenager’s care and treatment preference with the HCP.

7.2b The HCP Response to Teenagers Care and Treatment Preference

When the teenagers care and treatment preference had been established HCP were responsible for deciding how to act on that preference. As reported in Chapter 5, HCP recognised that acting on the care and treatment preferences of the teenager is weighed up and balanced against the notion of doing the right thing as determined by clinical consensus and acting in the best clinical interest of the teenager. That is observed here in practice, as HCP enact a number of practices to handle divergent care and treatment preferences of those under their care. Tables XX – XXII in the previous section outlined the number of discussions held regarding each decision, and the instances where a care and treatment preference was sought or offered from the teenager. Table XXIII below continues on to outline the number of times teenagers’ care and treatment preferences diverged from the plan or advice offered by the HCP.

Table XXIII. Number of Times when the Teenagers’ Care and Treatment Preference Diverged from HCP Plan or Advice for Each Decision

Decision	Number of times the teenagers’ initial care and treatment preference differed to HCP plan or advice	Number of consultations	Number of cases /7

Feeding	9	3	3
Minor procedures	9	6	1
Place of care	6	5	3
Disease direct treatment	4	4	2
Symptom directed treatment	6	4	3
Phase III Trial	1	1	1
Phase I Trial	0	0	0
Transplant	N/A	N/A	N/A
End of Life	1	1	1
Total	36	25	N/A

As is demonstrated, the teenagers' care and treatment preferences diverged from that of the HCP in 36 discussions across 25 consultations. Table XXIV below highlights in how many of these instances the teenagers care and treatment preference was acted on.

Table XXIV. Number of Times When the Teenagers Divergent Preference for Care and Treatment was Acted on by HCP for Each Decision

Decision	Number of times a teenagers divergent preference was acted on	Number of consultations	Number of cases /7
Feeding	2	1	1

Minor procedures	3	3	1
Place of care	2	2	2
Disease direct treatment	0	0	0
Symptom directed treatment	0	0	0
Phase III	0	0	0
Phase I	0	0	0
Transplant	0	0	0
End of Life	0	0	0
Total	7	6	N/A

As is evident, where the teenagers' preference diverged from that of the HCP (36 discussions across 25 consultations) the decisional outcome only aligned with the teenagers preference for seven decisions across 6 consultations. This occurred exclusively for decisions relating to minor procedures (3 discussions), feeding (2 discussions) and the logistics of place of care (2 discussions). The teenagers divergent preference did not determine the course of action for any decision relating to disease directed treatment, symptom directed treatment, phase III trial participation/ withdrawal or resuscitation status. Here I present the HCP response to these preferences, both those that accorded with the eventual outcome and those that did not.

Importantly, despite the legal importance of chronological age and the teenagers focus on the significance of turning 16 and 18, beyond physically signing consent HCP responded no differently to the preferences of 14 year olds or 20 year olds. The differences in responses highlighted below relate to the decision at hand and preference stated, not age.

HCP Put Teenagers Preferences on Hold

As mentioned above, there were occasions when teenagers volunteered a preference, usually with regard to place of care. Although HCP had suggested that this was a decision led by what the teenager wants, in practice, these preferences were often put on hold. Anwar's vocalisation of his preference about place of care was met with the following response,

Anwar Passi: I want to go home

Dr Joanna Clark: You want to get out of here – can't blame you for that really.

Dr Clark continued on to discuss the medical problems Anwar was currently facing, making no plan for Anwar's discharge. His preference was normalised and simultaneously shelved. Similarly, George's preference to re-start chemotherapy treatment was met with this response,

Dr Joanna Clark: Any sort of short-term goals?

George Mirzaei: Moving onto chemo

Dr Joanna Clark: You found that – you think that would be a, a positive step?

George Mirzaei: Yeah

Dr Joanna Clark: (laughing) well I'm not gonna rush that – just so you know – but let's see then. Shall we see where the bone marrow is [...]

Again George expressed a preference that the HCP were not yet ready to fulfil so the preference was acknowledged and put on hold while further tests were carried out. Both these examples reinforce to teenagers that their preference holds little power unless it aligns with the HCP. In line with this, as illustrated in earlier chapters, teenagers did not hold their own preference for decisions of

consequence in particularly high regard, instead acknowledging the expertise of the HCP.

As I discuss later the physical and clinical presentation of the teenager determined the outcome and timing of many of the options that teenagers voiced a preference on. This is observed during an outpatient consultation where Anwar expressed a preference to have a bone marrow test to 'see how his leukaemia is doing'. As Anwar was considered palliative Dr Talbot explained that information from a bone marrow would not change any of the symptom directed treatment Anwar was receiving because they 'know the leukaemia will still be there',

Dr Claire Talbot: I'm not saying no – if you really, really want to have the bone marrow –

Anwar Passi: Yeah.

Dr Claire Talbot: We can easily arrange it. It's just –

Anwar Passi: Yeah, I wanna have it.

Dr Claire Talbot: - That it doesn't change anything

Anwar Passi: Okay

Dr Claire Talbot: Do you want to have a think about it?

Anwar Passi: Yeah.

Dr Claire Talbot: And then you can, you can tell us what, what you want to do.

Though Anwar had clearly and freely expressed a preference to have the procedure, Dr Talbot addressed the preference by encouraging Anwar to go away and have a think. This preference is not acted upon until almost 3 months

later when Anwar is readmitted and HCP identify a clinical benefit to performing the procedure,

Dr Claire Talbot: Okay, so we know you've got a couple of bugs, which we're giving you treatment for. It may be that something has developed [inaudible]. One of the things that we thought might be worth doing – you mentioned to me ages ago when I saw you in clinic, was to just have a look at the bone marrow and see what's happening in the bone marrow.

Anwar Passi: (sound of approval)

Dr Claire Talbot: [...] Would you – do you think that's an ok thing to do?

Anwar Passi: Yeah

Dr Claire Talbot: Yeah? I know you wanted us to do that a while ago didn't you?

Anwar Passi: [Nods head]

Dr Talbot remembered Anwar's previous request to have the procedure and reintroduced his preference when the clinical team deemed the procedure worthwhile. This suggests that Anwar's preference was put on hold until it aligned with the clinical recommendation. This was only possible when teenagers expressed a preference for non-urgent decisions or decisions with no time-restriction.

HCP Bargaining with Teenagers in Attempt to Change a Preference

On occasions where teenagers expressed a preference that went against the suggestion of the HCP, HCP attempted to bargain with teenagers to encourage them to align their preference with that of the health care team [25 discussions, across 15 consultations with 5 cases]. This is demonstrated in the following extract from an interaction where Becky had stated her desire to come off the

UKALL2011 trial. Dr Clark attempted to explain why remaining on the trial was a better idea suggesting,

Dr Joanna Clark: And the way you've been drawn on the trial now is you won't be getting lumbar punctures and you won't be getting steroids and vincristine – you'll just be getting tablets. Okay?

Becky Aldea: (Make sound of approval)

Dr Joanna Clark: So actually that is what you wanted and that was the reason you went –

Becky Aldea: Yeah

Dr Joanna Clark: - into the trial, wasn't it – or went into this randomisation? So what I would do is give it a couple of days, let's see how you go, let's see what side-effects you have and then decide [whether or not to come off trial].

Dr Clark bargained with Becky by reiterating the preference she stated before going into the second randomisation. She stated that Becky got what she wanted and concludes that Becky should continue on trial for another couple of days and 'see how she goes'. The implication is that if Becky tries for another couple of days and is still unhappy she can then decide to come off the trial. This use of time to bargain with teenagers is reflected in another interaction between Dr Talbot and Anwar, where Anwar refused to have his NG tube re-inserted,

Dr Claire Talbot: You know I think you're, you're quite a bit better, looking at you, than you were when you were in hospital. What do you think? Yeah. So I think we're in a really good place at the minute. And I think we're in a good place because we're able to give you food and tablets and all the rest of it. So it seems silly to me to change what's a winning combination cause it's working really well for you at the minute.

Anwar Passi: Yeah

Dr Claire Talbot: Do you see what I mean? Why don't we just do it and then see how things go? We can always change our minds later – you know – in another couple of weeks, if it keeps coming out we can think again [...]

Dr Talbot repeatedly reinforced how well things were going and what a good place Anwar was in. Notably, Anwar's disease was not considered curable at this point, however, Dr Talbot focused on the day-to-day condition of Anwar rather than the long-term reality that he would not survive. She suggested that in light of this good position, Anwar should have the NG tube now and a decision can be made at a later date. Once again the HCP attempt to bargain with the teenager by suggesting that their preference will be acted upon in the future if they comply now.

HCP Restricting Teenagers Choices

A further strategy employed by HCP when faced with a teenager's preference that did not align with their preferred course of action was the gradual restriction of choice [5 discussions, across 5 consultations with 3 cases]. As observed in the following interaction between two HCP and Anwar discussing Anwar's preference to have his catheter removed and then to return home,

Dr Lindsey Phillips: You want it [catheter] out before you go home?

Anwar Passi: Yes.

Dr Lindsey Phillips: Because?

Anwar Passi: I just don't want it at home.

Dr Lindsey Phillips: If you had to have it at home?

Anwar Passi: I don't want it.

Dr Lindsey Phillips: But if you had to have it at home?

Anwar Passi: I don't.

(Pause)

Dr Lindsey Phillips: Hm, but if we – the difficulty is, Anwar, you've been trying without it and you can't manage. (Pause) It would be a bad reason to keep you in hospital.

Megan Jones: I suppose that's the question, isn't it, Anwar, would you rather stay here with it in or go home with it in, if, if, if you had to?

[Silence]

Anwar Passi: Go home with it in

Dr Lindsey Phillips: Thank you. We will try to avoid it we absolutely hear that you don't want it.

Here Anwar was clear that he did not want his catheter at home, until the HCP present the choice so that he had no real alternative but to align with the HCP if he wanted to return home. The HCP achieve the response they required by restricting his choice and removing the option of having the catheter out at all. The choice becomes one of remaining in hospital or returning home, both with the catheter. Dr Phillips thanks Anwar for aligning with them and acknowledgment of his original preference is made. Ultimately this decision would have been made by Anwar's clinical presentation, if he required the catheter it would remain in place, so his preference would not have been a determinant in decision-making.

HCP Warning of a Negative Outcome

As I discuss in section 7.5 Responsibility and Role Designation the warning of a negative outcome often coincided with designation of responsibility to the teenager. For decisions of minimal consequence, about feeding and fluid intake the warning made by HCP acted as gentle encouragement,

Sophia Wright: You're going to end up on fluids at this rate Harry. You didn't have enough yesterday.

Harry Bukoski: It's not my fault. I just don't feel like drinking that much.

Sophia Wright: We'll put some fluids up then, shall we?

Harry Bukoski: But I'm trying

Dr Scott Cowel: Try alright? And if not, Harry -

Here the knowledge that Harry did not want to end up on intravenous fluids is used to encourage him to drink more himself and take responsibility for increasing his intake. Going against the HCP advice becomes associated with a negative outcome, reinforcing that HCP are acting in the teenagers best interest even if that doesn't align with the teenagers preference. For options where the decisional outcome is of more serious consequence, the warning of a potentially bad outcome is also more serious,

Becky Aldea: But, for me, I don't want to have treatment.

Dr Lindsey Phillips: Well you know if you don't have treatment, what's going to happen?

Becky Aldea: Yeah

Dr Lindsey Phillips: Of course nobody wants to have treatment.

Here Dr Phillips alluded to the fact that without disease directed treatment Becky could die. The HCP normalised Becky's preference against treatment while simultaneously dismissing it, as seen earlier with place of care decisions. Ultimately, this, alongside several other consultations with similar themes, is effective in convincing Becky and she continued on with treatment. This strategy was less successful with Anwar when negotiating the insertion of an NG tube,

Anwar Passi: I don't want the tube.

Dr Claire Talbot: Well why don't you have a think. I, I think it's important cause if we want to keep you at home, it's a pretty crucial part of it [...]

Dr Claire Talbot: – we can't let you starve to death is the bottom line. Do you see what I mean? So I think the best thing is for you to have a tube today and it makes life really easier.

Anwar Passi: Nah

Here Dr Talbot escalated from the implication that without the NG tube Anwar will have to return to hospital, to the explicit verbalisation that without the NG tube Anwar may starve to death. Unlike Becky, Anwar's chance of cure was small and he was designated as 'palliative' by the haematology team, he had also spent most of his life in and out of hospital. The threat of death or re-hospitalisation therefore had little bearing on his preference and he continued to refuse the NG tube despite its purported life-saving properties. This interaction is continued below.

HCP Note the Importance of the Teenagers Opinion

In several interactions where the teenager's preference had been sought, regardless of whether it had been acted on the HCP concluded the discussion by reiterating the importance of the teenager's opinion [13 discussions, across 9 consultations with 4 cases].

In this interaction the consultant concluded a long discussion with Anwar about the re-insertion of an NG tube, which supplied both his feed and medications. Anwar repeatedly refused the insertion of the NG tube unless it occurred while he was under sedation for a lumbar puncture. Dr Talbot, who had no plans to perform a lumbar puncture anytime soon, presented Anwar with 2 choices, to have the tube today or to have it next week,

Dr Claire Talbot: Do you want to think about the two choices? Then you'll let us know? Yeah? I think what you're saying is very important but I'm just thinking, trying to find a way of coming up with a plan.

This followed a 30-minute discussion, some of which is presented in the previous section where Dr Talbot attempted to bargain, negotiate and warn Anwar into agreeing to have the NG tube re-inserted immediately. Ultimately, Dr Talbot concluded with a statement that afforded Anwar choice and some control in the process. Anwar's efforts were rewarded with the choice, but he was also left with the responsibility should something go wrong.

A further example highlights a discussion between Dr Phillips and Masood's older sister, Taalia Rossi, about pain control for Masood. Interestingly, Masood was present for this discussion but his preference on this decision to have the symptom control drug oxycodone set up as a twelve-hour infusion rather than oral tablet was not sought,

Taalia Rossi: We can try it (Oxycodone as IV infusion) [for] one day

Dr Lindsey Phillips: And if you [to Masood] don't like it, we stop.

Taalia Rossi: Yeah, its' all up to him.

Dr Lindsey Phillips: Yeah. Yeah, yeah, yeah.

Here, both Taalia and Dr Phillips agreed that the choice was up to Masood, interestingly however neither sought it. While asserting the importance of Masood's opinion the discussion was had and Dr Phillips and Taalia ultimately made the decision. Later in this consultation when Dr Phillips asked him, Masood stated a preference for Dr Phillips to communicate with his sister rather

than him. This was evidently already the way the consultation was being conducted, with Masood giving permission for this to continue rather than begin.

During a discussion with Saanvi, away from Anwar, regarding Anwar's place of care and deteriorating condition Sophia stated,

Sophia Wright: I just want him to have a voice in all this, I want him to have some kind of say in what he wants and – without scaring him of course, but ultimately we've said he's going to go home, just have the gentle treatment. I think he knows what that means, ultimately.

Importantly, Sophia reiterated the importance of Anwar having a voice in the decision-making process and the importance of that voice, whilst also acknowledging that what Anwar had been told about his prognosis was somewhat vague. I return to the impact of talk away from the teenager later in this chapter. Sophia makes reference to not wanting to scare Anwar with the information that his disease is no longer curative, she determines that Anwar knows this is the case because he is returning home for gentle treatment. Importantly, teenagers in remission often return home and have gentle treatment, whether the distinction was evident to Anwar is unknown.

7.2c Summary

As is evident understanding the involvement of teenagers as acting on the care and treatment preferences of the teenager, is not always feasible or desirable in practice. The notion of following the teenager's lead is complex and multifaceted and is attended to differently in the face of different decisions and when these decisions occur. There are instances where the teenagers preference is sought and others where it is not, instances where that preference is enacted and instances where it is not, throughout all of which ultimately a decision is made. HCP adopt a variety of practices to attempt to align teenagers'

care and treatment preferences to the preferred course of action, ultimately however; the teenager's care and treatment preference has little influence over the outcome of most care and treatment decisions, particularly for decisions of serious sequence. As I move on to discuss, understandings of teenagers' involvement that focus on doing what is right as determined by clinical consensus often take priority in practice, often superseding the preferences of the teenager.

7.3 Doing the Right Thing as Determined by Clinical Consensus

Previous chapters have highlighted how HCP, parents and teenagers recognise that doing the right thing as determined by clinical consensus often supersedes understandings of teenagers involvement as acting on the care and treatment preferences of the teenager when it comes to decisions about care and treatment. Here I present how following this consensus is established through interaction and how it influences the involvement of teenagers in practice. I separate practices used to present the 'right' thing and practices used to seek out the 'right' thing.

As before Table XXV highlights the practices I will discuss alongside the number of occurrences, number of individuals using the strategy and for HCP the type of HCP adopting the strategy.

Table XXV. Practices Employed by Each Party to Enact Principles of Doing the Right Thing as Determined by Clinical Consensus

Individual	Communication	Number of occurrence	Number of Individuals	Type of HCP using
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	Practice	s	using strategy	the strategy
HCP	Statement about the right thing to do	24	6	4 Consultants 2 CNS
	The presentation of options	37	11	5 Consultants 4 CNS 1 Nurse 1 SHO
	Presentation of Non-Optional Decisions	41	6	4 Consultants 3 CNS
	Statement that a Decision has been made	78	12	5 Consultant 4 CNS 3 SHO
Parent and family	Seeking Alternatives	5	4	
	Seeking HCP opinion or preference	7	3	
Teenager	Teenager seeking HCP opinion or preference	2	2	

7.3a Presentations of the right thing as determined by clinical consensus

In practice, the notion of the right thing as determined by clinical consensus appeared to guide the HCP presentation of options. This was enacted in 24 discussions [in 20 consultations with 6 cases] when HCP made explicit statements about a course of action they believed to be the right thing or the best thing for a teenager and their family. HCP also presented the clinical consensus more implicitly, as I now discuss.

The Presentation of Options

Teenagers and families were not present during clinical meetings and MDT meetings where their care and treatment was routinely discussed. Consequently HCP were responsible for informing teenagers and their families of the discussions had and the options available to them at each decision point. This reality allowed HCP to decide how and when to present certain information to teenagers and their families, implicitly acknowledging the option the clinical team have determined to be the right and most appropriate course of action. The presentation of options was observed during early diagnosis, relapse and end of life in 37 discussions, across 23 consultations with 6 cases.

This was demonstrated in the following interaction where CNS Sophia introduced the idea of PEG feeding to Becky. During several pre-ward round meetings and HCP-HCP discussions, the clinical team had agreed the PEG to be the best course of action moving forward. Efforts had been made to begin scheduling an appointment for the insertion of the PEG, Sophia then approached Becky,

Sophia Wright: And I'm gonna talk to you tomorrow about, maybe instead of the NG feed, about doing the same kind of tube in a little operation in your tummy

Becky Aldea: (Makes sound of reluctance and makes scared face)

Sophia Wright: But no, listen – cause then you won't have this [points to NG tube] showing. Okay?

Becky Aldea: I know, but –

Sophia Wright: I think it would be better. We're going to talk about it tomorrow though [with the consultant]. I would rather that – it's hidden away.

Sophia attempted to highlight the benefits of having the small surgery, appealing to Becky's dislike of her visible NG tube. She acknowledged Becky's hesitation and reinforced that she thinks the PEG would be the better option. The CNS was setting Becky up for a conversation with the doctors the following day. In this consultation the following day Dr Kamdar took the lead and continued this partial presentation of the options,

Dr Dora Kamdar: [...] And the advantages of having a PEG is, one, it doesn't come out. So if you vomited or anything like that it wouldn't come out like the NG tube

Becky Aldea: Yeah

Dr Dora Kamdar: Second thing is it's hidden under your clothes so don't have to worry about going around and having a tube that's kind of flapping around.

Becky Aldea: Yeah

Dr Dora Kamdar: And the third is that we've actually got quite a few patients who've had it and they find it very beneficial, and they really like the fact that when they feel sick they don't have the pressure of everyone saying to them you've got to eat [...]

Dr Kamdar did not discuss the disadvantages of having a PEG [for example, infection, potential discomfort] and moved on to give Becky the option of having the PEG under GA or sedation. Interestingly, in order to sell the idea of having a PEG to Becky she has to undo much of the work done to sell the NG tube, contradicting all that was said about the benefits of the NG tube. This suggests that the 'right thing' is fluid and responsive to the teenager's clinical condition. Although presented as an option and a suggestion throughout the consultation, no alternative to the PEG is offered. Becky's suggested alternatives, to just 'eat normally' are not accepted by the HCP and ultimately a PEG is later inserted.

Similarly, with regard to discussions and decisions about treatment following relapse only one option was presented,

Dr Joanna Clark: So they did the bone marrow yesterday. And the bone marrow has shown that you have relapsed, so the leukaemia has come back.

Harry Bukoski: (Starts to cry and his parents comfort him)

Dr Joanna Clark: It's really disappointing isn't it?

[Silence 12 seconds]

Dr Joanna Clark: So now we need to think about what to do next to try and get on top of the leukaemia okay? So what we know is that – because the leukaemia has come back while you were on the treatment – that those leukaemia cells are quite resistant, so normal chemotherapy on it's own isn't going to do the job. So it means that we need to give you some more intensive chemotherapy. And if we can get rid of enough of the leukaemia then the plan would be to do a bone marrow transplant afterwards. Okay? So the bone marrow transplant is your best chance of getting rid of the leukaemia for good.

Here the decision to have a transplant was presented as the plan of action. The consultant continued on to explain the process and start date of the treatment. Once again no viable alternative is offered, only the implication that without the transplant Harry will have a poorer chance long-term survival. Harry was not asked to provide his formal consent for the transplant until four months later when he had completed the high dose chemotherapy and radiotherapy work up and was due to receive his new cells.

The presentation of options was also apparent towards the end of the disease trajectory evidencing an important point for patients with limited chance of cure. A discussion was had regarding the options remaining for a teenager whose

disease had relapsed and high dose chemotherapy had failed to get him into remission for transplant. Following attempts to participate in a Phase I trial Masood had been refused entry onto the trial on medical grounds, Dr New proceeded to inform the family of the options from this point forward,

Samina Haider: So, what's the, what's the plan now? Is he going to stay like this? Without helping him out?

Dr Adam New: So, there are still other possibilities. So, there's two potential other things. Both of which there will be another process, which is similar to that process in [a different city hospital]. And it's whether overall you would be able to get any of these other drugs.

Samina Haider: So, apart from the one you were talking about?

Dr Adam New: Yes, so that one I think so, so, there's three all in [holds up three fingers] that one's now not there [puts one finger down], and there's two others. [...]

Dr New continued to explain the other two options both of which involved further attempts at disease directed treatment. The consultant did not offer the option of palliative treatment only. That is not to say the family would have welcomed it, but to note that the option of disease directed treatment was not presented alongside the others, despite the HCP awareness and acknowledgement that cure was unlikely.

This presentation of options is further apparent towards the end of the trajectory, in the following interaction during a consultation centred on stopping disease directed treatment and preparing for end of life. The teenager, Masood, was notably not present, after the family and HCP left the room to continue the discussion,

Dr Joanna Clark: Whatever we try to do we're in a bit of a catch 22. So if we try to do anything to keep the leukaemia at bay, it will most likely make the fungus worse. And so I think that we're in the position really that what we need to do is actually just keep him [Masood] comfortable and calm, not breathless, not frightened which is where Lindsey comes in really. Because anything – I don't, I don't think the fungus is treatable either. It's so widespread. Because he's got no immune system to fight it [...]

Dr Lindsey Phillips: Does that make sense?

[Taalía Rossi and Jac Rossi nod]

Dr Joanna Clark: You know, and I think the fairest thing is for him to sort of – really to be kept as comfortable as possible, and perhaps explore things in his own way with you guys if he wants to about what's happening, what he's afraid of [...]

Here the only option presented was to keep Masood comfortable. Dr Clark explains the 'catch 22' they were in with regard to continuing disease directed treatment alongside treatment to combat the fungal infection Masood had developed. Both the family and the clinical team acknowledged that there was no alternative and it was established that no further attempts at cure would be made. Masood died one week later.

Presentation of Non-Optional Decisions

For many decisions, HCP did not present options at all to the teenager and their family. Instead, the right thing to do from a clinical perspective determined the course of action and a statement was made about that pre-determined course of action [41 discussions across 33 consultations with 7 cases]. HCP made decisions based on the teenager's clinical presentation and treatment protocol that would be relayed to teenagers during consultations. Decisions about supportive treatment, symptom control drugs and disease-directed treatment were often made in the MDT. Changes in dose, changes to the specific drug

used and the initiation or cessation of certain medications to treat treatment side effects were rarely presented to teenagers and their families. Instead, as observed in the following interactions the decision would be relayed,

Raul Aldea: What's happened with the chemotherapy?

Dr Adam New: We, we stopped it. We may restart that in the middle of next week – only if you're [to Becky Aldea] well enough and if your blood count is ok. Alright?

Dr Joanna Clark: We've switched the IV acyclovir to oral acyclovir.

Tom Stephens: Yeah

Dr Joanna Clark: We've switched the cyclosporine to oral cyclosporine and upped the dose because you're still low with your levels.

Tom Stephens: Yeah, yeah.

Dr Joanna Clark: We've stopped the ursodeoxycholic acid.

Tom Stephens: Um hum.

Dr Joanna Clark: And –

Dr Scott Cowel: Vitamin K.

Dr Joanna Clark: We've stopped the vitamin K.

These exchanges are reflective of interactions that occurred in most consultations with all teenagers and families. The consultant would inform the teenager and family of the medication changes they have made in response to the teenager's physical condition. Teenagers and parents usually nodded along or offered verbal agreement. If no major decisions were on the horizon or the teenager's condition was unchanged this level of decisional involvement for

teenagers became the norm. On 75 occasions HCP made a statement about a decision that had been made, these ranged from decisions about transplant to symptom care and changes to disease directed medication. Teenagers and parents largely accepted that the changes HCP were making were the right thing to do.

Similarly, certain options such as transplant, the initiation of first line treatment, place of care, and minor routine procedures were all decisions where no alternative options were presented. As seen in this interaction where Harry sought information on how he might respond to his stem cell transplant,

Dr Joanna Clark: There's absolutely no way of telling – some people sail through it –

Sophia Wright: Strong [inaudible]

Dr Joanna Clark: - and others not so much. But you know it's the right thing for you so –

Harry Bukoski: Yeah

Dr Joanna Clark: Like you say, it needs to be done, doesn't it?

Harry Bukoski: Yeah.

Dr Clark echoed back a previous statement from Harry where he acknowledged the lack of choice he had if he wanted to live. HCP recognised the right thing to do as the medically necessary or rational thing to do in response to the teenager's physical condition. Transplant for Harry was recognised as both the right thing and the only thing to do.

7.3b Seeking Out The 'Right' Thing

Seeking Alternatives from HCP

Whilst parents and teenagers usually accepted the HCP statements about the right thing, on several occasions parents did seek alternatives [5 discussions, across 5 consultations with 3 cases]. In all the following examples, HCP draw focus back to the clinical protocols and treatment plans that determine their understanding of the right thing to do.

During a consultation where Harry and his parents were informed his leukaemia had relapsed and that a bone marrow transplant would be the 'best treatment long-term' [Dr Clark], Harry's dad, Adrian Bukoski asked the following,

Adrian Bukoski [via translator]: Is there no other solution apart from leukaemia, apart from the marrow transplant? Do you know about any other treatment?

Dr Joanna Clark: There are some novel drugs; there are some new drugs, which are antibody drugs. And if the next course of chemotherapy doesn't do as much as we want it to then that's what we'll look at next.

Dr Clark did not directly answer his question; instead informing Adrian of the possible treatment options available after his sons transplant had been attempted. Dr Clark informed Adrian of the process rather than the options at this stage in his sons' illness.

Another family questioned whether the treatment their child and brother received over the course of his illness was the right thing. Both Samina Haider and Taalia Rossi discussed earlier treatment decisions at a point when Massod's condition had deteriorated and disease directed treatment options were fading,

Samina Haider: Sophia I wish when, when Masood was well enough we could have done the bone marrow transfusion, seriously (crying)

Sophia Wright: I know what you are saying but, that's not, what –

Samina Haider: I know

Sophia Wright: But, that's hindsight isn't it, it's a wonderful thing now you look back, but it's a very risky thing to do –

Samina Haider: I know

Sophia Wright: – is a bone marrow transplant anyway.

Samina Haider: I know

Sophia Wright: I know now it seems like that but –

Samina Haider: I know

Sophia Wright: - it's not what we do when patients are doing well.

Samina Haider: I wish we had (crying)

Sophia Wright: I know you do. So do I

Here Sophia reiterated to Samina that transplant is not what HCP 'do when patients are doing well'. This suggests that when Masood was first diagnosed, as with other newly diagnosed patients, bone marrow transplant as first line treatment is not the best course of action thus, not considered the right thing to do. Both Sophia and Samina conclude this discussion wishing that transplant had been attempted earlier, despite both knowing that it was not the right thing at the time. Masood's sister had a similar discussion during an earlier consultation,

Talia Rossi: You know because the thing is people react differently because, I thought probably if – anyway I'm not going to go back to the past and say if, why, we didn't, why we didn't do this, why, it, it happened anyway. But, because we didn't know what was going on because if I

knew that this is what stages he [Masood] was going through and his spine was fine, I would probably have discussed it with you guys and say why don't we just be on the safe side and just do it – because people react differently, why don't we just be on the safe side and just straight away do the bone marrow transplant.

Dr Joanna Clark: Yeah, the problem with the bone marrow transplant is that it's not the safe side. It's a risky procedure –

Taalial Rossi: Yes we know.

Dr Joanna Clark: - and so the safe side is actually continuing on the chemotherapy and it's, it's what everybody would do, if you ask any national expert they would have done exactly the same thing as what we did.

Again, the argument was made for attempting bone marrow transplant earlier. Taalia Rossi suggested that if she had known more at the time she would have discussed the possibility of a transplant with the HCP. Dr Clark stood by the treatment Masood received and reinforced the idea that it would be nationally recognised as the right thing to do. Unlike Sophia she does not join the family member in wishing a different decision were made. None of these discussions include a reflection on what Masood himself wants or wanted at the time, focus instead is placed on what was the right or wrong course of action and what clinical protocol stipulates.

One teenager and her father both sought an alternative to the treatment she was receiving through a Phase III trial. Due to the side effects Becky was experiencing her and her father believed that reducing her chemotherapy dosage would be the best thing to do,

Raul Aldea: I – may suggest this – only one question: is possible, cause I think this one drug – this thing is very, very strong –

Dr Joanna Clark: Yes.

Raul Aldea: - Is possible to cut a little bit? Because they giving too many
–

Dr Joanna Clark: (Laughing) no, it's not, I'm afraid

Raul Aldea: no?

Dr Joanna Clark: It's strong for a reason

Raul Aldea: No, no – I only ask you – I know, you a doctor, you know better than me.

Dr Joanna Clark: Yeah – yeah when you're on trial the trial is very specific and tells you exactly what doses you have and exactly what timing and exactly how to rescue it. So I can't reduce that dose. Yeah, plus the dose is in now. So, I, I think we just need to –

Raul Aldea: Maybe for next time?

Dr Joanna Clark: Yeah – no, we don't reduce the dose...

Here Dr Clark reinforced the immutability of the treatment protocol and the restrictions it placed on individual HCP altering any dosage. Dr Clark firmly stated that they do not reduce the dose; the protocol determines the best course of action in this situation, despite the teenager and parents preference. A further point of interest is Raul's deferral to Dr Clark as someone that knows better than him. This raises another important point that parents and teenagers often sought out the HCP preference when left to determine the right thing to do independently.

Seeking the HCP Advice

In instances where HCP did not make clear statements about the right thing to do or the best course of action, parents and teenagers sought out the HCP advice [9 discussions, across 7 consultations with 4 cases]. This was particularly evident with options relating to Phase III trials, where the decision to

participate or not was left to the teenager and family. Following a discussion about the second randomisation of the UKALL2011 trial where the different potential outcomes were presented, Raul stated the following to his daughter's research nurse,

Raul Aldea: I need to know which one is bad – which one is different, which – I don't know exactly what's happened for – because you have two option yeah?

Mia Garner: So we weren't going to run the trial if we knew one was better. That would be unethical. So we genuinely don't know which one is – which option is gonna turn out to be the option – but one of these options –we'll do all of the analysis and one of these options will become our new standard treatment.

Raul and his daughter appeared to struggle with the choice of trial participation and both sought the preference of the HCP. This offered little guidance as the decision was considered the teenagers to make free of bias, and ultimately the HCP cannot state with any certainty which of the randomisations, if any, will be more or less successful. The same father and daughter sought guidance on the best thing to do from Sophia later that day,

Becky Aldea: But I dunno which one's better.

Sophia Wright: Well neither do we or we'd be doing it. That's the whole thing innit?

Raul Aldea: Which one you think is better?

Sophia Wright: I don't know or I'd tell you – we'd be doing it. That's the thing isn't it?

When HCP did not clearly present the 'right' thing to do or the best course of action this family actively sought it out. In response, Sophia presented the options (see above for examples), where she focused on the benefits of remaining on trial. After several weeks and several more discussions Becky and her family decided that they would remain on the trial.

One teenager sought the HCP advice in response to a consultant actively seeking his for a decision about stopping a symptom control drug and removing his PICC line,

Dr Joanna Clark: But you could probably do without the line if you wanted to stop the dalteparin. If you're happy on both – with both then we could hold fire for the moment.

Tom Stephens: Well I, I'm really not too fussed. It doesn't bother me. Like – I mean, what do you reckon –

Jane Stephens: – what would be best?

Tom Stephens: - Is the best idea?

Jane Stephens: Yeah

Tom Stephens: (Laughing) I mean...

Dr Joanna Clark: I think let's keep the line in until Monday –

Both Jane and Tom Stephens turned the responsibility back to the consultant to determine what would be best for Tom. Dr Clark made the decision and Tom and his mum were both content with it. As Tom suggested he was not 'too fussed' about the outcome of the decision and therefore does not appear to have a preference. In such a scenario the teenager was happy to rely on the HCP judgement of what would be best.

7.3c Summary

Observations suggest that how HCP present options to teenagers and their families goes a long way in determining the course of action taken. The presentation of options to teenagers and families, for a decision that has already been deemed the right thing to do by HCP leaves teenagers and parents in a position to agree to a course of action rather than make an informed choice. This presentation in practice may contribute to teenagers' recognition that the seriousness of their diagnosis constrained their ability to choose. Crucially however, when HCP do not present options in such a way, or when they do not explicitly or implicitly imply the best course of action, parents and teenagers show a tendency to seek out guidance on the right thing to do.

7.4 Provision and Exchange of Information

The exchange of information between HCP, teenagers and parents was central to each individual's understanding and principles of the teenagers' involvement. Here, I highlight the practices each individual uses to control and manage information provision and exchange to distribute information between the three parties in practice. I separate this section by attending to the role each individual plays in the provision and exchange of information in practice. As before Table XXVI details the practices and instances occurring throughout the data set.

Table XXVI. Practices Employed by Each Party to the Enact Principles Related to the Provision and Exchange of Information

Individual	Communication Practices	Number of occurrences	Number of Individuals using strategy	HCP Profession
HCP	Encouraging teenagers and parents to ask questions	43	9	4 Consultants 4 CNS 1 SHO
	Encouraging Parents to Provide their Child with Information	6	5	2 Consultants 2 CNS 1 SHO
	Information Holding	3	2	2 Consultants
	Checking with teenagers that they were happy to continue discussion	13	7	3 Consultants 3 CNS 1 Nurse
	Talk away from the teenager	12	5	2 Consultants 3CNS
Parent and family	Parents Restricting the Information they Receive	2	2	
	Parents and Family Members Seeking Information	46	14	
Teenager	Asking questions of HCP	34	6	
	Non-verbal responses	59	7	
	Delegate parent or	3	3	

	family member as spokesperson		
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7.4a The Teenagers Role in the Exchange of Information

Beyond providing information on their physical symptoms and their preferences teenagers also had a role in obtaining and restricting information from HCP.

Asking Questions of the HCP

HCP frequently gave teenagers and parents the opportunity to ask questions of them during consultations [43 discussions, across 35 consultations with all 7 cases]. Consultations were typically brought to a close by consultants encouraging first teenagers and then families to ask any questions they had about what had been discussed, or what lay ahead. Questions were most commonly asked about trial participation, updates on the progress of donor matches, and when returning home would be possible. Teenagers rarely [2 questions] asked HCP ‘why’ questions, instead focusing on questions about when, what and how treatments would be administered and decisions would be made.

Interestingly, Poppy who stated during interview that asking questions was ‘the key thing’ was the only teenager who was observed to have asked no questions during consultations. That is not to say she did not ask them more informally at different times. Becky asked many questions when making her decision to remain on UKALL2011 trial for the second randomisation. Questions focused on learning about the trial and all its elements,

Becky Aldea: Yeah, yeah does the bone marrow change anything?

Mia Garner: So –

Raul Aldea: You think it yes or no?

Mia Garner: - Bone marrow only changes – so they'll just want to make sure that the bone marrow's come back – that you can stay on the trial. But the result of the bone marrow won't change what you get – the computer – so it doesn't influence the computer.

Becky Aldea: Yeah, I know but does it change the dose or anything?

Mia Garner: No.

Becky asked considered questions about the impact of bone marrow results on the chemotherapy dosage she would receive. She continued on to question when the treatment would begin and what exactly she would receive. She asked similar questions with regard to feeding and place of care decisions throughout her treatment, often keen to know as much as she could. This was something HCP believed stemmed from anxiety, and consequently attempted to restrict the information she received, as discussed in Information Holding later in this section.

For Harry most of his questions centred on his work up treatment for his stem cell transplant, whether a donor had been found and how fast he would recover post-transplant,

Harry Bukoski: I wanted to know more about that five days and then four weeks off thing. Cause I'm still confused by that. So it's like 5 days of chemo –

Dr Joanna Clark: Yeah

Harry Bukoski: - And then...

As with Becky, Harry's questions focused on the practical, what will happen and when. Similarly, Tom's questions centred on requests for test results and information on minor procedures,

Tom Stephens: And what is a lumbar puncture?

Having been told he will have a lumbar puncture Tom inquired as to what a lumbar puncture involved. As with the other teenagers he did not question the decisions HCP made about tests, procedures and medication changes, instead enquiring for additional information. Similarly, George requested more information on the drugs he was being given by HCP,

Dr Adam New: Okay? We're gonna make some changes with your drugs and things but –

George Mirzeai: Right.

Dr Adam New: Everything's just to get you better, yeah?

George Mirzeai: (Makes sound of approval) what drugs do I actually take?

Dr Adam New: What drugs – so for the fungus you're on a drug called fluconazole. And then you're on a couple of drugs for your heart, to make your heart stronger. These drugs are not going to be forever. It's just to see you through. To get you better

George Mirzeai: Um hum

Dr Adam New: At the moment you're not on any treatment for the leukaemia –

George Mirzeai: Okay

Dr Adam New: We're going to have a think about that next week

Dr New's statement that the HCP are going to make some changes to his drugs encouraged George to enquire further about what drugs he was actually receiving. Dr New provides George with a partial answer, running through the reason he is on the drugs rather than the drug itself. Dr New continued on to explain to George about the drugs he will be on when chemotherapy re-starts. George was seemingly content with the answer he received and asked no more questions.

Masood's questions focused on when he would be able to transfer to other hospital sites for trial drugs and when he would hear whether or not he was eligible,

Dr Claire Talbot: Do you want to ask me anything?

Masood Farran: When will you know?

Dr Claire Talbot: When will I know? As soon as I've seen all the patients today I am going to give them a ring so, we'll just let you know as soon as we hear anything.

Masood's family often spoke of the trial drugs as Masood's last hope of a cure so he was eager to find out when and if he would be traveling to receive them. Importantly, the HCP had discussed how his death was short weeks away, and the relatively new trial had thus far not successfully salvaged any relapsed patients. None of the teenagers asked HCP questions about their prognosis, their long-term survival or their death. Questions focused on the practical concerns of the present and the immediate future, each specific to the principle treatment they were receiving.

Non-Verbal Responses

Observations of consultations suggest that in practice, teenagers themselves play a key role in controlling the information they receive from HCP. Though no

teenager ever verbalised a wish to not be told certain information they provided HCP with non-verbal cues to suggest they no longer wished to talk. HCP would come to know teenagers personalities; a usually chatty teenager who turned silent and offered just nods and shakes of the head were usually taken as a sign that the teenager was done talking.

Similarly, teenagers often made facial expressions that encouraged HCP to offer more information, offer reassurance or change the subject, though hard to represent without images the following examples offer small insight into non-verbal cues provided by teenagers,

Dr Claire Talbot: One other thing we can do is something called intravenous immunoglobulin

Tom Stephens: Oh [Looks at Dr Talbot with a confused face]

Dr Claire Talbot: (Laughing) which is a hard word to say

Dr Talbot picked up the cue from Tom's facial expression that he was confused and continued on to offer Tom more information on what intravenous immunoglobulin consists of. In a further example, Dr Phillips made the following suggestion to Anwar and was met with a strong non-verbal response,

Dr Lindsey Phillips: You need a carer so that your poor mum can have a rest

Anwar Passi: No [aggressively stares at Dr Phillips]

Dr Lindsey Phillips: Oh my gosh, look at that face.

Megan Jones: I know – I'm glad you said that Lindsey

Dr Lindsey Phillips: If looks could kill, I would be dead (laughter)

Anwar's response to the suggestion that someone other than his mum should take care of him let all the HCP present know that he is strongly opposed to the idea. Although coupled with the word 'no' the addition of the facial expression was enough to ensure such a suggestion was not made again to Anwar in this consultation.

Teenagers also used eye contact to indicate when they were not in the mood to discuss certain topics. It was typical of all teenagers to give the lead of the consultation eye contact throughout a consultation. However, there were occasions for each teenager where this norm was disrupted and eye contact was lost in favour of staring to the floor, staring to the distance or staring out the window. Breaks in eye contact were usually observed when HCP were discussing prognosis or options relating to place of care, typically that teenagers had to remain in hospital for longer than they anticipated.

On one observed occasion Anwar actively turned his head away from the HCP during a discussion about how transplant was no longer an option. After asking HCP to remain in the room to have the discussion with him present, he turned to face away from the HCP and looked out the window as Dr Talbot spoke about the limited treatment options now available to him. Anwar then asked for Dr Talbot to leave and continue the discussion with his parents. Anwar took control of the information exchange and when he had heard enough he let it be known. In this instance Anwar's body language contradicted his verbal request to have the discussion in his presence. Though outwardly he looked disengaged and unfocused he was paying close attention and recognised when he had heard enough.

Delegate Parent or Family Member as Spokesperson

In only a handful of situations [3 discussions, across 3 consultations with 2 cases] did teenagers verbalise their preference for HCP to communicate with their parents and families instead of them. In two consultations the HCP asked

the teenager whether they would prefer this to be the case as demonstrated by the following interaction,

Charlotte May: I think you met one of our consultants on Friday, Dr Phillips, and I wanted to come today after the bank holiday to see how you are. Are you feeling up to having a chat? Or do you – I could talk to your family, if you prefer? Whatever you find easier.

George Mirzaei: Family.

Charlotte May: That's fine. But do interrupt if anything they're telling me isn't right. [Charlotte turns to face the Mirzaei family]

HCP picked up on the non-verbal cues teenagers gave [see above] and provided them with an opportunity to opt out of verbal discussion but remain present while the conversation took place. This allowed the teenager to control his own level of involvement, opting for a less active role, while not missing the information provided.

The third situation was slightly different, where the teenagers attempt to delegate to a parent was not accepted by the HCP. Here Masood had just returned back from another hospital where he had consented for a Phase I trial and the HCP at the tertiary referral specialist treatment centre were keen to find out more,

Dr Claire Talbot: What did the people in [trial hospital] say about the trial?

Masood Farran: [Looks to Samina Haider] Mum?

Sophia Wright: What, what did you understand Masood? Tell us what you understand?

Masood Farran: [silence 8 seconds] I didn't understand

Dr Anup Moore: He didn't get it [understand the information].

Sophia Wright: Okay

Dr Anup Moore: That's fine.

HCP were trying to establish what information Masood had been given, Masood attempted to deflect this by turning to his mum and HCP persisted in seeking Masood's own understanding. Although Masood's initial attempt to delegate to his mum did not work, after his admission HCP turned to Samina and included her in the discussion allowing Masood to be less vocal for the remainder of the consult. Masood was focused on signing the consent and enrolling on the trial, the information provided regarding the trial was perhaps considered a secondary issue.

7.4b Parents Role the Exchange of Information

Parents Restricting the Information they Receive

Only one parent, Jasmine Mirzaei, verbalised a desire to not hear any more information about her son's condition. However, both Samina Haider and Anwar Passi's father expressed their preference to not receive information by removing themselves from consultations where discussions regarding prognosis and end of life were had. Similarly, they prevented their partners or families members from divulging the information they had received from such consultations. Jasmine however informed HCP that she had heard enough information about her son's deteriorating and potentially life-threatening condition with the following statement,

Dr Joanna Clark: Is there anything you wanted to ask?

Jasmine Mirzaei: If I ask more, I will know more and that just hurts more.

Dr Joanna Clark: Yeah. That's fine.

Jasmine Mirzaei: (voice breaking) I'd rather just wait and pray.

Jasmine had nothing more to ask of the consultant, but acknowledged that there was more to know. She recognised that in the circumstance more information equated to more hurt, something she did not want at this time point. The consultant was content with Jasmine's response and did not provide any additional information, allowing her to protect herself from any further hurt.

Parents and Family Members Seeking Information

As with teenagers, parents and family members too sought information from HCP during consultations [46 discussions across 23 consultations with 6 cases]. Unlike teenagers however, the questions they asked did extent to 'why' questions as well as what, when and how. As the what, when and how questions echo those asked by their children and siblings here I just present examples of the distinct questions these individuals asked.

After being told that his son had relapsed and he would be undergoing a bone marrow transplant Adrian Bukoski asked the following of Dr Clark,

Adrian Bukoski: Why don't you do it [transplant] then at the beginning of the illness?

Dr Clark explained the intensity of the treatment and the standard procedure to not offer transplant as routine at diagnosis. Parents questioned the process and decisions made in this way more than their children did. In addition to questions about why a decision had been made, parents also asked questions about prognosis and death, something the teenagers avoided,

Abdi Farran: So, what will happen?

Sophia Wright: If the medicine wasn't working and he [Masood] was getting more sick then he could potentially die in [Trial hospital city]. In the hospital there.

Abdi Farran: How can we bring him here then?

Abdi asked questions that no one else in his family asked, and specifically requested to have the discussion with Sophia alone. Not only did he want to know what would happen if the treatment did not work, he also wanted to know the practicalities of getting his son back home from the trial hospital in this instance. This highlights a further distinction between parent and teenagers' questions; parents often sought information on the practical matters associated with a certain decision. For example,

Harry Bukoski: {translating for Karina Bukoski} What if, if someone – if a member of the family has a sort of a

Karina Bukoski: Runny nose or –

Harry Bukoski: {translating for Karina Bukoski} Runny nose kind of thing – does he, does he have to be kicked out of the house? (laughter)

Olivia Curtis: No, and this it's not a silly question. [...]

Karina wanted to be sure that when her son was discharged from hospital she knew what he could and could not be exposed to so she could protect him as best she could from any infection. This is not something that seemed to occur to teenagers, at least not in the form of questions to the HCP. Parents' questions had different form and purpose to those asked by teenagers, suggesting distinct information needs.

7.4c HCP Role in The Exchange of Information

Health care professionals played a crucial role in the exchange of information, largely as the individual with the most information to offer [See Chapter 6 section 6.4b for distinct roles of different HCP as reported by teenagers]. They routinely encouraged parents and teenagers to ask questions [43 discussions, across 35 consultations with all 7 cases] at the end of each consultation. While, they were somewhat led by parents and teenagers practices to control information exchange, they also had their own practices to relay and manage information.

HCP Encouraging Parents to Provide Their Child With Accurate Information

One discussion that occurred without the teenager present highlighted one mothers desire to restrict the information given to her son. One Friday, following a deterioration in Anwar's condition Saanvi was taken out of Anwar's room by the doctors and a DNAR order was instated, three days later Saanvi had the following discussion with one of the CNS',

Sophia Wright: And I presume, has he mentioned anything about Friday, has he asked anything?

Saanvi Passi: No, only that night he was asking why you meeting with the doctors, am I going to die?

Sophia Wright: Did he, okay. What did you say?

Saanvi Passi: No, that's not the thing because there is a lot of people here [inaudible] sister and cousin, so after that he didn't say anything.

Sophia Wright: Why did you say no when he asked that? Because you just couldn't go there?

Saanvi Passi: Yeah I couldn't. He has hoped to improve he never think about, [inaudible] he's talking, I don't think so, he is thinking anything like this.

Saanvi explained that Anwar had explicitly asked her if he was going to die and she had said no, despite the fact he had a DNAR instated and HCP felt his condition to be seriously deteriorating. Saanvi appeared to acknowledge that she did not give her son an honest answer but supports her actions with a desire to protect her son from the loss of hope. Sophia continued,

Sophia Wright: The worrying thing is, not worrying, but, if he asks us that, we can't lie to him outwardly, I wouldn't be able to say to him no, yeah? Do you understand that?

[...]

Saanvi Passi: No, but if, if you are not, if you weren't saying no he might be broken, he might be, if you are not going to lie he will, because of things [inaudible] can happen.

Sophia Wright: I think it's, I don't think he will ask us because I think he will not want to know the answer, and you have answered him but, I think he worries about that.

Sophia acknowledged the fact that she, as a HCP, could not lie to Anwar if he explicitly asked her if he would die. Saanvi was not happy with this and reinforced her point about how the news would break her son. Saanvi also recognised that the answer she gave her son was a lie and warns Sophia of the risks if she were to not corroborate that lie. Anwar never explicitly asked any HCP this question and was therefore never explicitly informed that he would die. Death was never explicitly discussed with any of the teenagers; I discuss the implications of this on information exchange and involvement in Chapter 9. Whilst HCP were aware Anwar had not received completely honest information they noted that they would only rectify this should he ask them directly, otherwise they allowed the parent the comfort of controlling this information.

Information Holding

In three discussions [across 3 consultations, with 3 cases] within the data set, HCP explicitly verbalised the withholding of information from the teenager or parent. Either their preference to do so, or the reality that as HCP they are privy to more information than teenager and parents are.

On one occasion, during a discussion about a new medical protocol on which Dr Clark based Poppy's treatment, her mum, Nadia Conteh requested the protocol,

Nadia Conteh: Is it possible to have the publication or it's just for the doctors?

Dr Joanna Clark: No, no it's not widespread. This has just –

Nadia Conteh: Just for the –

Dr Joanna Clark: - This has just been circulating within the lead clinicians within the, within the country.

Nadia Conteh: Okay

Dr Joanna Clark: Lots of Italian and Spanish publications based on it though, if you're really interested in Googling them.

Dr Clark explicitly demarcates medical knowledge and patient knowledge. She had access to a document that she was not permitted to circulate to Poppy or her mother. Although the information existed in other forms and languages as she goes on to discuss, she dismissed the parents inclination to read them by suggesting she can Google them if she's 'really interested'.

A second example of attempted information withholding is demonstrated by the following interaction. HCP believed that Becky was getting overly fixated on the quantity of PEG feed she was receiving, which they argued worsened her

nausea when the feed was increased. Following an MDT discussion the HCP decided to approach Becky and suggest they withhold that information from her by covering her feed pump. HCP acknowledged they would only be able to do this with Becky's consent, and the following discussion was had,

Dr Adam New: But do you think it helps you to know everything, every detail of what's going in, you know? Why do you want to know?

Becky Aldea: Cause it's my body.

Dr Adam New: Yeah that – that's absolutely right. It's your body. But can you understand what I'm saying is that – I'm concerned that your focusing on the volume going in and that you then, if you see the volume going up, that you're gonna, you're gonna feel like you're not gonna tolerate it, that you might be sick. Not because of how you feel but because what the number is on the pump.

Becky Aldea: (Makes sound of approval) I, I, I don't look at the – I don't look at the pump but I tell them – it depends how I feel, that's how I tell it [...]

Dr New suggested that the restriction of information would help Becky to combat her nausea by removing what he believed to be a psychological trigger. Becky disagreed that this would help her and asserted that it was her body as a reasonable justification for knowing what was going into it. The feed pump was not covered up and Becky's desire to know all information about what was going into her pump was respected. The notion that restricting the information she received would reduce her anxiety and aide the provision of care highlights a further example of HCP denoting what information is necessary for a teenager to receive and what can be withheld.

Checking That Teenagers Were Happy to Continue a Discussion

A strategy used by seven of the HCP was to check whether the teenager was happy with a certain discussion continuing around them [13 discussions, across 9 consultations, with 4 cases]. This was only a strategy used when the discussion was focused on failure or difficulty of treatment or end of life issues. The following interaction occurred during a discussion about not escalating Masood's care to ITU, and is representative of the way this strategy was employed by the HCP.

Dr Claire Talbot: And, are you – is it ok that we are talking about this? Because it's, it's hard to talk about these things isn't it?

Masood Farran: [Nods]

Dr Claire Talbot: I think we're obviously worried about your leukaemia I know you are. [...]

Dr Talbot asked Masood if it was ok that they were talking about this, acknowledging how hard 'these things' are to talk about. Masood was given an opt out which he did not take, however the implication is made that he can opt out and the crucial information regarding his resuscitation status does not need to be relayed. In a separate consultation with the same teenager and a different consultant, a similar opt out is offered. Following his return from a different hospital where he was rejected for a Phase I trial, Masood returned to the ward where no further disease directed treatment would be offered. The HCP had to relay this information to Masood and his family,

Dr Lindsey Phillips: And so – yeah so, we – I think – I don't know whether – do you want to hear any of this – all of this Masood? Are you alright? Or shall we steal the fam[ily] – everybody and talk to them about it or?

Masood Farran: No, just speak to my sister

Dr Lindsey Phillips: Okay, okay.

Josie Page: Just speak to his sister.

Dr Phillips then changed the topic to focus on Masood's breathlessness and ways to ease the symptoms. Following this the family were taken out of the room and a discussion was had about Masood's now inevitable death. Dr Phillips' phrasing implied that the teenager's presence in the discussion was not essential, and the conversation could be continued with the teenager's family alone. This establishes the teenager's role in the receipt of information as less active than his families, something the teenager himself accepted and allowed.

Conversations had Without the Teenager Present

On several occasions [12 discussions] HCP and parents had discussions purposefully away from the teenager. Following an initial consultation parents and HCP would leave the teenager in his/her side room and reconvene in a meeting room on the ward. On all occasions this was done with the teenagers agreement. HCP would ask the teenager if they were happy for them to leave the room and continue the discussion, as the following interaction highlights,

Dr Joanna Clark: So will I – [to cardiology team] do you want to examine him and do your bit and I'll leave you to – mum, do you want to come and have a chat outside –

Jasmine Mirzaei: Sure.

Dr Joanna Clark: - and just sort of – (laughing) we can get a bit more technical with you, if you like.

Sophia Wright: Is that alright George?

George Mirzaei: [Nods]

George is asked if this is ok, after Dr Clark and mum have agreed to the discussion taking place. Dr Clark kept it light by laughing and stating that her

and mum can get a bit more technical, the implication being that mum will now be provided with more information than George. The conversation that followed detailed George's heart failure, the possible outcome of any surgery and the fact he was 'really quite poorly', and 'in danger'. Crucially, no information about George's prognosis or the danger he was in was relayed to him. The issues with George's heart were mentioned; the possibility of surgery discussed and George was able to relay his understanding of this information. However, the focus of the consultation with him present was more positive in comparison to when he was absent. The discussion away from George allowed HCP to inform Jasmine of the seriousness of her son's condition while allowing her the space to cry in response to the news, something she doesn't like to do in front of George.

This is similar to the interactions observed with another teenager and his mother. Anwar, who was designated as palliative by the haematology team, was fighting a recurrent infection that had kept him hospitalised. He had been transferred between his local hospital and the tertiary referral specialist treatment centre for a month and his mood and physical health were not improving. Following a consultation where his preferred place of care had been established as home the following discussion was had,

Ava Darby: Shall we talk to mum outside? Are you tired?

Anwar Passi: Okay

(Pause)

Ava Darby: Yeah? Shall we talk to mum?

Anwar Passi: Okay.

Ava Darby: Alright. We won't bother you with a bunch of women cackling and you having to listen to it (laughter)

Once again, the CNS leading the consultation kept the exit light and stated that Anwar did not want to hear women cackling. This implied that the conversation they were about to go and have would be light and chatty, rather than the reality. Ava and Saanvi reconvened in a side meeting room and discussed the practicalities of Anwar's preference to be at home. The absence of her son allowed Saanvi to open up about her fears of losing him and the hope she holds on to. Saanvi was able to cry, something she would not do in front of her son. Once again the discussion had without the teenager, in this case Anwar, was more open than when he was present, notably, more explicit information regarding his prognosis and the likelihood that he would die is discussed.

A final example of HCP and parents' interactions further reveals the difference in information exchange when the teenager is not present. The following interaction took place after a consultation where the whole family were informed that Masood was being transferred to a different hospital to participate in a Phase I trial,

Abdi Farran: Okay. Let's suppose now things they don't work there [CITY B], what is going to happen next?

Sophia Wright: with what?

Abdi Farran: thing, they, they don't work. The treatment it don't work.

[4 seconds silence]

Sophia Wright: I think he [Masood] will get sick quite quickly if it doesn't work and I think then, they will have to say this isn't working. Where do you want to be, you know, do you want to be here or, go back to [tertiary referral specialist treatment centre city] or, home, or what, what do they want to do.

Again, the absence of his son allowed Abdi space to ask questions about what happens if the trial does not work and Masood's condition were to deteriorate,

something that had not been discussed with Masood present. Sophia continued on to explain to Abdi the practical procedure if Masood was to die in the trial hospital city, or if he was to come back to the tertiary ward and die there. Abdi was able to cry, something he would not do in front of his son.

Of note, conversations away from the teenager, with parents independently were only had with Anwar, Masood and George. These three teenagers were recognised by HCP as the three with the poorer prognoses. Reflecting back to the differences in parents and teenagers information needs as observed by the questions they asked, differences around end of life information preferences must too be recognised.

7.4d Summary

As demonstrated, teenagers, parents and HCP all have a role in the exchange of accurate information. All parties are able to adopt a number of practices in attempt to control and manage the information they receive and provide. Teenagers and parents are both given the opportunity to ask for more information from the HCP, while HCP are able to control the information they provide. For teenagers, questions focused on what will happen and when it will happen, whereas parents also concerned themselves with why certain decisions had been made and the practical considerations to care for their child outside of the hospital. Parents were, on several occasions given space away from their child to discuss prognosis and end of life issues, something the teenagers themselves avoided explicitly seeking information on. This suggests that teenagers are able to control and manage their own involvement, alongside HCP and their parents and family members. I move on now to discuss how each party formulates their roles and responsibilities and those of others throughout the consultation.

7.5 Responsibility and Role Designation

HCP, teenagers and parents delineated several roles for themselves and one another when discussing the involvement of teenagers in interviews and informal discussions. Observation of interactions during consultations reveals the way each individual implicitly and explicitly assigns roles and responsibilities to one another in practice. Practices used by each party to influence how and when the involvement of teenagers is enacted and what type of involvement is achievable. I separate the practices parents and HCP use to assign responsibility and designate roles to themselves, one another and teenagers. While teenagers made no explicit designation of role to HCP or their parents during consultations, the data presented throughout this chapter highlights the implicit recognition that HCP role is that of principle decision-maker for all but a few decisions (trial participation, some minor decisions). Table XXVII presents an overview of the practices used and occurrences of each.

Table XXVII. Practices Employed by Each Party to Enact Principles Relating to Responsibility and Role Designation

Individual	Communication Practices	Number of occurrences	Number of Individuals using practice	HCP Profession
HCP	Implicit Designation of Roles	20	8	2 Consultants 3 CNS 1 Nurse 2 SHO
	Assign Responsibility to Other HCP	11	5	4 Consultants 1 CNS
	Assign Responsibility to Teenager	22	8	3 Consultants 1 CNS 3

Individual	Communication Practices	Number of occurrences	Number of Individuals using practice	HCP Profession
				Nurses 1 SHO
Parent and family	Explicitly Assigning Responsibility to HCP	2 [See also Seeking HCP opinion or preference]	2	
Teenager	Accepting Responsibility	22	7	

7.5a HCP Designation of Role and Responsibility

Implicit Designation of Role

Evident across the consultations was HCP implicit designation of roles and responsibilities to teenagers and parents/ family members [20 discussions across 18 consultations, with all 7 cases]. Through these statements HCP established a passive role for teenagers alongside a caring role for parents. The following interaction takes place after Harry and his family had been told he had relapsed,

Adrian Bukoski: How can we help our child?

Dr Joanna Clark: Just support him. We'll, we'll do the other side of things, the medical side of things.

Sophia Wright: There's no magic food or magic drinks or anything, I'm afraid. Just try and eat as much as you can – [to Harry] you know the routine, don't you? Let 'em spoil you (laughter).

Here both HCP clearly demarcated their role and responsibility on the 'medical side', assigning Harry's parents a supportive role to spoil their son and keep him well fed. Similarly, Harry himself is responsible for eating as much as he can. There is no mention of any greater decisional involvement in the foreseeable future for either teenager or parents.

A second interaction highlights how HCP set up their role as the authority teenagers should trust and be guided by. During a discussion about symptom control drugs for nausea, where Becky notes she is scared to try new drugs following negative reactions previously she remarks,

Becky Aldea: And I vomited and I'm scared to try new things [drugs] so...
if –

Dr Lindsey Phillips: Do you not trust us?

(Laughter)

Dr Lindsey Phillips: Thank you – [feigned offence]

Becky Aldea: Yeah, I do, I do.

Dr Lindsey Phillips: That's our job excuse me

Becky Aldea: (Laughing) I do.

Dr Lindsey Phillips: (Laughing) oh, not very much though? Yeah of course –

Though delivered in jest, the central messages here were that Becky should do as she is told by the HCP and take the symptom control drugs they suggest. Dr Phillips attempted to take away some of the control Becky had, up to this point, been asserting over the drugs she was being given. Dr Phillips reclassified drug dispensation as the responsibility of the HCP and the teenager's role to accept those drugs and trust in the medical decision.

Finally, HCP also designated teenagers' roles relating to information seeking. During a discussion about his upcoming transplant Olivia provides Harry with the necessary information sheets detailing the chemotherapy he would receive as part of his work-up,

Harry Bukoski: Oh god – that's a lot of chemo.

Olivia Curtis: It is – but it's not what you're going to take –

[Cross talk]

Harry Bukoski: That seven-day chemo thing?

Olivia Curtis: Yeah. Let me talk through it now from the beginning.

Harry Bukoski: (Makes sound of approval)

Olivia Curtis: (Reading from the sheet) First of all – before you get obsessed about it – let me tell you where we're up to. Alright?

Harry Bukoski: (Reading information sheet with wide eyes)

Olivia Curtis: Don't look at it too much (laughter).

Here Olivia recognised Harry's shock at the information he had received and encouraged him to not look at it too much or get 'obsessed' about it. Harry needed to have this transplant, as he himself acknowledged [see Chapter 7], the decision had been made before the information was received so this information had no role in aiding his decision-making. The transplant was Harry's only curative option at this point and therefore Olivia tried to down play the seriousness of the treatment, as teenagers, parent and HCP are aware there is no viable alternative. She does this by deflecting Harry's responsibility to read the information sheets provided instead verbally relaying the information she deems most important.

By default she assigned herself the role and responsibility of communicating accurate information to Harry and his mum. HCP assigned responsibilities to themselves and other HCP, in doing so they removed the responsibility for a decision away from the teenager or parent/ family member.

HCP Assign Responsibility for Decision-Making to Other HCP

On eleven occasions [11 discussions, across 7 consultations with 6 cases] the HCP leading a consultation informed the teenager and their family of a decision that was being made elsewhere, by another clinical team or another HCP. In such instances the HCP highlighted the different roles and responsibilities within the teenager's care team. Responsibility was assigned to consultants by CNS', reinforcing the hierarchical structure of the principle care team and the role of the consultant as the principle decision-maker. Informing George of the consultant rotation on the ward Sophia stated,

Sophia Wright: So you met her (Dr Talbot) once very briefly at the beginning yeah, so she's your main consultant. Because then you'd be so poorly she kind of kept it to whoever's – cause the consultants do a month on the ward each, so that's why you've seen Dr New and Dr Clark but Dr Talbot's on tomorrow so –

George Mirzaei: (Makes sound of approval)

Sophia Wright: - She can make some real big decisions and decide what we're going to do with you next.

George Mirzaei: Yeah, okay.

Sophia Wright: How do you feel about starting chemo again? What are your thoughts around that?

Sophia made the statement that a consultant George had briefly met once will come and make the 'big decisions' regarding his treatment and care moving forward. The decision Dr Talbot would make relates to re-starting the

chemotherapy that was stopped to treat a serious infection. After stating that Dr Talbot will decide what the HCP are going to do with George next, she asked George for his view. The implication being that though he will not be the decision-maker his opinion is still important to Sophia. Importantly, George accepts Sophia's assignment of responsibility to Dr Talbot, though he states a preference to continue on with chemotherapy he does not expect to make the decision himself.

Interestingly the consultants themselves also assign responsibility to other HCP for certain decisions outside of what they consider their clinical remit. Haematologists deferred responsibility to symptom control, and symptom control to haematologists. During the same consultation responsibility was passed between the two teams with Dr Phillips (symptom care) first explaining to Becky,

Dr Lindsey Phillips: The second thing is to, to – is if, if Dr New (haematology) feels that there is more acid in the stomach, even if you don't feel it, you should probably take it anyway to be honest but –

Becky Aldea: The lansoprazole?

Dr Lindsey Phillips: Yeah, we need to check with him what he feels

Becky Aldea: Yeah, yeah

Dr Phillips advised Becky to listen to Dr New (haematology), assigning him the responsibility to determine what is best. In the process she takes the responsibility away from Becky, suggesting she take the drug even if she doesn't feel that she needs it. These interactions occurred during a period where Becky was struggling with nausea and sickness but was anxious and wary of taking medications to combat them. Later, Dr New assigned responsibility back to the symptom care team,

Dr Adam New: We'll leave you to it. From our (haematology) point of view there is nothing major. All the focus is on – [nods towards Dr Phillips]

Dr Lindsey Phillips: (Laughing) thanks – no pressure.

Becky Aldea: (Laughing) yeah.

Dr Adam New: These guys (symptom care) – what you're doing. So, so their guys are in charge

Dr Lindsey Phillips: (Laughing) no we're not.

The haematology consultant stated that the symptom control team were now in charge, a role the symptom care consultant rejected. By shifting responsibility between the two in the presence of the teenager the focus is taken off Becky and placed on the HCP. Up to this point the focus had been on Becky encouraging her to take responsibility for taking her medication and increasing her food intake to little avail. Following this redistribution of responsibility within her health care team Becky begins to comply with symptom care and increases her food intake.

Assigning Responsibility for Decision-Making to the Teenager

Observations of interactions in practice also demonstrate the times HCP assigned responsibility to the teenager themselves [22 discussions, across 16 consultations, with 6 cases]. Unsurprisingly, this was most explicitly evident with regard to the decision to participate in a Phase III trial where the responsibility of coming to a decision was considered the teenagers. This is observed in the following discussion, where information on the second randomisation of the UKALL2011 trial was delivered to Becky and her family for the second time,

Research Nurse: Yeah, so two weeks and then – then either way, whichever you decide is absolutely fine. But yeah, by the, by the bone marrow (appointment) we need to make a decision.

Becky Aldea: Yeah

Research Nurse: And, you know, up to you entirely which way you go.

As mentioned previously and observed here, this decision is unique in its attribution of responsibility exclusively to the teenager. Notably, this was not the case for Phase I trials where the decision was considered one made by the teenager, the family, the clinical team and the trial team. Other decisions where HCP attributed responsibility to the teenager were minor, related to eating and drinking, taking medications, doing physiotherapy, reporting symptoms and adhering to advice if discharged from the ward. The teenagers themselves rarely made any attempt during consultations to redistribute this responsibility, though they accepted the responsibility (22 instances) HCP assigned them for these minor choices.

The only other time responsibility was explicitly assigned to teenagers was when they had rejected the advice of the HCP. In such instances teenagers were given the responsibility to think over options and decide what would be best. When Anwar repeatedly rejected Dr Talbot's plea for him to have an NG tube reinserted the consultation reached a stalemate, Dr Talbot concluded the interaction by stating,

Dr Claire Talbot: Okay. Well you have a think. I'll tell the team that you're thinking about it [whether to have an NG tube today or in a week under GA] and then we'll make a plan – we'll just have a bit of time. (pause) alright?

Saanvi Passi: (Small laugh)

Dr Claire Talbot: Lets see where we get to.

Dr Talbot left the responsibility of coming to a decision to Anwar; she suggested he take some time to think about what would be best. Presumably in the hope he will change his mind and agree to the re-insertion of the NG tube sooner rather than later. In this instance the responsibility is assigned as a way of encouraging the teenager to think about the choice he has made, knowing that should he make a choice against the judgement of the HCP the burden lies with him.

7.5b Parent and Family Members Assigning Responsibility for Decision-Making to HCP

As with teenagers, parents and family members implicit designation of responsibility for most decisions to HCP is evident throughout this chapter. The care and treatment of teenagers with cancer is in the basic job description of these HCP. The HCP implication and explicit statements that this is their role, results in parents, families and teenagers placing the responsibility of treating and curing teenagers on them. This was evident when treatment had failed and cure was no longer an option for Masood. The following interaction occurred towards the end of a discussion with the family where HCP informed them of this reality,

Dr Joanna Clark: It's, it's just miserable, isn't it?

Talia Rossi: Yeah.

Dr Joanna Clark: But we do our best. Sometimes it's just not good enough, is it?

Talia Rossi: It's just because we really trust - trusted you and – [tears up]

Dr Joanna Clark: [Tears up] (sound of approval) well I'm going to leave now but I'm on call this weekend so I'll pop in and see him tomorrow.

Taalia's amendment of present tense 'trust', to the past tense of 'trusted' marked a shift in how she views the HCP role. The implication being that Taalia placed the responsibility of Masood's treatment in its entirety on the HCP. The fact that in this case Masood's disease was no longer curable despite the best efforts of the HCP makes this a burdensome responsibility. Being able to attribute the responsibility outside the teenager and the family appears to be important to Taalia as she makes a point of acknowledging this directly to Dr Clark. With decisional authority comes responsibility, something HCP appear to recognise, perhaps aiding the attribution of decisional authority elsewhere on occasion.

7.5c Summary

Observations suggest that the HCP are able to assign certain roles and responsibilities to teenagers and their families through interaction. HCP encourage parents and teenagers to focus on getting better and supporting one another, while they attend to the medical condition. There was no observed rejection from teenagers of this distribution of responsibility. This sets up a precedent for decision-making regarding medical treatment and medical decision-making and the type of involvement expected of the teenager and family. In response some parents and family members hold HCP responsible when treatment is unsuccessful. HCP also distribute responsibility amongst themselves, with CNS' assigning decisional authority to consultants, and speciality consultants assigning responsibility to one another. Finally, HCP assign certain responsibilities to the teenager, beyond reaching a decision on trial participation; these mainly focus on eating, and adhering to care and treatment recommendations.

7.6 Summary

This chapter highlights the complex nature of the involvement of teenagers in practice. These observations of consultations have demonstrated the ways in which each party enacts the involvement of teenagers across decisions and

time. What is evident is that the principles individuals held about teenagers involvement are prioritised differently across different decisions and in the face of distinct immutable factors, impacting on how teenagers involvement is enacted in practice.

Data from consultations highlights how the idea of teenagers' involvement as tantamount to acting on the care and treatment preferences of the teenager is wrought with difficulty in practice. Though teenagers are able and competent to state a preference, one is not always directly sought. Assumptions made about the teenager's preference and HCP indirectly seeking a preference for decisions of serious consequence may prevent teenagers from expressing their own preference about EOL issues. The immutable realities of clinical protocol and clinical assessment also impacted significantly on how the preference of the teenager could be enacted in practice. HCP adopted a number of practices to realign the teenager's preference in accordance with the course of action often pre-determined by the MDT and clinical recommendations. HCP work hard in practice to make it appear as though the teenager's preference is central to decision-making when this preference rarely holds independent weight.

In line with these efforts HCP often presented the options available to teenager in such a way that there was only one viable choice for them to opt for. The HCP presentation of right thing to do led many of the decisions made by teenager and parents. To such an extent that when this guidance was redacted for decisions such as trial participation, teenagers and parents in particular sought out guidance from HCP on the best course of action. This suggests that teenagers and parents often appreciate the restrictions HCP and medical protocol place on their responsibility to choose a course of action or come to a decision.

Through reflection on consultations it is apparent that information exchange is central to how teenagers involve themselves in decision-making. HCP, parents and teenagers all play a role in the interaction that allows each party to control or manage the information they receive and the information they relay. Teenagers are competent and willing to ask questions of the HCP during consultations, though these questions focus almost exclusively on the when, what and how of treatment. They are also able to deflect information when they do not wish to receive it, providing non-verbal cues and verbal delegations to parents or family members.

Similarly parents are able to restrict the information they hear as well as probe HCP for more information during the consultation both with and without teenagers present. Parents sought more information on why treatment choices were made and notably on information relating to end of life and death, something their children did not broach in consultations.

HCP are able to hold information and deliver it when teenagers and parents request it, either simultaneously or independently of one another. HCP respect that parents and teenagers have different informational requirements that influence what their involvement looks like in practice. HCP provide teenagers with opportunities to opt out of discussions relating to end-of-life, something they do not offer at any other point in the trajectory. Similarly, HCP introduce the notion of consultations away from the teenager when cure becomes less likely, giving parents space to ask questions they may not feel comfortable asking in front of their child. This marks a shift in the type of involvement offered and expected of teenagers when cure is unlikely.

Finally, HCP assign roles and responsibilities to teenagers, parents, themselves and their colleagues across different decisions. Teenagers are largely assigned passive roles to adhere to medications and advice of the HCP and focus on getting better, while parents are assigned supportive roles. Almost by default

HCP thus accept responsibility for making decisions of consequence, something some parents and families reflect back to HCP when treatment is unsuccessful. Parents and teenagers expressed their trust in HCP to make the right decisions, following their lead and accepting their decisions. HCP therefore, also attempt to attribute certain decisions and responsibilities away from themselves to other HCP of a higher status or a distinct speciality. By doing so HCP are able to afford themselves distance from the more difficult decisions to be made, enabling group decision-making and apportioning of blame.

I now move on to discuss these findings as they relate more specifically to the previous chapters, including reflection back to pre-existing literature and how the findings of this work contribute to the field. A final chapter detailing the conclusions drawn and the clinical and research recommendations proposed follows this.

Chapter

8

The Discussion

8.1 Returning to the aims and objectives

Before moving to a discussion of the findings it is first important to recognise what this thesis initially set out to achieve. At the outset the aims and objectives were presented (see Chapter 1). Two central aims were stated,

- a. To understand the complex process of decision-making that takes place among health care professionals, families and teenagers independently, and together, when decisions regarding the teenagers care and treatment need to be made.
- b. To use the results of the study to inform the development of evidence-based guidelines for the role of teenagers (13-19 years), parents and health care professionals in decision-making regarding care and treatment.

In this chapter I will address the first aim, moving on to the second aim in the final chapter that follows. The main research objectives were also outlined at the outset,

- a. To investigate the principles and practices for involving teenagers in decision-making regarding their care and treatment.
- To clarify how parents, health care professionals and teenagers understand concepts of 'involvement' in decision-making.
 - To compare and contrast how parents, health care professionals and teenagers view their role and the role of one another in decision-making.
 - To document the role parents, teenagers and health care professionals play in the decision undertaken.

- To track when and how the teenager participates and is invited to participate in decision-making about their care and treatment in practice.
- To compare and contrast understandings and conceptions of involvement in principle with the process in practice.
 - b. To develop a conceptual model for decision-making, which can account for concordance, or lack thereof among parties, their professed principles and practices.
 - c. To develop recommendations and guidance for policy and practice.

The preceding eight chapters have gone part of the way in addressing these aims and objectives. In Chapter 2 I presented the literature and policy that served as a backdrop to this thesis, while Chapter 3 provided an extensive overview of the methodology I employed. The findings were separated into four chapters, initially focusing on involvement in principle as viewed by health care professionals (Chapter 4), parents and family members (Chapter 5) and teenagers themselves (Chapter 6). Finally, Chapter 7 focused on involvement in practice, reporting on data from observations of consultations. In this, the penultimate chapter, I draw findings together and reintroduce the research conducted by others in this field, attending to these early aims and objectives. I separate this chapter to draw focus to several key ideas presented throughout the thesis, namely, (1) Principles in practice, (2) The presentation of choice, (3) Unpacking information exchange, (4) The burden of responsibility, and (5) The importance of time, before moving on to conclude the thesis with recommendations for research and clinical practice. I begin with a discussion of principles in practice and discuss how these relate to those of pre-existing research and importantly, to policy.

8.2 Principles in practice

Findings from this study suggest that the involvement of teenagers in decision-making is a complex process that does not remain static across the trajectory,

individual or decision. Principles of involvement are weighed and prioritised in practice in the face of each decision, interaction, and a host of immutable factors relating to the clinical realities of the teenagers physical condition. I argue that affording more weight to a principle that purports a less active involvement for teenagers (i.e. following the HCP lead) does not equate to a failure to involve the teenager. Instead we must recognise that teenagers and families are willing and welcoming of involvement that affords their preference less weight in the decision-making process.

For decisions of serious consequence (see Box 1), those where non-compliance with HCP advice and the clinical protocol would result in death, serious side effects or prolonged suffering, principles relating to the ideal of doing the right thing as determined by clinical consensus were prioritised by HCP, parents and teenagers. This allowed decisions to be made based on the clinical determination that gave the teenager the best chance of long-term cure or reduced suffering. Accountability for making this determination was placed with the health care team. Consequently, all three parties employed communication practices (e.g. asking questions of the HCP, seeking HCP advice, presentation of options) to establish, understand and enact the principles of doing the right thing as determined by clinical consensus and following the HCP lead.

Box 1. Decisions of Serious Consequence

Decisions of Serious Consequence

Definition: Decisions where non-compliance with what HCP determine to be right would result in death, serious side effects or prolonged suffering. (e.g. Transplant/ EOL/ Disease directed treatment/ Symptom directed treatment/ Feeding if serious risk/ place of care)

Principles afforded most weight:

Doing the right thing as determined by clinical consensus,
Provision of information

Communication Practices:

Teenager:

Asking questions, seeking HCP advice, delegating to a family member, non-verbal cues

Parents:

Seeking alternatives, seeking HCP advice, restricting information to teenager, Explicitly assigning responsibility to HCP, asking questions of the HCP

HCP:

Put teenagers' preference on hold, Bargaining to align teenagers' preference, Restricting choices, Warning, Note importance of teenagers' opinion, Encourage questions, Encouraging communication between parents and children, Checking teenagers' are happy to continue throughout difficult discussions, implicit designation of roles, assign responsibility to other HCP, conversations away from teenager

Importantly, not only HCP but also teenagers and parents prioritised the principles of doing what is right as determined by clinical consensus and following the HCP lead over acting on the care and treatment preferences of the teenager for decisions of consequence. Teenagers in particular acknowledged that they did not have the capabilities to make good and sensible choices in the face of serious decisions. Instead they reported that they would opt for whatever was easiest and required the least hospital admission at the time, rather than thinking about the long term consequences. This is something to consider before advocating for the teenagers preference to be afforded greater power in the decision-making process for decisions of serious consequence.

For decisions of minimal consequence (see Box 2.), those where the outcome would not have any major impact on the teenagers physical wellbeing or progression through treatment, a view of involvement based on following the teenager's preference and giving the teenager a voice took precedence. For example, HCP, parents and teenagers viewed involvement in a Phase III trial, where agreement to randomisation would be necessary, as a decision driven by the teenager's preference. Regardless of the option chosen (to participate or not), the teenager would continue to receive disease-directed treatment in some form; therefore whatever the choice it is unlikely to cause serious harm to the teenager.

During interviews, consultants spoke of the benefit of offering teenagers a role in decisions of minimal consequence, suggesting that affording them a choice in such decisions allowed them a sense of control and perhaps aided their compliance for decisions of serious consequence. This was also reflected in the literature, De Vries and colleagues (2012) suggested that paediatric oncologists recognised that teenagers and parents have little influence over treatment protocols, instead assigning them influence over minor decisions. While the teenagers in Hokkanen's (2004) study believed HCP presented them with fake decisions and the illusion of control the teenagers in this study did not express as much discontent with being involved in this way.

Box 2. Decisions of Minimal Consequence

Decisions of Minimal Consequence

Definition: where HCP and medical protocol do not dictate, or where choice would not result in any major change to the teenager's physical wellbeing (e.g. Trial/ Minor procedures/ Feeding if minor risk/ Place of care)

Principles afforded most weight:

- Acting on the care and treatment preferences of the teenager
- Provision of information

Communication Practices:

Teenager:

Stating a preference, asking questions, Seeking HCP advice, accepting responsibility

Parents:

Seeking information, asking questions of the HCP

HCP:

Assign responsibility to teenager, note importance of teenager's opinion, Encourage questions, implicit designation of roles.

The conceptual model presented represents the decision-making process for decisions of serious consequence (Figure VIII) and decisions of minimal consequence (Figure IX).

Figure VIII.

Decisions of Minimal Consequence

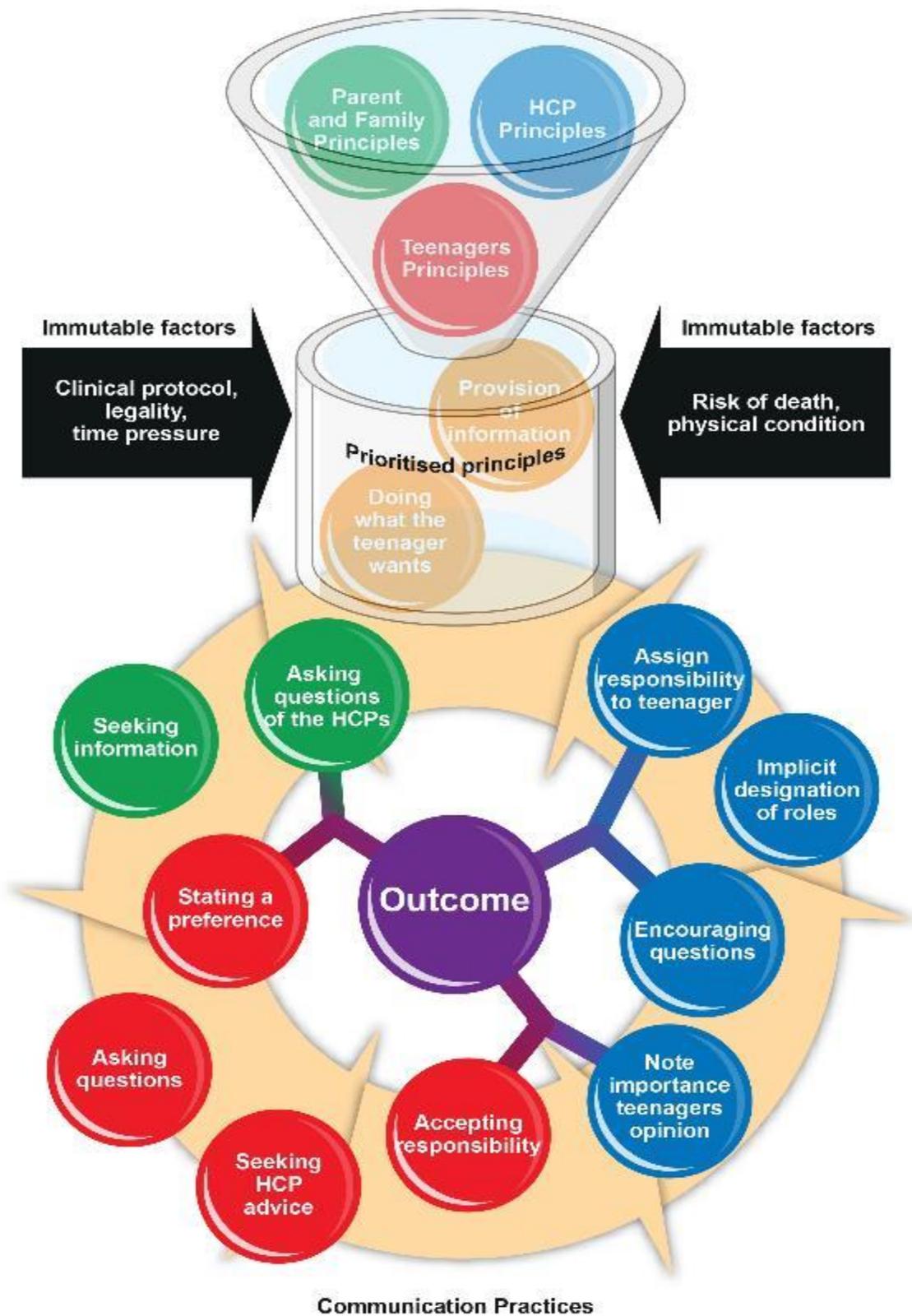
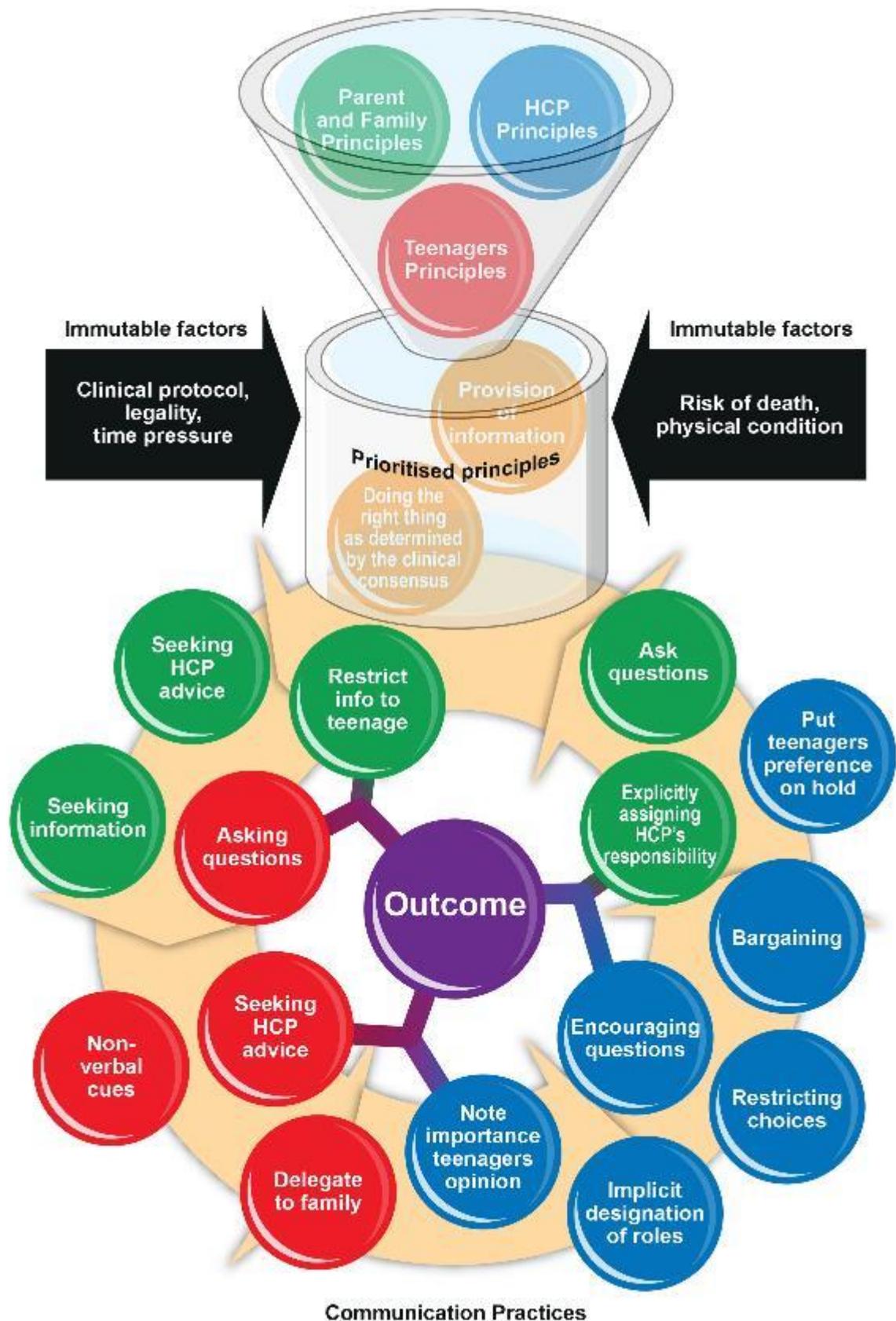


Figure IX.

Decisions of Serious Consequence



This model recognises that each principle and each individuals' possible contribution is significant. It rejects the linear or binary conceptualisations of HCP in one camp and teenagers in another, decisions are reached through contribution from each party. Each party brings their principles of involvement to the interaction; these are then acted on by immutable factors resulting in the prioritisation of certain principles in the face of different decisions. These prioritised principles then provide the backdrop to interaction, where each party enacts various communication practices to reach an outcome. Importantly, this model recognises that the process is not a rational linear process, but a fluid and dynamic one influenced by each individual in interaction.

No party is afforded priority. No individual is afforded preferential treatment; teenagers, parents and HCP are all active in the complex process regardless of the weight afforded to the teenagers' preference. Crucially, this signifies that the prioritisation of principles that place decisional-authority with HCP does not equate to a failure to involve teenagers and their families.

Additional principles and immutable factors can be added to each decisional scenario in line with new understandings, interactions and clinical realities. See also Appendix VIII for diagrams depicting teenagers, HCP and parents' principles and communication practices for each decision in turn. As I now move on to discuss in more detail, immutable factors play a key role in determining how teenagers, parents and HCP prioritise principles of involvement.

8.2a Immutable Factors

Throughout this thesis the term immutable factors has been used to reference those factors that cannot be changed. Factors that are beyond the control of any single party or any individual, these include; urgency of the treatment window, the treatment protocol, the risk of death, the legal responsibility, the urgency of symptom control to progress with disease directed treatment, and

the teenagers physical suitability for an activity. Appendix VIII demonstrates the key immutable factors that come into play for each decision.

Immutable factors were paramount in determining the weight HCP in particular gave to certain principles of involvement. In some instances, decisions of minimal consequence were transformed into decisions of serious consequence when immutable factors emerged. For example decisions around feeding, if the teenager was clinically well and at a stable weight their preference for method of feeding was attributed more authority in the minor decision. However, if the teenager had lost such a significant amount of weight that the provision of treatment was in jeopardy, immutable factors relating to urgency, treatment window, and protocol triumphed and the right thing to do took precedence. HCP consequently employed practices (i.e. bargaining, presentation of options, warning) to bring the teenager's preference in line with what they deemed to be the right thing to do. Immutable factors are therefore central to the enactment of teenagers' involvement in practice. Importantly, while factors such as age, communication style, and parental relationships influence the process of reaching a decision it is the immutable factors that determine what principles can be prioritised and ultimately what decision is made.

Interestingly, findings from this study do not align with the findings from Talati and colleagues' cross sectional survey of physicians (2010). They reported HCP views that when prognosis is good, best interest or doing the right thing dominates, and when prognosis is bad parental authority or minor autonomy (i.e. teenager and parents preference) dominates. Notably, this may be the result of their methodology, collecting perspectives through interviews as opposed to observations of actual practice. Arguably, for the majority of teenagers in this study at some point prognosis was considered poor, however this did not result in the authority of the parents and teenager taking precedence. Importantly, teenagers and parents were largely content with HCP retaining decisional authority throughout the trajectory, and the principle of doing the right thing as determined by clinical consensus and following the HCP advice was prioritised.

Even for minor decisions, teenagers and families still gave weight to the advice of HCP.

In this study more often than not the teenagers' care and treatment preferences aligned with the HCP determination of the right thing. In so much as teenagers and parents were eager to follow the lead of the HCP, their preference to do so enabled HCP to make decisions based on clinical judgement and medical protocol whilst still reflecting the importance of the teenagers' care and treatment preferences. To see involvement as solely acting on the care and treatment preferences of the young person is simplistic and belies the complexity of the process and of the term. Adhering to the teenager's preference to follow the lead of the HCP must not be categorised as a failure to involve simply because the teenager has not stated an overt and distinct preference for care and treatment.

Issues emerged however, when the principle prioritised by HCP was different to the principle afforded priority by the teenager or family. As one family came to realise, a decision they were led to believe was made in line with Masood's preference was in fact made by HCP assessment of best interest. Initially the two converged and HCP could champion involvement as acting on the teenager's preference as it aligned with their determination of the right thing to do. The teenager's preference to remain on the teenage ward over ITU was used to support the HCP decision to not escalate care and instate a DNAR. However, when Masood's preference later changed and he requested to go to ITU his preference was not taken up, now departing from what HCP deemed the right thing to do, the principle of doing what the teenager wanted was afforded less weight by the HCP. For the family and teenager however, interactions with the HCP reinforced the priority of the teenager's preference creating a disparity. By initially perpetuating a narrative of patient choice and championing the importance of Masood's preference, HCP contributed to a break down in trust that left the family confused and frustrated when his preference was seemingly overridden by the HCP and their clinical assessment

of best interest. We must question the utility of implying the teenagers' preference holds weight if the clinical and legal reality is that it only holds weight when aligns with the HCP determination of the right thing to do. In this scenario, the family recognised that ITU may not have extended their son and brothers' life by much but still acknowledged that it was his choice to make, not the HCP. Importantly, this is not legally the case as instating a DNAR is considered a medical decision, the framework for practice on decisions to limit treatment states 'clinicians cannot be compelled to provide treatment they feel not in the child's best interests' (Larcher et al, 2015 page 16). Had HCP communicated the immutable factors, such as the legality surrounding such decisions, teenagers and parents would have been able to reconsider how they prioritised the teenager's preference in this decision. How HCP present such choices to teenagers and their families thus requires more attention.

Whilst HCP, parents and teenagers hold principles regarding what involvement of teenagers in decision-making should and can look like, in practice these cannot all be enacted simultaneously. Immutable factors intervene and encourage certain principles to take priority over others. Communication practices are then employed enacting teenagers' involvement in decision-making. Despite the prioritisation of the HCP advice over the teenager's preference for decisions of consequence this, importantly, does not impede the teenagers' perception of their own involvement. Similarly, the prioritisation of principles centred on following the teenager's preference for minor decisions does not signal a process void of HCP advice and parental input.

For the most part decisions were made with little conflict of opinion, teenagers, parents and HCP prioritised similar principles of involvement across the trajectory. However, we must recognise the potential complications when the principle teenagers and their families prioritise differs from that prioritised by the HCP. When these do not align, immutable factors relating to the legal authority and accountability of HCP result in HCP determining the prioritised principle of involvement in practice. Thus, championing the principle that the teenager is

primary decision-maker whose sole preference determines a course of action in the face of serious and life-threatening decisions is unrealistic and rarely welcomed by teenagers, parents or HCP.

8.3 Presenting Choice to Teenagers

The NHS Choice Framework (2016) sets out 'patients' rights to choice in healthcare' focusing on choices relating to who provides care and treatment to adult patients, when it is provided and where it is provided (DoH, 2016). There is little written about what constitutes choice in care and treatment decisions for teenagers with life-threatening diagnoses specifically, or how and when choice should be enacted.

In this study teenagers made statements about the lack of choice they had over decisions relating to their care and treatment. For several teenagers the awareness that their diagnosis was potentially life threatening influenced how they viewed their options. Paraphrasing Harry Bukoski, he felt there was little choice if he wanted to avoid the '6ft hole in the ground'. The severity of his diagnosis and the urgency of treatment were immutable factors that shaped how he viewed his role in decision-making. Following the lead of the HCP was thus understood to be the most sensible choice a teenager could make. This is supported by previous research where both parents and teenagers recognise the restrictions the disease and the rigid protocols have on their ability to make any choices (Zwaanswijk et al, 2007, Stevens et al 2002) particularly at initial diagnosis (De Vries, 2012). This finding is echoed here at relapse as well as diagnosis.

Observations demonstrated communication practices that encouraged teenagers to take ownership of decisions and purported the importance of the teenager's preference and ultimate choice. However, these practices did not serve to elicit a preference to determine the HCP next move. HCP often had a

pre-conceived plan based on an immutable protocol, clinical knowledge and research evidence. Why then do HCP purport the value of acting on the care and treatment preferences of the teenager, seeking their preference and giving them a voice in the decision-making process if this is unrealistic in practice? Why do HCP continue to propagate a narrative in consultations that decisions are driven by the teenager's preference when they themselves understand the immutable factors and clinical reality that determine outcome? It could be argued that all parties understand the influence of immutable factors such as protocol and medical law. However, for teenagers and parents these understandings are likely to be based on a generalised understanding of medicine, rather than a specific understanding of the directives of their protocol and their legal position in the face of each decision, at each stage in the trajectory. HCP have access to these specifics in a way teenagers and parents do not, years of clinical training, experience and the ability to access information reserved for health care professional only – occasionally including the protocols themselves.

In the case outlined earlier the portrayal of the teenager's role as the central decision-maker, someone whose opinion and preference is paramount caused confusion, anger and a break down in trust when this did not materialise in practice. Masood was told on several occasions the importance of his preference and whenever given, his preferences were championed by HCP who reassured him that his voice mattered. However, when Masood's preference regarding admission to ITU for resuscitation changed and he requested to be taken to ITU, his family argued that he was ignored. His family took issue with the HCP recurrent suggestion that 'it's all about the teenager' and that HCP will 'do whatever the teenager wants', when the reality for this decision in practice was quite the opposite. Interestingly, Whitney and colleagues' "Decisional Priority Model in Paediatric Oncology" explicitly referenced the example of a teenager with relapsed ALL, stating that in such a scenario the decisional priority would lay with the teenager (Whitney 2006). This suggests that there still exists a discrepancy between presumed involvement and decisional priority in principle and in practice.

If we are to encourage HCP to deliver the message that teenagers are at the centre of the decision-making process, that their involvement in stating a preference and making a choice is paramount we must ensure the practice matches the principle. Where is the benefit in convincing teenager they have decisional authority when they do not? Not least because the teenagers in this study did not wish to be the principle decision-maker, nor did they voice any desire to have their preferences adhered to for decisions of consequence. Therefore to present them with this responsibility and then retract the sentiment when a contrary preference is given is to confuse them and their families at crucial decision milestones. It is these practices that ignite criticism of HCP tokenistic involvement of teenagers and children.

However, the interactions that allowed the teenager to believe that their preference contributed to the decision made did have a place in relationship building and enabling teenagers to feel informed. Teenagers happily reported that they had made one or more decisions about their place of care and their disease directed treatment. These decisions were in line with the HCP plans and thus resulted in no conflict and no need to prioritise one view over another. Communication practices such as imbalanced presentation of options, restriction of information giving and receiving enabled teenagers and HCP to interact and communicate information. Both were subsequently satisfied that they had been listened to and their preferences had been considered. Therefore, constructing a narrative through interaction that places teenagers choice at the centre of the decision-making process may hold value not in eliciting a preference to act upon, but in building relationships between teenagers, parents and HCP.

The communication practices used by HCP to seemingly restrict or limit information and choice assist in the construction of this narrative in interaction. By presenting options with no alternatives the teenager is directed to make the most viable choice as determined by HCP. As George stated, for him

involvement was not about choosing option A, B or C but about being kept informed of the decisions made. By reducing the choices available teenagers are able to contribute in a way that satisfies their view of involvement, and the role they willingly assign to the HCP as the ultimate decision-maker. Interlinked with this is the ways in which teenagers are kept informed, below I discuss the complexity of information exchange between HCP, teenagers and their families.

8.4 Unpacking Information Exchange Between HCP, Teenagers and Parents

There is much talk in the literature and throughout policy on the importance of 'honest' communication (Baker et al, 2013, Inglin et al, 2011, GMC 2007). Though often quoted the term is rarely defined, leaving one unclear about exactly what honest communication means for those that employ the term and support the practice. Whether we should equate honest communication to delivery of complete, unedited information or to the practice of always telling the complete truth, or to both, is unclear. Sisk et al (2016) highlight the changes in expectations for prognostic disclosure to children over the last 50 years. Focusing on children (not specifically teenagers) in America they identify a shift from a protective approach in the 1960's, to a more 'open' approach where recommendations were made to 'always tell' a child prognostic information by the 1980's. Sisk et al (2016) suggest that current understanding of prognostic disclosure in paediatrics is far from black and white. The GMC (2007) offer the following guidance for communication with 0-18 year olds,

- b. be honest and open with them and their parents, while respecting confidentiality.
- g. do all you can to make open and truthful discussion possible, taking into account that this can be helped or hindered by the involvement of parents or other people.

They then move on to state,

18. You should not overburden children and young people or their parents, but give them information at an appropriate time and pace, and check their understanding of key points.

This guidance recognises that although honest, open and truthful discussion is preferred; in some situations information can be withheld if it is thought to be burdensome to the teenager and family. This research, as I shall go on to discuss enables reflection on how such policy translates to practice in one tertiary hospital.

Along with policy, much existing literature has focused on the importance of honest communication between teenagers, HCP and parents. Baker et al (2013) concluded that teenagers and parents want straightforward and honest information from a regularly available clinician. Similarly, Inglin et al (2011) stated that parents of terminally ill children considered honesty and openness from HCP essential when delivering bad news. Zwannswijk and colleagues (2007) also found that teenagers (both currently receiving treatment and survivors) and parents 'highly valued' open and honest communication. Interestingly, and similarly to this research, Zwannswijk et al (2007) found that this did not extend to teenagers wanting complete information about prognostics and survival. What then is honest and open communication if we are to omit such crucial information?

I argue that to discuss and dictate the quality and efficacy of information exchange by its degree of 'honesty' is unhelpful. To do so polarises information exchange between HCP, parents and teenagers equating honesty with good communication practices and dishonesty with negative communication practices. As I go on to discuss, this black and white, good and bad division belies the

complexity of information exchange shown through observations in this research.

Findings from interviews and informal discussions highlight how information exchange is viewed, while consultations show how information exchange played out in practice. Importantly, the interaction between the individuals determined how and what information was delivered at any one time. To approach a consultation with the goal to deliver or receive information did not necessarily mean that goal was met. As I discuss now, the communication of options, the uneven distribution of knowledge and the information preferences of the teenager and parents and family members all contribute to how involvement through information exchange is enacted in the consultation.

8.4a HCP Communication of Options

As shown in Chapter 8, many decisions are seemingly pre-determined by the teenager's physical condition and the stipulations of the treatment protocol. The option the HCP deem to be the most suitable is often decided prior to the consultation for decisions of consequence (to have a transplant, to increase/decrease/ change treatment medications, to instate a DNAR). Consequently, the goal of communicating options to teenagers and their families is to align them with this course of action. The delivery of complete, unedited information on all options is therefore not a priority for the HCP. Instead HCP present the chosen option as positively as they can. The findings from health care professional interviews reflect this caveat on the exchange of information.

Throughout the interviews HCP suggested that telling the teenager first and providing teenagers with all the information was central to teenagers involvement in decision-making. However, several consultants alluded to the fact that too much information can be burdensome for teenagers. As shown in Chapter 4, Dr Mark Charwood suggests that not all teenagers necessarily need all the information about a care and treatment decision. He implies that the lack

of choice and the severity of the consequences often make information redundant. For example, if a teenager is to have a stem cell transplant it is because the health care team deem this the only viable treatment option available to give the teenager the best chance of cure. Therefore, to inform teenagers of all the risks, survival statistics and extensive possible side effects serves no purpose in the decision-making process. The decision has been made and there are no options to communicate, therefore information is restricted so as not to over burden or frighten the teenager and their family.

This was also shown with end of life decisions, notably the decision to instate a DNAR. Teenagers were not presented with an option; the information given was limited and indirectly eluded to not returning to intensive care ward. Explicit information about resuscitation was not presented; instead focus was placed on being made comfortable on the ward and the benefits of this pre-determined decision. HCP never explicitly verbalised the possibility of death to the teenagers on this study. Statements such as 'things are difficult now', or 'we know the leukaemia isn't going away' implied death was imminent. Despite this, parents and family members of the two teenagers that died recalled times when, towards the end of their lives, the teenagers had asked them about death and whether or not they will die. This suggests that the explicit verbalisation of 'you are going to die' is not necessary for teenagers to understand the severity of their prognosis. Informing teenagers and their families of negative outcomes does not necessarily extend to complete and overt information exchange. It could be argued that this lack of overt information exchange serves to protect the HCP as much as the teenagers and families. HCP openly admitted that telling a child they are dying is one of the hardest things they have to do, some suggesting that it takes something away from them each time they were faced with such conversations.

Similar practices were used by HCP when multiple options were available but HCP had a preference for one. This occurred mainly for decisions about feeding, where several options existed (oral feeding, PEG feeding, NG tube feeding) but

dependent on the teenager's physical condition one was deemed more appropriate. HCP presented the options by relaying the positives about the option they preferred while simultaneously dismissing the alternatives. The information presented was not dishonest but regulated, highlighting that which would help HCP promote the preferential option and improve the teenager's clinical condition.

An ethnographic case study of an older patient echoes some of the issues this research identifies with regard to the communication of options and presentation of choice. Hicks and colleagues (2012) summarise 'while accounts given by healthcare providers cast patient choice in respectful terms, an ethnographic approach illustrates that the "choices" are structured by a discourse which simplifies the complexity of what is offered and who gets to choose' (Hicks et al, 2012, Page 1). This suggests that regulating information is not a communication practice exclusive to HCP and teenagers. In line with findings from this research, if patient choice is not practical, we must challenge considerations of involvement in decision-making as tantamount to choice.

As I move through this section it is apparent that information relayed to teenagers was, comparative to the information available, rather limited. Despite this and the practices adopted by HCP to restrict information at certain times and certain decision points, teenagers reported satisfaction with the information they received. Teenagers stated they were well informed about their care and treatment and praised the HCP for keeping them so. This is important to note when considering the importance of open and complete information exchange. Teenagers are seemingly content with bite size information throughout their trajectory.

8.4b The Distribution of Knowledge

Research has highlighted how parents' view their role as information seeker, holder and advocate for their child (Holm et al 2003, Inglin et al 2011, Matsuoka

et al 2012). Teenagers however, have not been afforded such clear roles in information exchange and gathering. Though never explicitly stated, this suggests that parents may approach information in a different way to their child, something this research confirms. This thesis highlights how teenagers themselves acknowledged the uneven distribution of information and knowledge between themselves, their families and their health care team.

Observations of practice showed conversations were had away from the teenagers on twelve occasions. These conversations were with the three teenagers for whom death was considered likely. The chronological age of the teenagers had no bearing on this, with conversations had away from teenagers aged 14, 15 and 17. All three teenagers were aware of conversations in their absence, often granting permission for HCP to take their parents or family members away. As noted in Chapter 7, the way in which permission was sought from teenagers implied that the conversational content in the teenagers' absence would be casual and unimportant. HCP often made a joke as they left or suggested that the teenager was bored of listening, before continuing a discussion with the families alone about the teenager's prognosis. As George astutely summarised, the information he received was less detailed than that his mum received in his absence.

Despite this awareness that HCP and parents are holding discussions about their care and treatment in their absence, teenagers did not view this as HCP and/or parents being dishonest or withholding information. Teenagers appeared to recognise that their parents have different information needs to them and were able to separate their desire for information from that of their parents. Importantly, these discussions between HCP and parents allowed for parents to be much more explicit in their questioning regarding prognosis, to express emotion and seek support – something few did in front of their child. As Olechnowicz and colleagues (2002) summarised from observations of clinical trial consent consultations, parents asked significantly fewer questions if their child was present. The uneven distribution of knowledge in this study did not

alienate the teenager, instead it allowed the parents space to express their own emotions and get answers to their questions.

In interviews and informal discussions HCP made reference to never having a conversation without the teenager present, the implication being that doing so would be bad practice. To suggest that conversations should never be had without the teenager present neglects the distinct needs of the parents and family members. To refuse parents and family members time alone with HCP restricts information exchange between the two. As I will go on to discuss, the legal positioning of the parents of teenagers makes them central to the decision-making process should any consent be required. Parents and guardians can overrule a young person's decision until age 18, therefore keeping the parents and guardians informed is crucial. If the teenager is content with this taking place in their absence, there should be no call to prevent these discussions happening.

Teenagers also acknowledged the difference in knowledge held by HCP and information relayed to them. Harry Bukoski in particular expressed his view that the HCP were qualified to make decisions about his care and treatment, he trusted in them to make the best decisions to cure his disease. Like other teenagers in this study Harry stated that he was not capable of making these decisions, as he did not have the knowledge base and the experience of the health care team. The inevitable uneven distribution of knowledge between the teenage patient and the qualified health professional afforded the majority of teenagers in this study trust in their health care team. Notably, Becky Aldea and her family who had previous negative experiences with a family member in the health care service found this distribution of knowledge unsettling.

As with patients of any age, the teenagers and families are exposed to considerably less clinical information than their health care team. HCP attend regular clinical meetings; have access to patient notes, charts and test results.

Teenagers acknowledge that HCP regularly converse with other HCP over the weeks, months and years of their treatment. HCP are thus viewed as experts on their care and treatment, whose knowledge base can never be fully transferred to the young person, but whose intention to do what is in the teenagers best interest, must be trusted. Therefore, teenagers do not expect *all* the information, just that which HCP believe to be relevant to them. Crucially, teenagers did not report dissatisfaction with this distribution of knowledge, nor did teenagers equate this uneven distribution with HCP dishonesty or lies. Moving forward, I turn to how teenagers and parents control and often restrict the information they receive.

8.4c Providing information when information is not welcomed

As reported in both Chapter 6 and 7, teenagers had the ability to determine the course of an interaction and manage the type and amount of information they were privy to. As alluded to above, and recognised by Zwaanswijk et al (2007) teenagers did not always welcome information about prognosis or survival. Teenagers in this study did not ask explicit questions about their future, beyond those about when they could return home.

I observed several occasions where teenagers asked for HCP to talk to their parents or family members away from them, in another room. Teenagers were able to redirect a HCP or parental objective to relay information to them by explicitly asking or physically turning away. To assume teenagers are passive recipients of information is to neglect the less overt role they play in interaction. Similarly, to assume that teenagers must be present and vocal to be involved fails to acknowledge the important role they are able to play with their silence and their delegation. Findings call in to question the benefit of adopting the position that good practice translates to information being shared with the teenager. If a teenager has made their preference known should we encourage HCP to force information on to the teenager? Though easier to respect a preference to not receive information for those under 16, (who hold no legal

responsibility for treatment decisions), information needs should not be assumed in line with chronological age.

The allocation to the parent or trusted family member was most evident when cure was no longer likely. The three teenagers who faced the prospect of death most immediately were the three teenagers who delegated communication to their parents and family members as their disease progressed. Suggesting that consideration of the family and the teenager as a unit, is important throughout the trajectory. If HCP focus exclusively on the teenager as an independent decision-maker, they face potential problems as the disease progresses and cure becomes less likely. Open and 'honest' information exchange between HCP and teenagers becomes increasingly difficult for teenagers, parents and HCP. If, as this research suggests, teenagers facing death often prefer to delegate certain discussions to family members, the exclusion of family members is counter-productive. Similarly, as discussed above, HCP encourage conversations with family members away from the teenagers towards the end of the trajectory. This suggests that as death approaches the teenager is considered less independent by HCP, and we must be cautious about how we position the teenager prior to this. HCP should respect teenagers' delegation and/or opting out of receiving information about their prognosis. By viewing the teenager as part of their family unit we allow families to communicate information, come to decisions and negotiate involvement throughout the trajectory.

When a teenager's condition deteriorated, parents played a role in determining the degree of information their child received. For Saanvi Passi, the provision of information to her son, Anwar, about his prognosis and inevitable death was not welcomed. Following a discussion with HCP away from Anwar where Saanvi was informed that a DNAR was instated, her son had asked her if he would die, she had told him that he would not. This is the only occurrence where a teenager directly asked this question. For this mother, honesty in the face of this question was too much to bear and she admitted that she couldn't tell him the

truth. HCP did not intervene in this situation despite knowing that the teenager had been given less than accurate information about his prognosis. Respect for family dynamics and a parental choice was prioritised over the provision of explicit information to this teenager.

To a lesser extent for another family, Jasmine Mirzaei and her health care team agreed to limit the amount of information George received about various developments and deteriorations in his health so as not to panic him. Again, the parents and HCP agree to protect teenager from information they deemed to be burdensome. When George's health improved he was informed about some of these deteriorations. He acknowledged that his mum kept information from him, stating that at the time it was the right thing to do, as he would not have coped knowing the reality (particularly about the loss of sight in one eye, which he had since regained). He did acknowledge that he might have felt differently about the withholding of information, had the impairment been more permanent.

HCP, parents and teenager must act in the moment, although the benefit of hindsight allows reflection and evaluation of a choice as good or bad, in the moment a decision must be made. In this scenario, by the teenager's admission the HCP were right to rely on the parents' instinct to withhold information. The social order is thus contingent and provisional on the interaction (Atkinson and Housley, 2003); roles and actions are conceived in-line with the individual circumstances, not the predetermined objective of honesty. One of the apparently central reasons behind the withholding of information or the rejection of information is to protect one another and oneself from the consequences of knowing. In line with the work of Bluebond-Langner (1978), mutual pretence facilitates this protection between the three parties, an unspoken agreement is made that death will not be discussed; information is thus regulated so as not to void the agreement. As I move on to discuss, with knowledge comes the burden of responsibility.

8.5 Responsibility

When making decisions regarding the care, treatment, life and death of any individual there is an inherent burden of responsibility with each decision made. Previous research studies have attended to the responsibilities of HCP; as Oberle and colleagues' qualitative interview study concluded, the key difference between doctors and nurses 'was that doctors are responsible for making the decisions and nurses must live with these decisions' (Oberel et al, 2008). This conceptualisation of HCP responsibility has not faltered in decades, as highlighted in Stein's 1967 text *The Doctor-Nurse Game*, where he writes 'The physician traditionally and appropriately has total responsibility for making decisions regarding the management of his patients' treatment' (Stein 1967). However, the move towards shared-decision-making moves us closer to shared-responsibility, something patients of any age may find burdensome (Coulter, 1999).

In line with a consideration of responsibility, we must too recognise the importance of accountability and authority. While teenagers, HCP and parents may all feel responsible for making the right decision, it is HCP that will be held accountable and consultants who hold the authority. HCP must be able to justify a choice and provide retrospective review accounting for the decision made (Weydt, 2010). By virtue of their position consultants have the overriding authority to make a final decision, though parents and teenagers may feel responsible for a choice and accountable for their child, they have no authority in the clinical world to order a test, organise transplant or commence chemotherapy.

In light of this, I here draw focus to the ways in which teenagers, HCP and parents distribute responsibility amongst themselves in interaction, before turning specifically to the unique responsibility of parents and guardians. It is important to note that although there are specific legal mandates outlining levels of responsibility, and the authority that should be legally afford to teenagers'

care and treatment preferences, these were rarely referenced explicitly by participants in principle or in consultations. The varying levels of legal responsibility each party holds at each decision were not discussed despite their observed centrality in determining which principles could be prioritised in practice.

8.5a The Distribution of Responsibility

As a society we allocate generic roles and responsibilities to individuals based on their membership to various groups such as profession, gender, or age. Over time we become socialised into these roles, each individual adapting to an institution and each institution adapting to its individuals (Atkinson and Houseley, 2003). HCP, parents and teenagers all have unique assumed roles and responsibilities before they come together in interaction. HCP are assigned the responsibility and authority to provide care and treatment to the sick and do no harm, parents allocated responsibility to raise their children and act as their advocate, and teenagers assigned the responsibility to learn and develop. Within these broad responsibilities exist smaller responsibilities that make up the day-to-day roles of each individual and shape our understanding of them. My intention is not to reduce an increasingly diverse population to basic categories and fixed roles, but to ignore these systems of meaning is to ignore the background of understanding from which teenagers, parents and HCP originate. The authority and responsibility of HCP, particularly doctors is instilled in children through nursery play, children's literature, TV shows, films and more. Prior to any personal experience of the hospital, children as young as four have an understanding of how the medical world runs (Eiser, 1989), who holds the power and who makes the decisions.

In addition, research has suggested that children and teenagers are traditionally accustomed to a passive role, listening and following rather than making their own independent decisions (Coyne, 2008). Teenagers at 13-19 years are just beginning to take responsibility for certain life decisions, which GCSE/ A-Level subjects to take, which university to choose, whether or not to drink, take drugs,

or start relationships. Responsibility is often something they earn and are awarded by parents and other adults. That is not to say parents pass on responsibility completely, as I go on to discuss in the following section. In line with interactionist thought I argue that these roles are not fixed and unchanging but creative and dynamic (Attkinson and Housely, 2003). When these three individuals come together in interaction in a health care setting their roles are negotiated as each individual adapts to their social circumstances.

For both teenagers and parents, responsibility for decisions of consequence was handed back to the HCP. For the Aldea family when provided with the information regarding the second randomisation in a Phase III treatment trial they sought the advice of HCP despite HCP attempts to leave the responsibility with Becky and her parents. On other occasions where HCP asked teenagers and families for input or for their preference on place of care, minor procedures, and disease/ symptom directed treatment, families turned back to HCP agreeing to do whatever they thought was best. By deferring to the HCP, teenager and families distance themselves from a decision and its consequences, handing over the responsibility to the HCP. They place responsibility with the individual who is legally accountable and holds the authority and specialist knowledge.

Consideration should be given to the implicit burden that is associated with a decision and its potential consequences. What may seem minor to an experienced HCP may be significant to a medically inexperienced family or teenager. Similarly, when things go wrong, disease directed treatment is unsuccessful and side effects are severe the benefit of encouraging teenagers and their parents to take responsibility at this point must be questioned, particularly if they do not hold any authority in the process. Further investigation, following bereaved families after the death of a teenager would be required to better understand the impact this responsibility or lack thereof for EOL decisions has on the family. What is apparent from this work however is that HCP also

engaged in practices to distance themselves from certain decisions and redistribute responsibility amongst the MDT.

Observations have shown the distribution of responsibility between HCP. Perhaps unsurprisingly nurses and clinical nurse specialists assigned responsibility for care and treatment decisions to consultants. This distribution of responsibility was observed during MDTs and ward round meetings as well as consultations. Nurses and CNS' often informally spoke with teenagers and their families prior to structured consultations, during these discussions CNS' and nurses would inform teenagers that the doctor was on the way to 'make some big decisions'. Through these interactions CNS' and nurses communicated the message that the doctors were in charge. This was also demonstrated between specialist teams, an observation of an interaction during a consultation highlighted how two consultants, one palliative care one haematology, passed responsibility back and forth for one teenager's symptom care and feeding. Whether intentional or not, the implicit message is that consultants are ultimately responsible and accountable for decision-making, something teenagers and parents echoed.

The distribution of responsibility was also observed in MDTs where the family and teenagers were not present; discussions were had where all HCP turned to the attending consultant for a final decision. In turn the consultant either accepted the responsibility and made a decision, or requested time to speak with the other consultants in the wider team. Often the suggestion was made that the teenager's allocated consultant should be accountable for the decision rather than the attending. Ultimately, the lead consultant or allocated consultant accepted responsibility, accountability and authority for making decisions of consequence. They often voiced their struggle with coming to a decision and welcomed support from the team. The impact this responsibility has on consultants regularly making decisions of consequence needs to be considered and the emotional and psychological burden must not be taken for granted.

8.5b The Parental Responsibility

Research by Matsuoka and colleagues (2012) highlighted, through interviews, the roles bereaved parents assigned themselves during their child's treatment. What was evident was that parents viewed their role as protectors and supporters of their children. They suggest that HCP can help parents' fulfil their unique roles and responsibilities as parents towards the end of life. Further findings from Stevens et al (2002) suggested that mothers (fathers did not participate) carry the burden of responsibility for treatment decisions experiencing 'regret and recrimination' once treatment begins. Similarly, Bluebond-Langer et al (2007) suggest that parent's role as protector and advocate were expressed through a continued search for further cancer-directed therapies and interventions. Importantly, Inglin et al (2011) found that parents appreciated when HCP respected their unique position as advocates and experts in taking care of their child and actively involved them in decision-making. This echoes findings of this thesis that suggest parents have an intrinsic responsibility that cannot and should not be ignored.

This responsibility is also reflected in UK law and NHS policy for seeking consent from minors. The GMC themselves acknowledge that 'the law on parents overriding young people's refusal is complex' (GMC 2007) and suggest seeking legal advice in each individual circumstance where treatment deemed to be in the best interest is refused by a teenager. Broadly, in England it is understood that while the teenager is able to consent to treatment after their 16th birthday, they are not afforded the right to refuse life-saving treatment until they are 18 years of age. Parents, guardians and HCP can overrule the refusal of life-saving treatment by a young person up until this milestone birthday. That is not to say that parents and HCP actively seek to alienate teenagers, quite the opposite, but the legal responsibility afforded to parents places them in an undeniably unique position to ride shot-gun with the HCP, while teenagers, by virtue of their age, are legally resigned to the backseat. It is understandable therefore that parents and guardians acknowledged their responsibilities to seek information and remain informed regardless of the age of their child.

Some parents in this study spoke of their parental responsibility to teach their child right from wrong long before the teenager's diagnosis, suggesting that this facilitated the teenager's competence in making medical decisions. For two of the older teenagers in this study, parents spoke of their abilities to make sensible choices in the face of minor care and treatment decisions. They acknowledged their child's capabilities to make sensible choices, choices that they themselves would make based on the family values they had instilled. Parents of younger children, who feel they may not have sufficiently instilled their values in their child yet, may be less inclined to encourage their child to take initiative. Acknowledgement of their child's capabilities did not extend to a complete transfer of responsibility. Parents still recognised a role for themselves and a responsibility to support and guide their child through decisions.

Jasmine Mirzaei (see Chapter 6) demonstrated how this parental responsibility and protective instinct materialised regardless of the teenager's age. When asked hypothetically if she would consent for her son to receive a second round of similar disease directed treatment, Jasmine said no. She spoke about taking responsibility for this decision, despite her son George being of consenting age (17 years old), and him being the one who would have to formally consent. This highlights a fundamental point, that parents often feel responsible for their child, regardless of age and regardless of whose signature is inked on the consent. This is crucial to recognise when discussing the involvement of teenagers in decision-making, particularly involvement in decisions for life-threatening diagnoses. To exclude the parents and family or consider the teenager in isolation is to belie this relationship and natural instinct at a time of crisis.

8.6 The Importance of Time

The nature of this research enabled findings to reflect involvement in decision-making over time, decisions, and at various stages in the disease trajectory.

Doing so highlights the importance of considering involvement as a flexible and dynamic concept rather than a static notion. Throughout the chapter I have made reference to the importance of understanding involvement across decisions and stage in the trajectory. Here I highlight two further areas that demonstrate the importance of considering teenagers involvement over time, namely age and mental wellbeing.

8.6a Age

There is limited research that documents teenagers' involvement over a period of time or across a disease trajectory. However, research has highlighted that maturity and disease experience, not age, is an important factor affecting teenagers' role in decision-making (De Vries 2012, Crawshaw 2009, De Vries 2009, Olechnowicz 2002, Talati 2010, Zwaanswijk 2007, Bluebond-Langner et al 2005). Despite this, law and policy retain focus on the capacity and capabilities of teenagers as accorded with age. On the sixteenth birthday adults allow teenagers responsibilities they did not have the day before. This stratification by age is of course nothing new and is reflective of societies approach to teenagers, both in the UK and further afield. UK law determines when teenagers can have sex, drive, vote, drink and get married; medical decision-making thus follows this trend.

Some more recent work has taken experience of the disease and the health care setting rather than age into account. As Larcher and colleagues suggest in their Framework for Practice – Making decisions to limit treatment in life-limiting and life-threatening conditions in children, 'in the case of children who have extensive experience of illness and medical treatment it will often be reasonable to presume a greater degree of competence in decision-making' (Larcher et al, 2015 page 11). This experience was something several of these teenagers had by virtue of the leukaemia trajectory. Having been recently diagnosed, three teenagers were new to the disease, the treatment and the ward when recruited into the study. The remaining four had been in and out of hospital receiving treatment for a number of years before relapsing and returning. This experience

did not afford the teenagers any greater decisional authority than those new to the ward.

Perhaps unsurprisingly given societies legal focus on age, the teenagers in this study understood their involvement in line with the legal responsibilities a change in age afforded them. For example, those over 16 made reference to their role to sign the consent form. At 17 years old, Poppy Conteh spoke of being an adult and deciding what happens with her care and treatment because of her age. She acknowledged the greater responsibility her age afforded her in hospital compared to her everyday life outside of hospital. Harry Bukoski, the only teenager who turned 16 during his treatment acknowledged the redundancy of age-based competency; he noted how he did not feel any more or less able to consent for himself on his birthday, which happened to fall the day before consenting to transplant. However, Harry did concede that after he turned 16 he had a role in decision-making that he did not have before, acknowledging his new responsibility to consent [formally with a signature].

Despite this acknowledgement, observations of teenagers' involvement in practice did not demonstrate that age had a substantial influence on how and when teenagers were involved in decision-making. Beyond those over 16 physically signing the consent there was no difference in how HCP communicated information or sought preference. Nor was there any difference in how parents and families were involved or excluded by HCP or teenagers themselves. Parents still wanted to know what their child was consenting to and teenagers still sought guidance from their parents. Age was rarely referenced by HCP, unless the teenager was nearing or exceeded the age for transition to adult services.

Tom, the oldest teenager in the study at 20 years old reflected back on preferences he had voiced when he was first diagnosed at 18-years old, interestingly he referred to himself as 'just a kid'. This is reflective of Epstein's

suggestion that childhood has been 'artificially extended' (Epstein 2007) and now proceeds long into adulthood delaying the adoption of full decisional authority over life, education and health choices. This modern teenager although legally recognised as an adult does not see the value of his input, or perhaps does not believe his input would be valued. Along with several others he believed that his opinion should not hold much weight and was pleased HCP took certain decisions away from him [particularly place of care; the decision to be treated at the research hospital rather than his local hospital was made for him]. Despite Tom's legal status as an adult he acknowledged the centrality of the HCP in making the right decisions for him. Interestingly, all teenagers bar one recognised the HCP as the main decision-makers regardless of their age. Arguably, such a view is born from a combination of societal influences, HCP communication practices and personal preferences identified elsewhere in this thesis.

No teenager made reference to the details of the law that placed the right to withdraw or refuse life-saving treatment with parents until 18 years old. Whether this was not fully understood, or simply did not matter to these teenagers is unclear. The input and advice of parents was acknowledged for 18 year olds as it was for 14 year olds. For 18-year-old Becky, who claimed to have made all her own decisions, she recognised that her parents had also advised her and told her what to do. Parents advising their children and making choices for them is an intrinsic part of the parent/child interaction even as the teenager graduates to adulthood. While we must recognise teenagers growing independence and capabilities this should not necessarily equate to a separation from their parental figures when decisions of consequence need to be made.

Though teenagers acknowledged the new formal responsibility turning 16 and 18 afford them, notably the right to sign their own consent, outside this they did not view their role in decision-making any differently at 14 or 20. Teenagers in this study did not reject advice and support from HCP and parents once they were able to consent. From 14 years through to 20 years teenagers recognised

the experience and wisdom of parents and HCP, welcoming their role as principle decision-maker and advisor across the trajectory.

8.6b Mental Wellbeing of Teenagers Over Time

Mental wellbeing is something that has not been afforded a great amount of attention thus far. While several of the teenagers in the study did see a member of the psycho-oncology team at some point across their trajectory, these meetings were never observed. Rather than attempt to present any overview of the mental health challenges faced by the teenagers in this study I instead focus on how teenagers viewed their mental health in relation to their involvement in decision-making.

One teenager in particular made reference to the impact his changing mental health over time had on his ability to make rational decisions. Though he was not formally diagnosed with a mental health issue, he reported that HCP should attend to his preferences differently in accordance with his mental health state. He argued that after being admitted as an inpatient for 100 days his preferences and choices were different to what they would be after just 10 days, or even 50 days. He goes on to discuss how his desire to be discharged from hospital and return to his 'normal life' dominated his preferences and choices. For example, the option to re-start chemotherapy after a break following severe side effects was presented. George acknowledged that the preference he had stated at the time, to restart treatment as soon as possible, was based on a desire to get discharged as soon as possible. In hindsight, he stated he was pleased his consultant did not act on this preference instead allowing him another week to get physically stronger before recommencing treatment.

This suggestion that teenagers who have undergone extensive treatment and prolonged hospitalisation may be stating preferences that enable them short term gain rather than long term survival is something to consider. Research investigating brain development in adolescence has shown that adolescence is

a time where decision-making is particularly regulated by emotion and social factors, rather than reason (Blakemore, 2012). Teenagers may not be making decisions based on a rational assessment, weighing up pros and cons. In the moment for this teenager, the benefit of returning home sooner outweighed any risk he envisaged from starting treatment before he was clinically ready.

In such situations, HCP often intervened and determined the course of action based on the justification that they are doing the right thing as determined by prescribed clinical consensus and what is in the teenager's best, long term, interests. As mentioned earlier, teenagers do not have any issue with this and with hindsight often championed the HCP for intervening and directing them away from their preferred choice.

8.7 Strengths and Limitations

The strength of this research lies in the rich accounts from all three parties (HCP teenagers, parents and families), combined with observations of practice, across multiple decisions over a 9-month period. To the best of my knowledge no other study has investigated the involvement of teenagers in decision-making across the trajectory in this way. No previous studies have been identified that explore teenagers' involvement in decision-making in real time practice, as decisions are being negotiated in interaction. The presentation of teenagers' views about their own involvement in real time also demarcates this research from existing studies in the field, where focus has been placed on parents or HCP exclusively. This work provides unique insight into teenagers' involvement in decision-making, in a manner that accesses the information hereto neglected in the research literature. While this work has given rise to important findings it would be remiss of me to ignore the limitations of the work.

The idea of an 'outsider' being present with an audio-recorder during meetings and consultations does, for many, raise concerns relating to the influence of my

presence on how individuals behaved and how they reported information to me. It is for this reason I went to extensive lengths (see Chapter 3) to embed myself in the field and in the clinical team. The team's responsiveness to me and the study, and their willingness to learn and improve their practice negated these risks and HCP engaged in unguarded open discussions over the course of data collection. While it is difficult to completely eliminate the potential of my presence influencing the setting, I believe everything feasible was done to reduce this.

Some may draw issue with the small sample of teenagers and parents from which these findings are derived. Given the intensity of the fieldwork and the importance placed on building relationships with each teenager and their family the participant numbers were kept intentionally small. As a lone researcher, in order to attend consultations and meetings for each individual, as well as engage the teenager, parents, families and HCP in informal and more structured conversation before and after consultations and rounds, a smaller sample was essential. Further, the numbers of teenagers recruited reflect the number of teenagers eligible for recruitment during the study period. Three additional teenagers were receiving treatment for AML or ALL during the recruitment period however they were not approached to participate in this study. Two were receiving outpatient treatment several months post diagnosis and thus faced no immediate care or treatment decisions, nor were they present on the ward for any length of time. One teenager was deemed to have an exceptionally complex social and legal situation that would have prevented appropriate consent from being obtained. The small population available at the research site also restricted the extent to which theoretical sampling was possible.

Despite the small sample size, the depth of findings over a 9-month period provided fascinating insight into how these teenagers, their families and HCP negotiate their involvement in decision-making. The sample included teenagers both male (5) and female (2) across the age range from 14 years to 19 years. In

addition, families recruited were from a variety of socio-economic, religious and cultural backgrounds, speaking a variety of languages of which English was often the second. Therefore the diversity within this small sample is an asset to the research and reflective of the patient population in a major metropolitan hospital.

This research was also conducted predominately at a single site, though observations and interviews were carried out with HCP from a secondary site these were infrequent and concerned just one teenager. Given the importance placed on observing teenagers, HCP and families over time and across consultations, ward rounds and MDTs a multi-site study of this nature, in this time frame with a lone researcher would not have been possible. To prevent data from being spread too thinly across sites, a secondary researcher would have been required or, alternatively a longer data collection period where multiple sites could have been visited sequentially.

In relation to this, a decision was made during the analysis phase that data from HCP would be treated as one unit, rather than separating responses by specialism or training. I feel this decision was justified as the consultant and nurse teams on this ward worked very closely together making it difficult on occasion to separate the views of one from the other. All members of the team were given opportunity to contribute to discussions, with consultants, ward nurses and CNS forming a particularly close working relationship. It therefore seemed inappropriate to separate a team in analysis that presented such a united front in practice. A similar decision was made with data from parents and family members; data were not separated by relationship with the teenager. This was principally due to the small numbers of both parents and family members independently. Though I believe the decision to be justified, further research and analysis may garner interesting insight from separating HCP by professional group or parents and family members by their unique relationship with the teenager.

Not all teenagers, family members or HCP were interviewed. For some, the frequent informal conversations enabled topics and questions that formed the interview guide to be covered naturally over the course of several meetings, making a 'formal' interview unnecessary. For others however, an interview was not conducted for reasons ranging from the language barrier for some parents, the engagement of the individual with the study and receptiveness to be interviewed 'formally', HCP other time commitments, and the teenager's health status. In these instances the lack of an interview with participants could be considered missing data. However, in order to continue data collection in a non-intrusive, non-interventionist way I accepted participants had priorities other than my study and did not force HCP to carve out time to meet with me, or encourage unwilling mothers to leave their child to sit with me for an hour. The data presented in this thesis therefore is that which was possible with a single researcher responding to the unique situations, time restraints and availability of families and professionals.

In addition, it would be naive to assume that this research captured every discussion between every participant as they negotiated decisions over the 9-month period. Discussions between parents and teenagers in the early hours of the morning or late at night when everyone else was asleep were not captured on an audio-recorder. Conversations held between HCP via text, email or over the phone were not captured, nor were those held every day over coffee, lunch or walking in-between meetings. There is therefore a degree of missing data that would only have been possible to collect if every participant agreed to wear a microphone for the entirety of the study. Further, though I was able to capture 9 months of interactions, for parents and their children in particular, a long history of interactions prior to this, shape their roles and how they negotiate decision-making. These histories were not accessible and therefore represent missing data when discussing these groups as they come together in interaction. This research had to work within the confines of what was possible, reasonable and desirable given the manpower, time frame and ethical perimeters.

Finally, it is important to note that the teenagers in this study were diagnosed with leukaemia, a specific cancer characterised by highly prescriptive, protocol driven care. Further, the disease directed treatments and trials available for leukaemia are extensive and consequently acknowledgement that death is likely or imminent is often late in the trajectory. Therefore the experiences of these teenagers may not be reflective of other teenagers with life-limiting conditions, where the dying phase is acknowledged months or years before death, where there is a less established protocol and more time is available to discuss and negotiate the choices available.

In the final chapter I turn to concluding this thesis with recommendations for research and clinical practice.

Chapter

9

Conclusions and Recommendations for Research and Clinical Practice

In this final chapter I close the thesis with recommendations for research and clinical practice. Initially I present recommendations for researchers conducting studies in the health care system, with teenagers or with individuals diagnosed with life-limiting or life-threatening conditions. I then turn to recommendations for clinical practice derived from the findings of this research project. Following this I present a final concluding summary.

9.1 Recommendations for Research

Prospective participant-observation

This research has highlighted the benefits of conducting research in real time, observing decision-making as it occurs across time and place. While retrospective interviews offer fascinating accounts they are inevitably influenced by hindsight and our nature to construct a narrative of an event that is acceptable to us, especially in grief (Gillies and Neimeyer 2006). By collecting data in real time across the trajectory views are not influenced by the outcome, nor are they constrained to a single time point. In addition, to make recommendations for clinical practice it is important to observe the clinical practice as it functions rather than relying solely on retrospective accounts of the practice. This research demonstrated times when what teenagers thought and advocated changed with the benefit of hindsight; these subtleties would be neglected in research that focuses on retrospective interviews at a single time point. **Therefore, researchers and HCP should consider the benefits of prospective participant-observation to produce robust and in-depth accounts of individuals in interaction. Research that seeks to provide recommendations for clinical practice should include accounts in real time, so as not to neglect the realities of interaction in practice.**

Research with teenagers with life-threatening diagnoses and their families

This research has demonstrated that teenagers with life-limiting conditions and their families are willing to participate in qualitative research that involves observation and interviews over a period of time. Teenagers were happy to express their views and opinions and share their experiences. Teenagers spoke positively about the experience, with one specifically noting the benefit of participant-observation,

'It didn't bother me at all who is in there (consultation) really. But, that's just me. But I do think that because you (ED) don't, you don't say anything or anything you just sit there quietly and take it on board what I am going through as well. So, that gives you a better understanding of I don't know, in your research and that, and obviously that educational wise it is a lot more beneficial to you being in the clinics with us just going through it rather than just talking to us sort of thing. Because we can't explain it as much as the doctors – so, I think it is very beneficial on both parties'

Other teenagers spoke of the research making them feel 'special', 'appreciated' and noting that it gave them 'someone to talk to'. Similarly one mum commented on how her daughter was able to open up to me as a researcher and share her experiences, something this parent welcomed,

'I think it's a good idea really... for you to have a one to one with her. So, it is never a challenge for me at all, she (daughter) is always looking forward to see you because you have more in common in terms of how she is feeling'

Ethics committees and health care professionals often stress the burdens of qualitative research with these populations, claiming such research is intrusive and unwelcomed. Crocker et al (2015) note how these views influence HCP recruitment of children, teenagers and their families into studies such as these. This study should help alleviate HCP concerns, as teenager and families were open, willing and engaged with the study. The employ of a clear research plan, aims and objectives coupled with common sense, sensitivity and respect of boundaries allowed the views and experiences of this population to be accessed in a unique way. **HCP, ethics committees and research teams should embrace these methodologies and welcome the insight they provide as well as the potential benefits participants recognise.**

Embedding the researcher in the field

In line with the recommendation above, this research highlighted the benefit of embedding the researcher in the field. As stated at the outset permissions were gained so that I was able to attend ward meetings and clinical MDTs prior to obtaining consent from all the participants. By doing so I was able to embed myself within the clinical team from the outset. As a result I was afforded access to meetings and discussions allowing the clinical team to become familiar with my presence and my objectives. The influence of my presence on day-to-day life was thus minimised and eventually taken for granted. Not only did this facilitate recruitment and reduce gatekeeping as I was not reliant on HCP to approach patients on my behalf, but it also facilitated data collection in its entirety throughout the project. **Researchers should consider the benefits of obtaining the appropriate approvals so as they are able to minimise the risk of gatekeeping, reduce the observer effect and build positive relationships with HCP.**

Ensuring the researcher has access to regular support or clinical supervision

The researcher must not underestimate the emotional impact of embedding oneself in an environment with very sick children and teenagers, some of who will not survive. The success of a participant-observation project lies, in part, in the researchers ability to form relationships and create bonds with those they are observing. To do so over time with teenagers who are dying, their families and their health care professionals carries a high emotional burden. Importantly, whilst HCP are able to receive support from one another, the researcher is unable to access this same support. Despite attempts by clinicians to offer support, the researcher must always consider the participant-researcher relationship and avoid turning to HCP for emotional support. In addition, whilst HCP and families are able to reconstruct a narrative of an encounter, the researcher has audio-recordings and verbatim transcripts which she/ he must regularly return to. These data encapsulate the emotion of the moment, retain the voice of those no longer alive, and encourage the researcher to relive a family's distress. **Researchers entering into such work must be provided with regular clinical supervision from an individual outside their study team. Opportunities must be given for the researcher to off load and debrief, to address the emotional impact of working with very sick children and teenagers.**

Box 3. Recommendations for Research

Recommendations for Research

1. Include prospective, real time accounts in research that aims to produce recommendations for policy and practice.
2. Embrace ethnographic methodologies for health care research.
3. Include teenagers themselves in research about their care and treatment, including those with life-threatening or life-limiting diagnoses.
4. Where possible obtain the appropriate permissions to embed researchers in the field, taking note of Recommendation 5.
5. Provide appropriate support and supervision to researchers entering the field.

Future research

As with any research the completion of this thesis has given rise to further questions and potential research projects. Though by no means exhaustive, below I highlight several ideas for future research and further analysis that this thesis has brought to the fore.

- *Analysis of HCP principles and practices separated by professional group.* As discussed earlier further insight may be gained by recognising the professional bodies that make up the multidisciplinary team, and analysing data from each distinct group rather than as one unified team.
- *A focus on the discussions had between parents and teenagers as they encounter and negotiate decisions across the trajectory.* This research did not capture all the conversations and discussions had, particularly between parents and teenagers. There may be scope to conduct a study that focuses on these discussions, encouraging participants to complete a diary or blog about the discussions they have with their child/ parent over the course of decision-making. Not without its problems and limitations this methodology would be more appropriate than an observational study attempting to access these discussions.

- *A comparison between involvement in practice at a large metropolitan hospital with a designated teenager cancer team and at smaller, local hospitals where there is less provision for teenage specific care and treatment.* This research was conducted at a large internationally recognised specialist site for teenage cancer care. The multidisciplinary team was vast and dedicated to understanding teenagers as a unique population. Focus on smaller community hospitals, where teenagers are treated on paediatric or adult wards would afford insight into how teenagers' involvement is enacted in practice and viewed in principle throughout the health service.
- *A prospective ethnographic study investigating teenagers with solid tumours characterised by a longer and more clearly defined phase when cure is not likely and disease directed treatment is no longer possible.* This research focused on leukaemia where disease directed treatment often continues until death is imminent. Focusing on a disease where the unlikelihood of cure is acknowledged months or years before death would provide an interesting account of how teenagers, parents, family members and HCP enact involvement in palliative care and end of life issues over a longer period of time.

9.2 Recommendations for Clinical Practice

As highlighted in Chapter 2, guidance has been produced detailing how to involve children and young people in the health care setting. This guidance has focused largely on involvement in clinical research (Nuffield, 2015), or involvement in service development and provision (RCPCH 2011, Blades et al 2013). There is also extensive guidance detailing the legal mandate for the involvement of teenagers at certain decision points, notably end of life (DoH 2009). Guidance focuses on teenagers capacity, and lack thereof, to engage in certain decision-making processes. We extend this guidance by including teenagers' perspectives of their own capabilities and involvement preferences. This research focuses on recommendations for involving teenagers with life-limiting or life-threatening diagnoses as they face minor decisions and decisions

of serious consequence about their care, treatment, future life and potential death. Below I present several recommendations for the involvement of teenagers facing decisions as a result of a life-threatening diagnosis.

Information Delivery

Despite the preference for honest and open information exchange in principle, in practice these teenagers did not need or want information to be complete, open and provided equally to all parties to feel involved. These parents had different information needs to their children and their children respected these across the trajectory (see End of Life). Teenagers in this study acknowledged that their parents occasionally received more detailed information than they did, and recognised parents and HCP and HCP within and across teams had conversations about their care and treatment that they were not privy to. Moreover, some teenagers actively encouraged this. Teenagers concurrently praised HCP for keeping them so well informed and involved. **HCP must acknowledge that teenagers with serious leukaemia diagnoses do not always need full and detailed accounts of their care and treatment to feel informed and involved. HCP should respect that teenagers' information needs may be distinct from their parents and families. Similarly, HCP must respect teenagers' delegation and opt out of information exchange when possible.**

The Role of the Teenagers Preference

Teenagers themselves voiced their views that they do not have the experience or knowledge to be the main decision-maker for decisions of consequence. This was supported in observations of practice where teenagers and families had access to limited information compared with their health care team. Teenagers and parents in this study did not advocate involvement that was centred on HCP acting on the care and treatment preferences of the teenager and doing what they wanted. Instead teenagers and their families acknowledged that consultants were the principle decision-makers. Teenagers welcomed involvement that was based on information exchange rather than choice. **HCP**

should not focus on involving teenagers with life-threatening leukaemia diagnoses by encouraging them to state preferences that then may or may not be acted on. HCP should be candid with teenagers and their families about when the teenagers' preference actually holds weight and when it can be overruled by other principles as a result of immutable factors relating to the teenagers physical condition, clinical protocol and legal responsibilities. By following this recommendation HCP should avoid confusing families and leaving them feeling as though their child's preference, and their own were ignored at crucial decisional milestones. While HCP expressed confidence and competence with clarifying this for decisions such as transplant, they are less able or willing when faced with decisions relating to end of life and DNARs. This is a crucial area in need of greater research attention to better understand the distinct nature of these types of decisions and produce policy responsive to clinical practice.

Involving the Family

Accounts from teenagers, parents, health care professionals and observations of consultations highlight how the involvement of the family as a unit is paramount to the involvement of the teenager in decision-making. To attempt to separate the teenager from their family and view them as an independent decision-maker is simplistic and belies the complexity of family dynamics and relationships between parent and child. **Neither teenagers nor parents advocate encouraging teenagers to make decisions about their cancer care and treatment independently. HCP must recognise the teenager with life-threatening cancer as part of their family unit when making minor decisions as well as decisions of serious consequence and not attempt to isolate them and their preference.**

Reassessing Competency

The provision of relevant information is central to how policy guidance conceptualizes the involvement and competency of young people in decision-making. The British Medical Association state that for a teenager under 16

years of age to be considered competent he/she should have ‘the ability to understand that there is a choice and that choices have consequences’ (BMA 2010). In addition, they state that the teenager should have ‘the ability to weigh information and arrive at a decision’ and ‘an understanding of the alternatives to a proposed intervention’ (BMA 2010). For decisions faced by teenagers with life-threatening diagnoses, this study and others with similar populations highlight how there often is no choice and no viable alternatives when it comes to care and treatment decisions. In addition, teenagers, often alongside HCP and parents do not have access to all the information. Moreover, uncertainty surrounding prognosis and treatment efficacy limit how much the teenager can be and wants to be informed. **This current understanding of competency does not speak to teenagers with a life-threatening diagnosis. Policy makers should not equate competency to the ability to recognise a choice, arrive at a decision and understand the alternatives.** By doing so the teenager who opts out of information exchange, recognises their limited choice and is unable to reach a final decision fails to meet the stipulations of competency. In addition, HCP could be accused of denying teenagers with life-threatening diagnoses the opportunity to be considered competent by failing to provide all information, on all alternatives. Under these stipulations all teenagers in this study, regardless of age, would be considered incompetent at one time point by virtue of their disease, limited choices and stringent protocols. To an extent, immutable factors outside the teenagers control determine how competent a teenager or adult of any age can be deemed, this needs further investigation.

End of Life

Observations and interviews with the teenagers and families of those who passed away suggest that teenagers nearing death are able to understand death is imminent without the explicit verbalisation. Both teenagers who died during or shortly after this study asked questions of their families about their death, something none of the other teenagers did. **In line with existing guidance HCP need not explicitly verbalise the inevitability of death to teenagers with leukaemia. HCP must be responsive to each individual**

teenager and family and respect the dynamics and communication practices used to protect one another.

In line with the recommendation above, this study suggests that parents need space to talk to HCP without their children present towards end of life. Parents' information needs become increasingly distinct as they move towards their child's death. Parents required space to discuss practical arrangements (i.e. relocating a teenager's body), grief and uncertainty. Their desire to remain strong and supportive for their children in a time of need prevented this from occurring in the presence of teenagers. Teenagers are not opposed to this, often welcoming and encouraging parents and families to engage in discussions away from them when cure is unlikely. **HCP must respect parents' distinct information and support needs when cure of their child becomes less likely. They must make time and space to communicate with the parents alone if this is what the family request, in doing so they must not feel as though they are doing the teenagers a disservice. Similarly, HCP must respect teenagers' delegation and opt out of information exchange relating to end of life when possible.**

Mental Wellbeing

Teenagers in this study generally acknowledged that their preferences were not and should not be afforded much weight in reaching a decision of serious consequence. However, one teenager spoke of how his mental wellbeing influenced how he believed his preference should be weighted by HCP. Mental wellbeing in this sense is distinct from clinically diagnosed mental health conditions such as depression and anxiety. It was acknowledged that after a lengthy and difficult hospitalisation the teenager prioritised the short-term gain of returning home. Consequently, preferences were voiced that would enable him to achieve this, despite them not being in his best clinical interest. **HCP should acknowledge that teenagers' mental wellbeing after prolonged hospitalisation might influence the preferences they state, prioritising options that offer short-term gain over those that offer long-term cure.**

Attending to these preferences may be detrimental to teenagers' long-term survival. As with the teenager who made this acknowledgement, other teenagers may be grateful their preferences were not acted upon and HCP advice was prioritised.

Trust

Integral to decision-making with HCP, teenagers and their families is the development and maintenance of mutual trust. Teenagers and parents need to trust that HCP are acting in their/ their child's best interest, trust that they were experts in the care and treatment of leukaemia and trust that they would provide the information they needed as and when they needed it. Similarly, HCP needed to trust in the teenagers and their families, trust that they were committed to treatment and trust that they were adhering to medical advice. Observations of interactions in practice suggest that relationship issues between HCP and parents or teenagers emerge when a break down in trust has occurred. This was observed in instances where HCP appeared to overrule or ignore a preference that the teenager or family has stated, or when teenagers begin to refuse medications, treatment regimens and minor procedures, or when parents refuse HCP access to their child.

HCP must work to develop and maintain the trust of teenagers and their families. This is made easier when HCP do not overstate the role of the teenager with life-threatening cancer in the decision-making process. Mutual trust is tested when a decision that HCP purport to be led by the teenagers preference, is actually made in line with the HCP determination of best interest or other clinical benchmark. **Rather than asserting the importance of the teenagers preference HCP should clearly communicate the immutable factors that often restrict the extent to which principles of involvement can be enacted and drive a decisional outcome.**

Box 4. Recommendations for Clinical Practice

Recommendations for Clinical Practice

1. Do not overstate the role of the teenagers' preference, instead be candid about the immutable factors that restrict freedom of choice and drive decisional outcomes.
2. Recognise that teenagers and their parents **may** have distinct information needs and respect these throughout the trajectory.
3. Be respectful of the individual information needs of each teenager, rather than championing full and 'honest' information exchange.
4. Do not encourage teenagers to make decisions independently of their parents, instead recognise the teenager as part of their family unit, acknowledging and respecting the unique relationships between all members.
5. If sought, HCP should provide guidance for teenagers and families when making decisions of serious consequence.
6. Make time and space for parents and family members to have discussions with the health care team away from the teenager when cure is less likely.
7. Move away from conceptualisations of competency based on the ability to recognise a choice, arrive at a decision and understand the alternatives. These do not speak to the experiences of teenagers with life-limiting or life-threatening diagnoses.
8. Recognise the influence long periods of hospital admission have on the mental wellbeing of teenagers, and be responsive to how this may impact on the preferences they state when decisions arise.
9. Understand that involvement is a complex and fluid process the roles and responsibilities of each party are shaped by interaction, including those interactions where a decision is not explicitly discussed.

Implementation of recommendations

Implementing recommendations to improve patient care is often considered a challenge (Grol 2007). Whether they require change at a local, institutional, policy or societal level determines how they can and should be implemented, as well as the ease of facilitating that change. As Grol and colleagues (2007) note, to implement any change in the health service it is important to recognise the

interaction between the change recommendation and the 'complex setting' within which it is proposed. Unlike interview or survey studies these recommendations do not rely on HCP retrospective or generalised accounts of a setting alone. As an embedded participant-observation study, the recommendations from this research are born from observations and first-hand understanding of the setting for which they are intended, alongside accounts from all parties.

Some of the clinical recommendations presented here align with those already offered in existing guidance, others encourage HCP and policy makers to reconsider how they conceptualise and advocate for the involvement of teenagers with life-threatening leukaemia diagnoses in decision-making. They require policy makers to recognise that involvement in decision-making in practice is a complex and fluid process that needs to be explored in greater depth in future guidance. Though the GMC presents comprehensive guidance for involving children and teenagers in certain decisions; a more considered reflection on what this means for teenagers with specific diagnoses and trajectories is required.

By further specifying policy and guidance on decision-making, and crucially including the real-time views of teenagers themselves, HCP will be able to respond to each teenager individually, allowing them to be involved as much as they are able at each decision without feeling as though they have failed to involve a teenager when immutable factors intervene. Importantly, HCP in this study implicitly or explicitly recognised the failings of current guidance for involving teenagers in decision-making when translating it into practice. By acknowledging the concerns of HCP, the preferences of teenagers and their families, all parties should welcome change that better reflects the realities of their everyday practice with this unique patient group.

9.3 Concluding Summary

This thesis examined how teenagers, parents and health care professionals' view and experience the involvement of teenagers in decision-making regarding their care and treatment in principle and in practice. As discussed in the early chapters, there has been limited work to date on the views and experiences of teenagers themselves, and less still exploring the realities of involvement when these three parties come together in practice. Acknowledging a gap in the research literature and the implications of this gap on health care policy, this thesis presented empirical data to fill this gap. By employing ethnographic research methods, overtly centring the work in the theoretical perspective of interactionism and utilising principles from Glaserian grounded theory methodology throughout, this thesis has addressed the aims and objectives presented at the outset.

The initial review conducted and presented in Chapter 2 identified no evidence that parents or teenagers indicate a preference for a high degree of independence in decision-making, and rather cooperative partnership appeared to be desired (Broome 2003, Crawshaw 2009, Zwaanswijk 2007, Yap 2010, Young, 2010). Further, the review suggested that teenagers and parents preferences for information and involvement vary between individuals and over time. Findings from this research develop this conclusion suggesting that teenagers with life-threatening diagnoses want a different kind of involvement in decision-making than much policy advocates. Importantly, in this study teenagers and parents expressed no desire for independent decision-making, nor did they encourage following teenagers' care and treatment preferences for decisions of consequence.

Involvement is not static and consistent across the trajectory, nor is it dependent on the chronological age of the young person. Instead, immutable factors relating to the stage in the trajectory, the decision to be made, and the

legal positioning of each party determines how principles can be prioritised and enacted in practice.

Through interaction teenagers, parents and HCP employ communication practices to establish roles for themselves and assign roles to others in the decision-making process. These communication practices manage the flow of information between these players and shape the role teenagers are able and willing to play in decision-making. Importantly, teenagers felt they had been involved and kept informed despite acknowledging their preference was rarely adhered to, recognising HCP as the ultimate decision-makers and arbiters, and knowingly receiving limited information about their care and treatment.

These findings have given rise to fourteen key recommendations for both research and clinical practice. For the former, this thesis demonstrates the benefits of conducting prospective research in this setting, particularly in utilising participant-observation and informal discussions. Recommendations have been made to encourage researchers and ethics boards to embrace these methodologies and recognise the insight they provide for policy makers, clinical practice and personal development. In line with this, several recommendations have been made to health care providers to reconsider involvement in principle and practice. Findings urge HCP and policy makers to reconsider the value of encouraging and advocating one type of involvement centred on providing the teenager with information, seeking their preference and following their lead. Immutable factors must be considered as key contributors to how the involvement of teenagers with life-threatening diagnoses can be enacted for decisions of consequence; to ignore these is to set an unrealistic precedent and idealistic expectation for involvement in practice.

This thesis provides accounts from teenagers themselves who place much less weight on the value of their own preference and welcome the input and advice of their parents and their HCP across the trajectory. Health care professionals

and policy makers should acknowledge this key finding and move towards a view of involvement that reflects the complexity observed in practice when involving teenagers with life-limiting diagnoses in decisions regarding their care and treatment.

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Appendices

I. Systematic Narrative Review Published Article

Review Article



Current understanding of decision-making in adolescents with cancer: A narrative systematic review

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Abstract

Background: Policy guidance and bioethical literature urge the involvement of adolescents in decisions about their healthcare. It is uncertain how roles and expectations of adolescents, parents and healthcare professionals influence decision-making and to what extent this is considered in guidance.

Aims: To identify recent empirical research on decision-making regarding care and treatment in adolescent cancer: (1) to synthesise evidence to define the role of adolescents, parents and healthcare professionals in the decision-making process and (2) to identify gaps in research.

Design: A narrative systematic review of qualitative, quantitative and mixed-methods research. We adopted a textual approach to synthesis, using a theoretical framework of interactionism to interpret findings.

Data Sources: The databases MEDLINE, PsycINFO, SCOPUS, EMBASE and CINAHL were searched from 2001 through May 2015 for publications on decision-making for adolescents (13–19 years) with cancer.

Results: Twenty-eight articles were identified. Adolescents and parents initially find it difficult to participate in decision-making due to a lack of options in the face of protocol-driven care. Parent and adolescent preferences for information and response to loss of control vary between individuals and over time. No studies indicate parental or adolescent preference for a high degree of independence in decision-making.

Conclusion: Striving to make parents and adolescents fully informed or urge them towards more independence than they prefer may add to distress and confusion. This may interfere with their ability to participate in their preferred way in decisions about care and treatment. Future research should include analysis of on-ground interactions among parents, adolescents and clinicians across the trajectory.

Keywords

Cancer, adolescence, decision-making

What is already known about the topic?

- Decisions made by adolescents with cancer and their families have lifelong consequences.
- Guidance and bioethical literature increasingly advocate the participation of adolescents in decisions about their healthcare.
- Little guidance is offered to elucidate what this involvement looks like in practice, over time and across decisions for 13 to 19-year olds and their parents.

What this paper adds?

- This review enhances understanding of parents and adolescents' informational preferences as well as their actual and preferred roles in the decision-making process.

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- Adolescents exercise agency in decisions in a variety of ways but do not find a clearly defined role in decision-making comparable to that of parents and clinicians.
- No studies identified parental or adolescent preference for a high degree of independence in decision-making. Partnership and cooperation were most frequently stated or implied.

Implications for practice, theory or policy

- Assuming or advocating that all parents and adolescents desire to be or should be fully informed or independent in decision-making may increase their distress and confusion. This, in turn, may interfere with their ability to participate in their preferred way in decisions about care and treatment.

Introduction

Adolescents with cancer are both biologically and psychosocially distinct from children and older adults with the disease. National incident rates of teenage cancer are rising with some suggesting an increase of 50% in the last 30 years.¹ Outcomes for adolescents are poorer than for children and older adults. Five-year survival rates for acute lymphoid leukaemia, for example, decrease across by 30%–40% across the 10–19 years range.²

Undifferentiated from adult and paediatric populations in the past, there are limited psychosocial and biological data that attend specifically to 13 to 19-year olds. However, Weaver et al.³ state that 'pediatric and adolescent age oncology patients and their families have identified their psychosocial care needs as both complex and unique from adult psychosocial care needs'.

It is increasingly being argued that the concepts of palliative care are a valuable resource in helping oncologists care for this population. Aimed at preventing and alleviating suffering, the use of palliative care concepts and skills is now thought to be appropriate from diagnosis forward, even in cases for which cure is likely.

One of the areas in which palliative care concepts provide a resource for the oncologist is in support of communication and decision-making. This is an area of high importance in the treatment of adolescent cancer. Decisions must be made about treatment, fertility preservation, transplant, enrolment in clinical trials, discontinuation of treatment and place of care and death when standard therapy has failed.

A first step towards the successful integration of palliative care principles is to analyse and understand decision-making in this population. This may reduce the possibility that despite the best of intentions, suffering is increased or prolonged through the application of principles, which do not respect the situation or align with the needs of participants.

Objectives

In this article, we report on a systematic narrative review of empirical research published internationally between 2001 and 2015 that illuminates the role of adolescents, parents or healthcare professionals (HCPs) in the

decision-making processes surrounding care, treatment and future life. We sought to understand current qualitative, quantitative and mixed-methods research evidence on decision-making for adolescents (13–19 years) with cancer. We understand 'decision-making' to mean the process of interaction between two or more participants when information is processed and a judgement or conclusion is reached at any point across the disease trajectory.

We aimed (1) to identify recent empirical research that investigated decision-making regarding care and treatment in adolescent cancer, from the perspective of the adolescent, their parents and families or their HCPs; (2) to produce a narrative synthesis of existing evidence defining the participation, role and place of adolescents, parents and HCPs in the decision-making process; and (3) to identify gaps in the current literature in terms of methodology, perspective and design to inform future studies.

Method

Search strategy

We searched the databases MEDLINE, PSYCHINFO, SCOPUS, CINAHL and EMBASE to ensure inclusion of medical, social science and bioethics literature. For papers that were not accessible online, we contacted authors directly and requested copies. If authors failed to respond within 6 months, these papers were excluded.

We limited our search to papers published between 2001 and 2015. This time frame was chosen as 2001 saw the publication of the UK NICE Guidance on Cancer Services Improving Outcomes in Children and Young People with Cancer,² which set out to improve communication and informed choice with this age group.

We used the following search terms:

1. Cancer* including, leuk*emia or, lymphoma or neoplasm*;
2. Adolescen* including, p*ediatric or child or children;
3. 'Decision-making';
*=-Truncation.

Inclusion/exclusion criteria

We included English-language qualitative, quantitative and mixed-method studies that focused on 13 to 19-year olds diagnosed with any form of cancer and dealt with decision-making about care, treatment and research participation over the course of illness. We also included articles that reported the perspective of the adolescent, HCP or parent(s) in isolation or in combination with one another. Retrospective studies were included if an adult participant was discussing decision-making with regard to care and treatment when he or she had been diagnosed with a cancer as an adolescent. We considered studies where patients aged 0–18 were investigated and included those studies where the mean age of participants was clearly reported and fell between 13 and 19 years as well as those where reporting was stratified by age such that findings for 13–19 year olds could be discerned.

We excluded papers which discussed adolescents who were not themselves diagnosed with cancer, those that discussed decisions about cancer screening or cancer prevention as well as participation in non-clinical studies and general texts on paediatric palliative care or cancer that did not focus specifically on 13 to 19-year olds or decision-making.

Papers identified from the initial database searches were screened for duplicates, which were removed. Citations were then screened for relevance and those that did not meet our inclusion criteria were removed. Full-text articles were independently screened by two reviewers (E.D., L.J.) and included articles were assessed for study quality (Figure 1).

Quality appraisal

Qualitative research was appraised using recommendations from the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist.⁴ Mixed-methods and quantitative research was appraised using recommendations from Guyatt, Sackett and Cook's Users' guides to the medical literature II.^{5,6} To produce a robust synthesis of findings, only studies deemed good quality (those scoring over 60% on the relevant appraisal tool) were included in the review. A total of 28 studies were retained and included in the analysis.

Method of synthesis

We used narrative synthesis, which is well suited to consideration of studies that are heterogeneous in method. Previous reviews have successfully used this approach to summarise existing research and to synthesise evidence on decision-making in a medical setting.⁷ We have 'adopted a textual approach to the process of synthesis, to "tell the stories" of the included studies⁸ through a preliminary analysis, exploration of relationships and assessment of the robustness of the synthesis. In accordance with Popay's

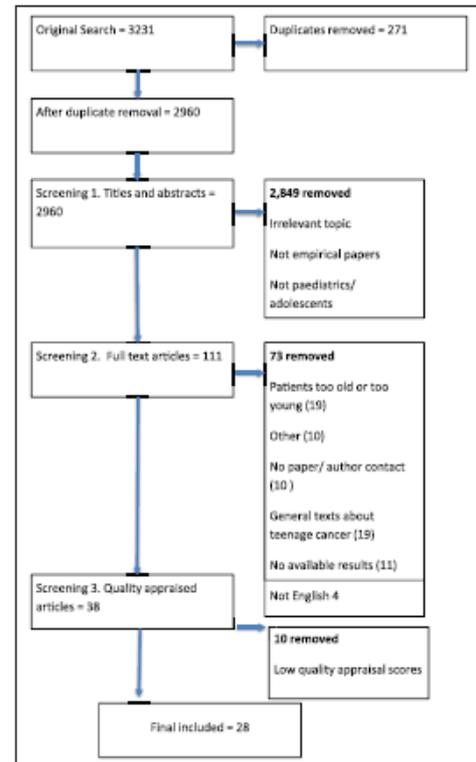


Figure 1. PRISMA flow chart.

guidance (2006), we employ a theoretical framework of interactionism to interpret the findings.⁸

Theoretical perspective

We use interactionism as our overarching theoretical framework. By this we recognise the social world as a place where meaning is formed through interaction between individuals, in this case adolescents, parents and HCP.⁹ We understand behaviour as more than individual responses and social rules; rather it is the product of human interaction, allowing the roles of adolescents, parents and HCPs to alter and develop over time and place.¹⁰ It is supposed that people attempt to make sense of the world by viewing and interpreting themselves in the context of the behaviour and actions of others in any given situation.⁹ Consequently, individuals are not seen as passive recipients of information but as active agents in the formation and interpretation of behaviour and action.^{11,12} This interpretive narrative synthesis organises the current literature by focusing on the ways adolescents, parents and HCP

interpret their own roles and the roles of those around them, defining their place in the decision-making process.

Having a place in or participating in decision-making is understood here as being able to interact with others in a clinical consultation or an informed consent conference. The ability to interact and to have an impact on a decision-making interaction we refer to as agency, or self-efficacy (see Box 1). In framing consultations and the decision-making process in this way, we locate them within a general account of human behaviour and within the everyday lives of maturing children and their parents. This contrasts with approaches that construe clinical encounters as activities with their own unique rules.

Box 1. Defining agency.

Agency

Agency in interacting with others refers to the ability of a person through expressing a thought or a wish, for example, to make a difference to the activity in which he or she is engaged with others. Agency does not equate to power or authority or dominance. It is often exercised through negotiation, a process of give and take.^{13,14}

Notably, interactional roles in these situations align with categories used to define populations in the various studies and with the participants identified in professional and ethical guidance, namely, adolescents, parent and HCP.

Results

The descriptive characteristics of the included studies and quality appraisal scores are presented in Table 1. A summary of study characteristics, including populations studied, is presented in Table 2. A model of synthesis results is presented in Figure 2.

Synthesis

The 28 studies included are heterogeneous in methods, in the nature of the data presented and in types of decisions and issues studied. The evidence ranges from records of audio- and video-taped consent conferences, retrospective surveys of parents, adolescents and HCPs, to reports of preferences and recommendations concerning the decision-making process. The evidence is a mixture of what was observed to have happened, what is recalled as having happened and what participants would like ideally to occur. Against a backdrop of interactionist theory we present a synthesis of these study findings, identifying to what extent adolescents, HCPs and parents are able to participate in decision-making.

The Impact of protocols. A shared aspect of the experience of participation in decision-making is the impact of

protocol-driven clinical treatment, following the diagnosis of a life-threatening cancer when initiating a treatment plan is thought to be in the best interests of all concerned.²⁰ Parents and adolescents experience a lack of choice because decisions are guided by a medical protocol.^{19,35,39,42}

In describing their experiences at diagnosis, parents and adolescents report that the pace in consultations was too fast and that they lacked time to grasp what they were being told about protocols and treatment options, so that they could participate by asking questions.^{15,19,22,35,41} Participants report a desire and a need to alter the pace of interaction in order to gain a place in the discussions and to establish agency.

The loss and re-establishment of agency. Parents' and adolescents' descriptions of their experience at diagnosis report a loss of control and agency in early interactions. Eight studies^{18,19,23,25,28,29,35,39,41} report variously that parents (eight studies) and adolescent (one study) initially experience a lack of control, a feeling of loss of power or a sense of being overwhelmed, under time pressure and unable to participate in decisions.^{15,20,35,38}

Kars et al.²⁵ identify parents striving for control as an issue continuing throughout the illness of their child. They found that 'Parents who lost their control surrendered their actorship' (p. 32). Woodgate and Yanofsky³⁹ report on parents faced with a decision about participation in clinical trials, usually immediately after diagnosis, experiencing feelings of distress and helplessness (p. 17). As a result, parents and adolescents put their trust in physicians; they tend to follow and agree with them. Parents report a sense that they would have signed anything. Stevens and Pletsch³⁵ go so far as to say 'The process of enrolling their children in clinical research was, therefore, not a calculated rational decision-making process of analysing the purpose and procedures and risks and benefits of particular research protocols' (p. 84). All of these findings reflect the participants' sense of self-efficacy or agency and the manner in which they are able to engage in making the decision under study.

Only one study⁴¹ of parents reported no experience of a loss of power or agency, possibly attributable to the exclusive recruitment of parents considered 'veterans of the hospital'. Establishing or re-establishing agency in the clinical setting requires time and experience with the disease, the HCPs and the setting, something adolescents receiving palliative care may have opportunities to develop.

Six studies state that over time, with experience of the disease, agency is re-established as parents gain some sense of control.^{18,19,23,35,41} Parents employ various strategies to establish their place in decision-making, for example, gathering information,²³ strategising to get more time to consider options⁴¹ and equipping themselves with the skills to judge medical information.¹⁸ Miller et al.²⁸ note

Table 1. Descriptive characteristics.

Author	Publication year/country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Baker et al. ¹⁵	2013/USA	57 parents and 20 patients (mean age 17)	Multiple, prospective descriptive interviews	Content analysis	6/10	Patients and parents want additional information about trials in different formats, they want more time to prepare and make decisions, they want straightforward and honest communication from a regularly available clinician
Broome and Richards ¹⁴	2003/USA	34 children (9–22 years) with a diagnosis of diabetes or a haematological malignancy	Semi-structured interviews	Narrative analysis	10/10	Chronically ill children are willing to talk about involvement in trials and describe how relationships with others influence their decisions. They have faith in their parents to listen to them and make decisions for them. Caregivers were markedly different as the physician approached child and parent together rather than parent first. They had a greater level of involvement in research decisions
Crawshaw et al. ¹⁷	2009/UK	38 young adults diagnosed with cancer between 13 and 20 years old, aware of fertility effects and not currently on treatment	In-depth single interviews	Informed by grounded theory	8/10	Addressing fertility issues is important regardless of the options available, teenagers express a clear wish to have a choice in who is involved in discussions. Girls are less likely to have issues raised than boys. Argue that assumptions about how much information on fertility the adolescent wants can be made based on the age of the adolescent
De Vries et al. ¹⁸	2009/ Netherlands	14 physicians and 15 parents of male adolescents undergoing cancer treatment	In-depth semi-structured interviews		7.5/10	Physicians did not accept parents' strategic control around decisions relating to fertility preservation. Unlike other treatments, physicians spoke to child first regardless of parents' position on the matter
De Vries et al. ¹⁹	2010/ Netherlands	15 paediatric haematologists/ oncologists	In-depth semi-structured interviews		7/10	Clinicians regard most adolescents as not capable of meaningfully participating in discussions about research. Clinicians do not always provide adolescents with all the information. Proxy consent is obtained and deemed sufficient. Clinicians judge treatment protocols as not harmful and in best interest of adolescent
De Vries et al. ²⁰	2013/ Netherlands	Parents, paediatric oncologists and 8- to 18-year-old (mean 13) cancer patients	One-to-one semi-structured in-depth interviews		8/10	All felt it is in the best interest to defer to medical judgement/protocols in beginning. There was recognition that as the disease progresses there is more choice and differences in what 'best interest' means. Parents reported little choice at diagnosis and the shock when they do have to make a decision about things like fertility preservation. Parents recognised that as the adolescents disease progresses they become 'layman-experts' and make more decisions. However physicians regard parents/children as having little influence on treatment protocols, claiming their influence starts with minor decisions
Hinds et al. ²¹	2005/USA and Australia	20 patients aged 10–20 years	Interviews		8/10	These adolescents realised they were involved in an end-of-life decision, understood the consequences and were capable of participating in a complex decision process that involved risk to them and others. Decision factors most reported were relationship based, contradictory to existing developmental theories
Hokkanen et al. ²²	2004/Finland	Twenty 13- to 18-year olds currently living with cancer and attending a cancer adjustment camp	Focus groups		7/10	Adolescents stated that they felt HCPs asked them unnecessary questions and presented them with like decisions and the illusion of control. They stated that information received in the early stages was irrelevant and they only needed it when treatment was over. They wanted practical advice on what they were allowed to do and how to cope with the disease, as well as more future-oriented information. Adolescents felt improvements were needed in staff, priority and physical care facilities

(Continued)

Table 1. (Continued)

Author	Publication year/country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Holm et al. ²³	2003/USA	25 parents of 26 children who had completed treatment for cancer at least 1 year prior to the focus group	Focus groups (5–9 people)		7/10	Parents see themselves as advocates for their children, informing HCPs and keeping themselves informed during both diagnostic and treatment phases. They have a role in limiting actions of medical professionals and supporting them
Inglis et al. ²⁴	2011/ Switzerland	15 parents whose child died or was receiving palliative treatment in one of three diagnostic groups – cancer, neurological disorders and non-oncological neurology	Qualitative interviews		7/10	Honesty and openness from HCPs considered essential by all parents when delivering difficult news. Parents appreciated when HCPs respected them as experts in taking care of their child and actively involved them in decision-making. Parents highly valued supportive home care and long-term bereavement care
Kans et al. ²⁵	2011/ Netherlands	44 parents of 23 children (6 months–19 years) with advanced and incurable cancer	One-time and repeated open interviews Multi-centre study		7/10	Parents don't accept death with the loss, parents who made the transition to letting go had increased acceptance to child's real situation and needs. Parents stated it is not a linear process from pre-arrival to lettings go. Feelings of loss begin in the EOL phase not post death. Parents delay negotiating treatment has failed. Dominant perspective of parents influences the child's situation. Best interest for who argue that parents can act in ways that have negative consequences for the child. Professional focus should shift from decision-making to guiding process of relinquishing – from the preservation of the child to letting go
Kelly and Gancig ²⁶	2011/USA	15 custodial parents, non-residential parents and step parents who had previously made major treatment decisions for their child with cancer	Minimally structured interviews	Grounded theory	8/10	Parents focus on ill child until the crisis has passed. Biological parents 'step up' to responsibility while their partners step back or are pushed away. Step-parents play a supportive role to their spouse if they are allowed to
Mizusaka and Narana ²⁷	2012/Japan	23 parents bereaved 1–3 years previously	Semi-structured open-ended retrospective interviews	Content comparison analysis	5.5/10	How parents understand impending death is complex and impacts on decision-making. The key thought of parents is to protect and support their child. Parents argued that HCPs can help this to happen
Miller and Luoga ²⁸	2011/USA	219 parents who made a decision about research or treatment for a child	Questionnaires – completed measures for external influence, distress, decision-making preference and coping		6.5/11	More external influence was associated with more hostility, uncertainty and confusion. Decision-making preference and coping style moderated the influence between external influence and distress
Miller and Nelson ²⁹	2012/USA	184 parents of children with cancer who made a decision about enrolling child in treatment protocol within previous 10 days	Questionnaires assessing voluntariness, external influence, concern of negative effects on care if diagnosed, time pressure, information adequacy and demographics		6.5/11	Several groups of parents appear to be at risk for decreased voluntariness when making research or treatment decisions for their seriously ill children, including fathers, non-White parents and those with less education. Parental voluntariness may be enhanced by helping parents to mitigate the effects of unhelpful or unwanted influence by others and ensuring that their information needs are met

Table 1. (Continued)

Author	Publication year/country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Miller et al. ²⁴	2014/USA	61 patients aged 7–21 who were offered participation in a phase I trial	Audio-recorded consent conferences	Statistically coded	5/5	Mean proportion of informed consent conferences for trials in which the patient was involved was 43%. Proportion was greater with older patients. After controlling for age, the more patient to doctor communication, the more patients reported understanding
Olechowitz et al. ²¹	2002/USA	14 informed consent conferences involving children with leukaemia over age 7 parents and clinicians completed a self-administered questionnaire	Audio-recorded ICC and follow-up interviews with parents, clinicians		4.5/5	Who the clinician identified as the primary decision maker was not related to the age of the patient. Older patients asked more questions than young patients HCP interaction with patients based on a number of factors: patient age, disease status, training style and preferences. Parents asked significantly fewer questions if child was present
Pousses et al. ²⁰	2011/ Belgium	165 physicians who signed death certificates for 1- to 17-year olds	Anonymous population based post-mortem survey		8/11	Minor patients commonly kept in continuous deep sedation until death (21% non-sudden deaths, 53% sudden deaths); indications that this is sometimes used with life-shortening intention without involving the patient
Simon et al. ²³	2003/USA	108 parents of children with leukaemia 21 – non-English-speaking 27 – English-speaking minority group 60 – English-speaking majority	Audio-recorded observations and interviews		4/5	Christians were more likely to omit certain information from discussions with non-English-speaking parents, relating to randomisation, right to withdraw and consent documentation. Significantly more non-English-speaking parents failed to grasp key aspects of informed consent. Parents in non-English group asked fewer questions. Consultations took on average the same amount of time, despite the added time normally required to speak through interpreters
Sternmarker et al. ²⁶	2010/ Sweden	10 paediatric oncology physicians with more than 10 years' experience	Interviews	Grounded theory	6.5/10	HCPs reported the decision burden for adolescents as they are at a stage calling for independence. They speak of the significance of seeking knowledge and information. They avoid identification with families and keep empathetic distance, dealing with their own attitudes to central life issues
Sievers and Pletsch ²⁵	2002/USA	12 mothers whose children had undergone BMT	Qualitative semi-structured interviews		6/10	Findings suggest that BMT is often a non-decision for mothers, as a life or death situation the voluntary nature of the decision is altered. Emotional trauma decreases mothers' ability to absorb information. Urgency further constrains mothers' time to understand and be informed. Mothers have the burden of responsibility, experiencing regret and re-examination once treatment begins
Talati et al. ²⁸	2010/USA	421 randomly selected general paediatricians and subspecialists from web-based directory	Online or mailed cross-sectional survey		8/11	Paediatrician's decisions to respect refusal from minors are multifaceted. When prognosis is good, best interest dominates, when prognosis is bad parental authority (younger children) and minor autonomy (older children) dominates
Vrakking et al. ²⁷	2005/ Netherlands	63 paediatricians 125 GPs 208 clinical specialists	Structured interviews about hypothetical cases – all questions answered on a Likert scale		6.5/11	A substantial proportion of Dutch physicians are willing to use lethal or potentially life-shortening drugs in children. Paediatricians are more willing than GPs to grant request from parent for ending life of unconscious child. Female and religious physicians are less likely. When parents disagree physicians are less likely to grant request of child

(Continued)

Table 1. (Continued)

Author	Publication year/country	Sample	Methods of data gathering	Methods of data analysis	Appraisal score	Main results
Wicks and Mitchell ¹⁶	2010/New Zealand	Ten 16- to 22-year olds diagnosed with cancer during adolescence	In-depth semi-structured interviews		6.5/10	Support for fostering involvement of young people. They reported experiencing a loss of control as the doctor took over, which led to rebellion and non-adherence. Many factors could be implemented to enhance sense of control, for example, benefit finding, maintaining positive outlook, confidence, motivation, remaining focused
Woodgate and Yanofsky ⁸	2010/Canada	31 parents of children with cancer (6 months post-diagnosis –5 years after treatment completion)	In-depth, open-ended, semi-structured interviews		8/10	The suffering of parents is complicated by not only making decisions but by having to come to terms with them afterwards. This is made bearable by relationship with child/other HCPs. Parents experience is a relational process shaped by evoking intrapersonal, interpersonal and transpersonal relationships and communication. As such HCPs can help parents achieve sense of being a good parent
Yip et al ⁹	2010/USA	103 physicians	Cross-sectional questionnaire survey		7/11	Physicians believe providing information about phase I study entry to families is most important goal of informed consent process 84% report providing an unbiased description Families more likely than males to report influencing
Young et al. ⁴	2010/USA	3 patients (13–22) 6 mothers (Hick-en U18) 6 physicians 8 nurses	Focus groups		7.5/10	All agree autonomy is paramount to conducting ethical research. Young people didn't talk about decision-making but physicians did. Differences in status, role definition and information exchange were identified as important in the information consent process. Teenage patients described a loss of agency during informed consent process
Zwaanwijk et al. ²¹	2007/ Netherlands	Seven patients aged 8–17, 11 parents and 18 surgeons aged 8–17 at diagnosis	Online focus groups – three separate groups for patients, surgeons and parents of current patients		7/10	All three highly valued open and honest communication, but not all adolescents wanted to know prognostic and survival rate information. Adolescents emphasised lack of information specifically for their age group. Majority of participants wanted decisions about treatment to be made in collaboration with HCPs and families. Surgeons and patients believed they should be the ones to make the final decision. Parents and young people recognised the prescriptive protocols constrained their choice, as did lack of sufficient knowledge, lack of trust in physicians expertise, practical circumstances and feeling too ill or depressed to decide

HCPs: healthcare professionals; EOL: end of life; ICC: Informed Consent; Conferences; BMT: bone marrow transplantation; GP: general physician.

Table 2. Summary characteristics.

Characteristic	Perspective studied			
	Healthcare professionals	Parents	Adolescents	Combination
Total number of studies	5 ^{19,34,36,37}	1 ^{23-30,33,35,39}	5 ^{16,17,21,22,38}	6 ^{15,18,20,31,41,42}
Methodology	Qualitative	Qualitative	Qualitative	Qualitative
	Quantitative	Quantitative	Quantitative	Mixed
Methods of data gathering	Interviews	Interviews	Interviews	Interviews
	Survey/questionnaire	Focus groups	Focus groups	Observation
Focus of article	Clinical trials	Clinical trials	Clinical trials	Clinical trials
	Treatments	Treatments	End of life	Treatments
	End of life	End of life	Fertility	Fertility
	Communication	Communication	Lived experience	Communication

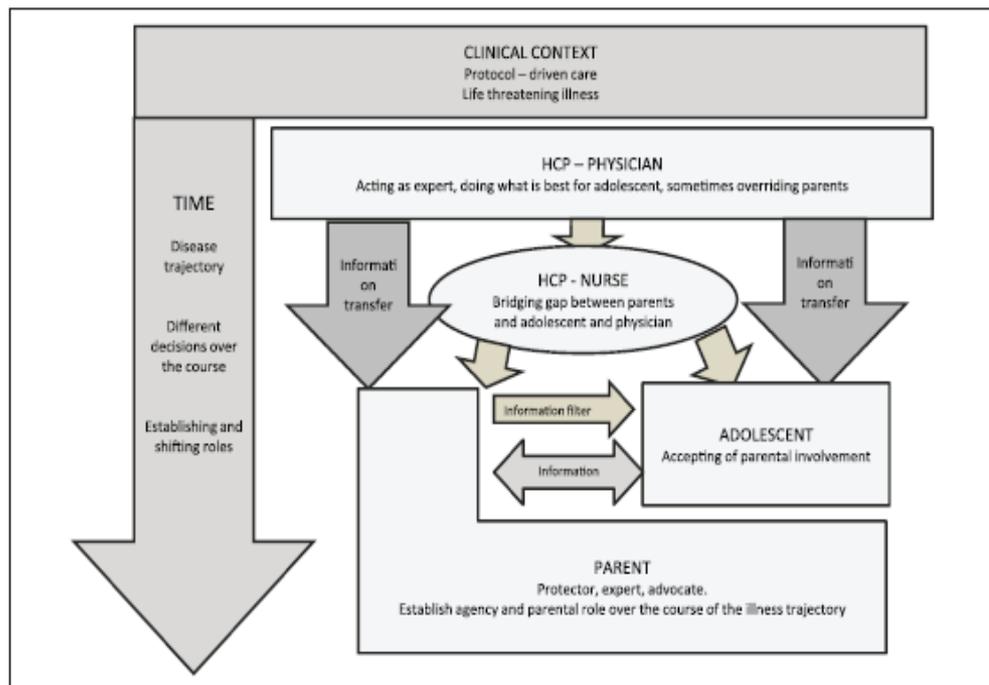


Figure 2. Model.

that parents of adolescents with a shorter duration of illness, and consequently less time to establish a role, experienced more distress.

Adolescents describe a loss of agency in decision-making about research trial participation,⁴¹ feeling their power is reduced to their ability to sign the consent form once they attained legal majority. Adolescents also describe a loss of control, throughout the process of diagnosis and treatment.³⁸ De Vries et al.¹⁹ focused on clinicians' views of adolescents, reporting that at diagnosis they are overwhelmed by their situation and thus are incapable of participating in decision-making; this was true even for older adolescents. The adolescents who were deemed capable were those facing relapse, that is, those who had experience with the disease and those who were likely to be receiving palliative care.

These studies document a critical difference between the reaction of parents and adolescents in response to loss of agency. Some adolescents can become less involved in decision-making as a means of coping with loss of control. This contrasts with the behaviour of parents which takes the form of struggling to re-establish agency within the process.

The role of adolescents, parents and HCPs. Role is an expression of how participants see themselves and how other participants see them. Adolescents, parental and HCP roles both guide and drive decision-making interactions (Model 1). Kars et al.'s²⁵ study of parental experience at the adolescents' end of life found that 'The need for control is immense and seems a precondition to fulfilling parental tasks' (p. 32). Thus, agency is required in order to realise one's role and meet expectations. Agency is lost when participants are unable to fulfil role-related behaviours and it is regained by asserting that role. Having a clear role and being able to express agency are interdependent.

Role of the adolescent. The studies reviewed provided few findings about the role of the adolescent. Young et al. report that adolescents had little to say about their role, deferring to parents or HCPs. They continue to state that the adolescent's role is a passive one, quoting one adolescent who stated his role was simply to sign consent forms (pp. 634, 637).⁴¹

Role of the parent. Different dimensions of the parental role are presented including parent as advocate, expert, protector of the adolescent and protector of family values.^{16,20,23,27,39,41}

Holm et al.²³ found that advocacy was the overarching theme in parents' perception of their role in their child's healthcare. In the treatment phase, advocacy includes gathering and managing information, deciding about medical treatment, including limiting procedures and actively fostering good relations with medical staff. Young et al.⁴¹ expand on the role of information gatherer and describe

parents as actively and ardently seeking information from multiple sources, not limited to consultations.

Parents also assume the role of experts about their child's condition and quality of life, both as viewed by HCPs and by themselves.^{18,24,26,37} Parents become protectors of family identity and values as well as of their child,¹⁸ with adolescents expressing their trust in parents to make decisions on their behalf.¹⁶

Role of the HCP. Physician. Physicians are reported as regarding themselves as primary caregivers,⁴¹ charged with doing what is best for the adolescent,¹⁹ as experts, and as providers of information. This can extend to overriding parents when they deem it necessary.¹⁹ Stenmarker et al.³⁴ suggest that HCPs also view themselves as the 'bearer of bad news', seeking knowledge and information as a central part of their role throughout the trajectory of their patient.

Parents recognised a difference in status between themselves and clinicians, requiring respect for physicians.²³ Physicians, by virtue of their status, were perceived as intimidating.²³ There was a lack of research identifying adolescents' perception of HCP's roles, or research referencing the relationship between adolescents and HCP.

Nurse. The reports on the role of nurses' role focus on bridging the relationship between parents and physicians.⁴¹ In describing their interactions with parents and physicians during meetings aimed at establishing consent for treatments or trials, nurses use terms like 'witness', 'advisor', 'legal liaison', 'interpreter' and 'conduit of information'. Indeed a primary role reported is to ensure that parents and adolescents receive and understand all the information they need. They also wanted to ensure that adolescents were informed. Carrying this out, however, sometimes led to conflict with parents.⁴¹

Information preferences. Studies indicate that adolescents differ in the amount and type of information they prefer to receive, particularly about survival rates and prognosis.⁴² Some adolescents state that early stage information was irrelevant because it was about issues arising after treatment had been completed. At the same time they express a preference for receiving more detailed information in subsequent consultations on 'here and now' matters and 'practical' matters (pp. 300, 331).²² Crawshaw et al.¹⁷ report that adolescents found 'broad-brush' information to be sufficient at first although parents, patients and survivors in that study all said that overall their preference was for being fully informed. Studies report the tailoring and limiting of information to adolescents and parents by HCPs.^{19,41} Simon et al.³³ report this tailoring with non-English-speaking families in particular, stating clinicians were more likely to omit certain information from discussions with non-English-speaking parents, relating to randomisation, right to withdraw and consent documentation.

Miller and Nelson²⁹ suggest that both too much information and too little information are undesirable; both are negatively associated with parents' perception that they were in control of making a decision.

The studies reviewed indicate that parents exercise, or try to exercise, an influence on the type and presentation of information that adolescents receive. Young et al.⁴¹ state that parents express a clear desire to control the kinds of information their children received and how it was delivered. Zwaanswijk et al.⁴² state that parents shield children from upsetting information by excluding them from consultations. Desire for parental control of information is particularly evident in studies of decisions about fertility preservation. De Vries et al.¹⁸ reported that 8 of 14 parents wanted 'to protect their child from this information, or at least wanted control over what was being discussed with their child' (p. 389).

Participation in practice. The participation of adolescents, parents and HCPs in the consultation itself was reported directly by several studies. In three studies,^{30,31,33} informed consent conferences were audio and video taped. Miller et al.³⁰ report that a mean 36% of the conversation (by word count) was directed from HCP to adolescent (standard deviation (SD)=31.23, range=0–87.44). Communication from adolescents to HCP was substantially less, accounting for 3.21% of the total dialogue. Olechnowicz et al.³¹ also report few questions being asked by the adolescent (mean 4 per conference). While these studies report on conferences where the adolescent and parent are present, in other studies discussions are held with adolescents or parents in isolation.

In a study of discussions of infertility risk and cryopreservation, De Vries et al.¹⁹ reported that 'most' physicians spoke with parents about the subject before discussing with the adolescent. Still, 14 of the 15 said that they would then proceed to discuss the issue with the adolescent even in the face of clear objection from the parents. In the study by Crawshaw et al.,¹⁷ 5 of 33 adolescents had fertility discussions without parents present. Based on the analysis of online focus groups, Zwaanswijk et al.⁴² state that parents sometimes report having consultations without their child being present. Olechnowicz et al.³¹ report that in the case of an 18-year-old patient, an informed consent conference was held with the adolescent alone and then a second conference was held with the parents alone.

Broome and Richards¹⁶ report that with regard to a decision to participate in research, in a minority of cases the clinician approached the mother about the study first and the mother then approached the adolescent.

In several studies, parental involvement is explicitly recognised as acceptable to adolescents or even positive.^{16,17} This involvement took the form of buffering information exchange between physician and adolescent¹⁷ taking their views into account and making sure that they

were represented.¹⁶ Based on a post-mortem record review, Pousset et al.³² express concern that a significant number of minors may have been unjustifiably excluded from their end-of-life decision-making.

Overall, the primary reason reported by parents and HCPs for excluding adolescents is the potentially upsetting or burdensome content of the discussion. Quotations from parents indicate that without exception parents' concerns were based on the specific issue before them – semen preservation, for example – rather than challenge to parental authority.

Studies consistently find that it is maturity and/or disease experience and not age that determines HCPs estimate of adolescents' ability to participate in decision-making and partake in discussions.^{17,31,36,37,42} This may be the case even when adolescents are legal adults.

Who is regarded as primary decision maker? Several studies offer reports on who makes the final call in decisions relating to fertility, trial participation and treatment. Evidence for treatment decision-making varies with some suggesting HCPs make the decision,²⁰ others that parents and HCPs decide²² or, as Talati et al.³⁶ state, 58% of HCPs believed the adolescent (over 16years) is the primary decision maker.

Decisions relating to fertility were often assigned to the adolescent,¹⁷ in spite of many parents' reluctance to have fertility discussed with their adolescent.¹⁸ Studies of decisions to participate in clinical trials also show mixed results ranging from HCP paternalism¹⁹ to parental directing^{16,40,41} or active participation by adolescents in the decision.¹⁶

Preferred models of decision-making. When looking at decision-making overall, Baker et al.¹⁵ find that the majority of parents 'prefer to share responsibility for decision-making with the physician' (p. 4158). Families want to know 'how an expert ... would make a decision about trial participation if the expert shared the family's goals and values' (p. 4156).¹⁵ In Zwaanswijk et al.,⁴² the majority of participants preferred collaborative decision-making between adolescent, parent and HCP, with the adolescent making the final decision. These findings are consistent with the conclusions of Miller et al.,²⁸ using scores from a decision-making scale, they conclude that parents did not show a strong preference to control the decision-making process themselves.

Discussion

Key findings

In this review, we have assembled research evidence highlighting current understandings of decision-making in adolescents with cancer.

First, we found that at diagnosis, possibly on receipt of news of relapse, parents initially lose agency (Box 1) as a result of rigid care protocols. They subsequently re-establish agency acting in the role of advocate and protector. It is in their role as protector that parents sometimes try to control the information that the adolescent receives.

Second, we found that for adolescents there appears to be no such clear way in which they can establish agency in the decision-making process. One reported ironic feeling that his role was simply to sign consent forms. This in itself could constitute an obstacle to participation. Stated simply, this could indicate that in decision-making situations no one is sure, including the adolescents themselves, how the adolescent is to be involved. Of note, within current published research, data collected from adolescents directly were scarce accounting for only 12% of total subjects.

Third, we identified that parent and adolescent preference for shared decision-making was clear. Adolescents welcomed parental involvement and parents wanted to know HCPs' opinions. Neither parents nor adolescents showed a desire for a high degree of autonomy in decision-making. Maturity and disease experience, not age, is an important factor affecting attitudes of adults towards adolescents' participation. Hinds et al.²¹ suggest that adolescent decision-making towards the end-of-life shows a maturity exceeding that predicted by developmental theories.

Preferences concerning information exchange in decision-making were by contrast variable. Adolescents differed with regard to the amount, the specificity and the timing of information that they received.

In practice, many adolescents reported expressing their views to their parents, who in turn represented the adolescent in decision-making. Adolescents seemed relatively satisfied with this process, when parents were aware of their views. In fertility preservation decisions, adolescents were more directly engaged by HCPs. More often, HCPs see parents rather than the adolescents as the primary figure in decision-making.

Robustness of the synthesis

Strengths. One of the strengths of this review is the inclusion of qualitative, quantitative and mixed-methods research. By acknowledging research from a variety of methodological approaches, we have been able to provide a more complete overview of the current evidence. We also assessed carefully the quality of each article identified and excluded those which failed to score over 60% on the appropriate critical appraisal tool.

Limitations. The included studies generally offer little information about sample selection (11 purposive sampling, 9 inadequate information including no response rate, 7

response rates < 55%, 6 part of larger study, 4 had response rates above 70%); therefore, it is not possible to assess how representative these findings are of adolescent cancer, parent and HCP populations as a whole. Second, qualitative studies largely employed thematic analysis and there is a lack of clarity across studies with regard to the strength of emergent themes and their relative importance.

The nature of the research methods produced largely retrospective accounts of decisions made weeks, months and occasionally years ago. One participant had completed treatment 9 years prior to the study. In addition, the outcome of these decisions researched, the subsequent support received and the current status of their health/child's health or patient's health will influence how these decisions, and their role in making them, are then interpreted by participants and then reported. In conducting our review, we were reliant on the evidence selected and presented by the studies.

Studies identified originate from several countries, predominantly the United States and the Netherlands. We recognise the disparity between and within these countries with regard to practice of shared decision-making as well as legal age of consent and assent and differences in practice with regard to the adolescent's participation in delivery of healthcare and in society. We also recognise the term adolescent, as a transition between childhood and adulthood, may have significantly different application in different cultures. These issues are beyond the scope of this review and are not attended to. Finally, due to limited resources, only English-language articles were included in this synthesis.

Clinical implications

The provision and receipt of information is a concept that arose in many studies. While some adolescents and parents retrieve as much knowledge as possible to maintain control, others limit the information they receive for the same reason. Within and between studies of adolescents, there are differences in preferences for information sharing, with some reporting a desire to know more and others content with minimal information. HCPs should be aware that adolescents might be asserting control by opting out of receiving certain information.

Research with adolescents themselves has highlighted a need for more information and more direct doctor-patient communication to help them understand what is happening, suggesting there may be a discrepancy in practice with regard to what the patient wants to know and how and when the HCPs and parents provide that information.

Miller et al.²⁸ report that few or no parents reported wanting to make healthcare decisions 'on their own'. Similarly, adolescents, regardless of age, report preferences for parental involvement in decision-making. A number of studies reported a parental or adolescent preference for shared decision-making (without defining that

term) and guidance from HCPs. If clinicians resist requests to offer their own opinions, they may be impeding the interaction with the parents and adolescents, making their deliberations more difficult as the parents and adolescents may feel more stressed, less confident and more confused without the guidance which they request.

Coyne et al.⁴³ set out to identify randomised controlled trial (RCT) studies examining the effects of shared decision-making interventions on the process of shared decision-making for 4 to 18-year olds with cancer. They were unable to identify any such studies, concluding among other things, that much 'evidence promoting young people's participation in decision-making is authored by policy makers and that we lack strong evidence from research that supports these recommendations'.⁴³ Taken together, our findings suggest a view that may differ from current ethical guidance and regulation that promote full information and minimal external influence for adolescents and parents, encouraging autonomy of the adolescent. Striving to impose this approach, particularly in the face of a poor prognosis, may add to distress and confusion, interfere with their agency and their ability to determine or participate as fully as they are able in decision-making about the course of their own/their child's healthcare.

Directions for future research

We found little evidence on the role of adolescents themselves in decision-making (data found in 11 of our included studies – 12% of total participants in these studies). We suggest that further work is needed to increase our understanding of how adolescents, and others, view the role of adolescents in making decisions for their own care and treatment both in principle and in practice. The importance of this focus is recognised in the appearance of recent work such as Weaver et al.,⁴⁵ published after the limits of our search. This study confirms the value of the perspective we have taken in this review. It reports that adolescents' 'overriding perspective of decisional involvement' is as an interactive process (p. 4423).

The majority of studies to date utilise similar methods, calling on semi-structured interviews, focus groups or surveys to elicit the views of parents, HCPs and occasionally adolescents on decisions that they have recently made. Although interview studies were often categorised as prospective,^{15,16,21,22,25} they remain dependent on recall, employing interviews and focus groups anywhere between 7 days and years after a decision has been made. We found three studies that included observations of real-time interactions.^{30,31,33} They focused on one decision at a single time point, thus suggesting that each party's role in decision-making can be understood by examining a single decision in isolation. Notably, none of these studies included interviews or informal

conversations with adolescents themselves. It can be argued that such studies constrain understanding of participation in decision-making by categorising it as simply the amount of verbal communication, the number of questions asked or the amount of information given and ignoring the effect of time.

In this review, we have identified that important changes take place over time as parents and adolescents gain experience with the hospital and treatment protocols. The methodological consequence of this is that studies that seek to understand participation in decision-making must be longitudinal, beginning at diagnosis and documenting decision-making throughout the entire disease trajectory.

Conclusion

Striving to make parents and adolescents fully informed or to urge them towards more independence than they prefer may add to distress and confusion. This, in turn, may interfere with their ability to participate in decisions about care and treatment in their preferred way. Future research should include analysis of actual on-ground interactions among parents, adolescents and clinicians across the trajectory and decisions.

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II. Glossary of Medical Terminology and Clinical Meetings

Medical Terminology

Term	Definition	Source
Bone Marrow Examination	Bone marrow examination refers to the pathologic analysis of samples of bone marrow obtained by a bone marrow biopsy and bone marrow aspiration.	http://encyclopedia.thefreedictionary.com/Bone+marrow+examination
Bone Marrow Transplant/ Stem Cell Transplant	A technique in which bone marrow is transplanted from one individual to another, or removed from and transplanted to the same individual, in order to stimulate production of blood cells. Prior to the transplant high dose chemotherapy and radiotherapy are administered.	Bone marrow transplant. (n.d.) <i>The American Heritage® Medical Dictionary</i> . (2007). Retrieved April 28 2016 from http://medical-dictionary.thefreedictionary.com/bone+marrow+transplant http://www.webmd.boots.com/cancer/acute-lymphoblastic-leukaemia?page=2
Chemotherapy	Treatment that uses drugs to stop the growth of cancer cells, either by killing the cells or by stopping them from dividing.	http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=45214
Intravenous fluids	The infusion of fluids into a vein by means of a steel needle or plastic catheter. This method of fluid replacement is used most often to maintain	Intravenous. (n.d.) <i>Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition</i> . (2003). Retrieved April 28 2016 from http://medical-

	fluid and electrolyte balance, or to correct fluid volume deficits after excessive loss of body fluids, in patients unable to take sufficient volumes orally.	dictionary.thefreedictionary.com/intravenous
Intrathecal	Occurring within, or introduced into, the space between the layers of tissue which cover the spinal cord, or the space between the layers of tissue which cover the brain	<i>Collins English Dictionary – Complete and Unabridged, 12th Edition 2014.</i> (1991, 1994, 1998, 2000, 2003, 2006, 2007, 2009, 2011, 2014). Retrieved July 20 2016 from http://www.thefreedictionary.com/intrathecal
Immunoglobulin	Any of a group of large glycoproteins that are secreted by plasma cells and that function as antibodies in the immune response by binding with specific antigens. There are five classes of immunoglobulins: IgA, IgD, IgE, IgG, and IgM.	Immunoglobulin. (n.d.) <i>American Heritage® Dictionary of the English Language, Fifth Edition.</i> (2011). Retrieved July 20 2016 from http://www.thefreedictionary.com/immunoglobulin
Methotrexate	An antimetabolite drug used in the treatment of certain cancers	<i>Collins English Dictionary – Complete and Unabridged, 12th Edition 2014.</i> (1991, 1994, 1998, 2000, 2003, 2006, 2007, 2009, 2011, 2014). Retrieved July 20 2016 from http://www.thefreedictionary.com/methotrexate
Myelodysplasia	Displasia of myelocytes and other cells in the bone marrow.	Myelodysplasia. (n.d.) <i>American Heritage® Dictionary of the English Language, Fifth Edition.</i> (2011). Retrieved July 20 2016 from http://www.thefreedictionary.com/myelodysplasia
NG Tube	Nasogastric tube: A tube used for feeding or	NG tube. (n.d.) <i>Medical Dictionary for the Health Professions and</i>

	suctioning stomach contents; inserted through the nose and down the esophagus directly into the stomach.	<i>Nursing</i> . (2012). Retrieved April 28 2016 from http://medical-dictionary.thefreedictionary.com/NG+tube
Oramorph	Brand name for morphine – an opioid analgesic and respiratory depressant used for the relief of severe pain.	Morphine. (n.d.) <i>Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition</i> . (2003). Retrieved April 28 2016 from http://medical-dictionary.thefreedictionary.com/morphine
Oxycodone	An opioid analgesic derived from morphine	Oxycodone. (n.d.) <i>Miller-Keane Encyclopedia and Dictionary of Medicine, Nursing, and Allied Health, Seventh Edition</i> . (2003). Retrieved April 28 2016 from http://medical-dictionary.thefreedictionary.com/oxycodone
PEG	Percutaneous endoscopic gastrostomy. The creation of a new opening in the stomach for enteral tube feedings. PEG is accomplished by puncturing the abdominal wall after the stomach has been distended. A tube is then inserted through the abdominal wall into the stomach. Provides a means of feeding when oral intake	PEG. (n.d.) <i>Mosby's Medical Dictionary, 8th edition</i> . (2009). Retrieved April 28 2016 from http://medical-dictionary.thefreedictionary.com/PEG

	is inadequate.	
Radiotherapy	The use of high-energy radiation from x-rays, gamma rays, neutrons, protons, and other sources to kill cancer cells and shrink tumors.	http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=44295
Relapse	The return of a disease or the signs and symptoms of a disease after a period of improvement.	http://www.cancer.gov/publications/dictionaries/cancer-terms?search=relapse
Remission	A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared, although cancer still may be in the body.	http://www.cancer.gov/publications/dictionaries/cancer-terms?cdrid=45867
Vincristine	Cytotoxic drug used in the treatment of leukaemia	<i>Collins English Dictionary – Complete and Unabridged, 12th Edition 2014.</i> (1991, 1994, 1998, 2000, 2003, 2006, 2007, 2009, 2011, 2014). Retrieved July 20 2016 from http://www.thefreedictionary.com/vincristine

Meeting Terminology

Ward round meeting	A twice-weekly meeting had before every ward round, led by the attending consultant. Junior doctors, CNS' and ward nurses are regularly in attendance, as are dieticians and pharmacists. Medical students
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	occasionally attend. This meeting allows HCP to share patient updates and treatment plans before a ward round, ensuring all have up to date information on medical, social and psychological condition of the patient.
Teenage and young adult MDT	A weekly meeting attended by the entire multidisciplinary team, inpatient and outpatient including; psycho-oncology team, play therapy team, physiotherapy team, schoolteachers, social workers, consultants, nurses and CNS'. A forum for any team member to raise concerns or discuss a teenager or family members psychosocial needs. Concerns and issues are discussed with input and advice offered by individuals for a number of professional backgrounds.
Paediatric and young adult haematology MDT	A fortnightly meeting attended predominately by consultants, junior doctors and clinical nurse specialists, as well as a radiographer and a XXX. Test results and diagnostics are reported scans are discussed and plans for treatment made. Plans for treatment are often made here.
Palliative care MDT	A weekly meeting attended by the palliative care team consultants, CNSs and junior doctors. Children and teenagers are discussed and plans for symptom control and wellbeing are made.
Day care MDT	Attended by the consultants, CNSs, junior doctors and a day care nurse. A weekly overview of teenagers attending clinic appointments in day care for the week following.

III. Interview Guides

Interview guides for semi-structured interviews with health care professionals, young people, and parents

These interview schedules are to be used as a guide with each health care professional, young person and family member interviewed. Content of the interviews will be driven by the participant and their individual experiences. With sensitivity and care we will take account of the individual circumstances of each interviewee, and only relevant topics will be raised.

1. Health Care Professionals

(Those not interviewed in the pilot study)

Part I. Introduction

If you could start by telling me what it is you do?	Who makes up your team? Who do you work with most closely? What sort of patients do you see?
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Part II. Decisions

What are the key decisions that need to be made when a patient is first admitted?	Where?	Who?	What happens if there's a disagreement?	Who do you think should be involved?	
What are the main treatment decisions that then need to be made?	Chemo? Transplant? Donor? Sperm banking?	Where?	Who?	What happens if there's a disagreement?	Who do you think should be involved?
When it's clear that curative treatment isn't working anymore what	Place of care? DNR? Feeding tubes? Termination of active treatment?	Where?	Who?	Disagreement?	Who do you think should be involved?

decisions need to be made					
What are the hardest decisions you have to make?	Why?				
How do you feel about your role in decision-making?	Responsibility?	Burden?			

Part III. Involvement

What are your thoughts about involving young people?	What experiences?	Example?	
What tools/methods do you use?	To involve?	To 'protect'?	Example?

2. Parents and guardians

Part I. Introduction

If you could start by telling me a bit about your family?	Members? Household?	Children?	Spouse?	Other? (step-family, boyfriends etc)
Can you tell me about (YP's) diagnosis?	When?	Signs?	Impact on daily life?	

Part II. Decisions

What's happening with (YP's) treatment now?	Where was that decided?	Who was involved?	Was there any difference of opinion?	Who do you think should have been involved?	
What decisions have had to be made	Transplant? (if relevant) Sperm banking/ egg preservation?	Other?	Who?	What happens if there's a disagreement?	Who do you think should be

over the course?	(if relevant) Clinical Trial? (if relevant) Stopping curative treatment? (if relevant) Place of care? (if relevant)				involved ?
Are you currently making any decisions ?	What are the options?	Who's helping?	Do you have a preference ?	Disagreement ?	Who do you think should be involved ?
Who do you think ultimately decides what happens?	You? YP? Health care professional?	Why?	Example?	Is that how you prefer it?	
How do you feel about your role in decision-making?	Responsibility ?	Burden?			
How would you make a non-medical decision about YP?	Bedtime? Curfew?	YP Involved?	Collaborative ?	You and your spouse?	

Part III. Involvement

What are your thoughts about involving young people?	At 13?	At 19?	Example?	
What tools/methods do you use?	To involve?		To 'protect'?	Example?

Part IV. Knowledge

What advice would you give to someone who just had their child diagnosed and was facing the same sort of decisions?	
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3. Young people

Part I. Introduction

If you could start by telling me a bit about your family?	Members? Household?	Parents?	Spouse?	Other? (step-family, boyfriends etc)
Can you tell me a bit about you?	What do you like to do?	Who are your friends?	School/College/Job?	

Part II. Illness Experience

Can you tell me about your illness?	When did it start?	Signs?	Impact on daily life?	
What was it like when you first found out?	Fears?	Concerns?	Hopes?	
How has life changed now you have this illness?	Family life?	Social life? Relationships?	Plans?	What hasn't changed?

Part II. Decisions

If you have to make decisions about things outside the hospital how do you start?	Talk to a friend/parent?	Alone?	Social network?	
If there are decisions to be made about your illness how are	Parents	Health care professionals?	You?	

they made?					
If you have a question or want to know something about your illness who do you ask?	HCP?	Parent?	Internet?	Friends?	
Have any decisions been made yet?	Transplant? (if relevant) Sperm banking/ egg preservation? (if relevant) Clinical Trial? (if relevant) Stopping curative treatment? (if relevant) Place of care? (if relevant)	Other?	Where?	By who?	Did anyone have a different decision?
Were you asked about what you thought?	By who?	What was it like to be asked/ not asked?			Who do you think should be involved?
Who do you think ultimately decides what happens?	You? Parents? Health care professional?	Why? Example?	Is that how you prefer it?	Who do you think should decide?	

Part III. Involvement

How do you feel about your role in decision-making?	Responsibility?	Burden?	How would you like to make decisions?
Does anyone help you make decisions?	How?	What do they say? Do?	
What do you	Brain storm?		

think 'being involved in decision-making' means?			
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Part IV. Knowledge

What advice would you give to someone who was just diagnosed and was facing the same sort of decisions?	
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IV. Code Book – Data Analysis

I Codes

#	Code	Definition
1	Trials	Any discussion with any participant or at any MDT where trials were discussed a decision was made. NB. Including Phase 1 trials and Phase 3 trials
2	Place of care	Any discussion with any participant or at any MDT where place of care was discussed a decision was made. NB. Including discussions about home, hospital or hospice care.
3	Palliative Care- DNAR	Any discussion with any participant or at any MDT where DNR was discussed a decision was made.
4	Palliative Care - Place of death	Any discussion with any participant or at any MDT where place of death was discussed a decision was made.
5	Feeding	Any discussion with any participant or at any MDT where feeding was discussed a decision was made. NB. Including NG Tube, TPN, Oral and PEG
7	Transplant	Any discussion with any participant or at any MDT where a decision was made or a discussion was had about transplant.
8	Palliative Care - Prognosis	Any discussion with any participant or at any MDT where a decision was made or a discussion was had about the patient's prognosis.

		i.e. Length of life, estimated survival, likelihood of remission/ relapse or overall survival
10	DDT -Stopping disease directed treatment	Any discussion with any participant or at any MDT where a decision was made or a discussion was had about stopping disease directed treatment.
P1	Diagnosis	Any discussion with any participant or at any MDT regarding the period of initial diagnosis.
P2	Disease directed treatment	Any discussion with any participant or at any MDT regarding disease directed treatment (chemotherapy, steroids, radiotherapy)
P3	1 st relapse	Any discussion with any participant or at any MDT regarding first relapse.
P4	2 nd relapse	Any discussion with any participant or at any MDT regarding second relapse.
P5	Symptom directed care	Any discussion with any participant or at any MDT regarding symptom directed care.
P6	Death	Any discussion with any participant or at any MDT regarding death of a teenager.
S1	Teenager	Any speech by teenager
S2	Parent	Any speech by parent

S3	Other family member	Any speech by family members other than parents
S4	HCP	Any speech by HCP
NVivo to calculate percentage of speak in consults by YP/ Parents/ HCP		
D1	ALL	Any data from discussions regarding teenagers with a diagnosis of ALL
D2	AML	Any data from discussions regarding teenagers with a diagnosis of AML

A –codes – Principles of Involvement				
#	Codes	Subcodes	Definition	Illustrative Quote
A	Involvement of teenager	Doing what teenager wants	Any discussion with any participant or at any MDT where the involvement of the YP was directly discussed or referred to.	<p>POPPY CONTEH: Involvement as in from my point of view?</p> <p>ED: Yeah from your point of view.</p> <p>POPPY CONTEH: Involvement means me being the main orchestra –</p> <p>ED: Right.</p> <p>POPPY CONTEH: As in make sure my points are being heard –</p>
B	Right thing		Any discussion with any participant or at any MDT	SOPHIA WRIGHT: Yeah, she's very sweet. And, we just said we'll do everything from the ward but, he's

A –codes – Principles of Involvement				
#	Codes	Subcodes	Definition	Illustrative Quote
			where an individual made reference to the idea of doing the right thing in the clinical or moral sense.	[Masood], we don't think it's right to put a tube down to breath for him, we'll give him drugs to keep his blood pressure. We didn't mention the word resuscitate. ED: Okay.
C	What the patient or parents know or understand	Teenager not knowing Uncertainty Awareness	Any discussion with any participant or at any MDT where the knowledge or understanding of a patient or family member is expressed or discussed.	SOPHIA WRIGHT: She said he [Masood] was asking to go downstairs. He said he couldn't breathe. JOANNA CLARK: Oh, to the ITU. SOPHIA WRIGHT: So she feels – I think she feels, you know, he couldn't breathe, he couldn't breathe – [inaudible, multiple conversations at once 00:00:11-00:00:31] SOPHIA WRIGHT: Who did? SOPHIA WRIGHT: Masood did? Yeah. He obviously knew what was going on – you know, how bad it was –
D	Trust	Following HCP advice	Any discussion with any participant or at any MDT	NADIA CONTEH: So, I think most of the decision being made will be her now

A –codes – Principles of Involvement				
#	Codes	Subcodes	Definition	Illustrative Quote
		Teenagers delegating to family members	where trust in any other participant is discussed.	<p>because she is in that age of consent but, at the same time I know she is making the right decision –</p> <p>ED: Yeah.</p> <p>NADIA CONTEH: - and when she makes that decision she will tell me. If I felt that what you have just done might not be right okay, let me see how it is so, I have to accept this other options.</p>
E	Honesty	Protecting YP Presentation of options Managing expectations	Any discussion with any participant or at any MDT where honesty or 'open communication' from any other participant is discussed.	<p>JASMINE MIRZAEI: - and he felt sick, they added another sickness and I thought this is what happened last time. Somehow inside me I had a good feeling. I kept telling George –</p> <p>EMMA DAY: Yeah.</p> <p>JASMINE MIRZAEI: - “oh, I’ve got a good feeling”. You know, you want to convince him –</p> <p>EMMA DAY: Yeah.</p> <p>JASMINE MIRZAEI: - you wanna be optimistic, but, still, I was - I wasn’t sure.</p>

A –codes – Principles of Involvement				
#	Codes	Subcodes	Definition	Illustrative Quote
G	Information seeking	Information person assigned Questioning decisions Role designation	Any discussion with any participant or at any MDT where information was sought from one participant, or any discussion where the seeking of information was discussed.	<p>HARRY BUKOSKI: Which would, which would make more sense to come back here cause then I could just stay here, instead of being transported here.</p> <p>EMMA DAY: (sounds like approval)</p> <p>(laughter)</p> <p>HARRY BUKOSKI: I'm gonna have to raise these points.</p> <p>EMMA DAY: Yeah. Yeah, who do you talk to about that kinda thing?</p> <p>HARRY BUKOSKI: Well maybe if I - maybe I'll get to see Sophia or someone –</p> <p>EMMA DAY: Yeah.</p> <p>HARRY BUKOSKI: Cause it doesn't make sense to go up to XX if they're just gonna transport me up here.</p>
H	The involvement of 'others'	Family involvement	Any discussion with any participant or at any MDT where a decision was made or a discussion was	<p>MARK CHARWOOD: Yeah, I think, I think they do and I think that is one of the big unknowns. You just don't, you really don't know what the influences of parents in both directions as in</p>

A –codes – Principles of Involvement				
#	Codes	Subcodes	Definition	Illustrative Quote
			had about how to involve other people i.e. Schools, friends, and family members.	often there is not appropriate levels of guidance given because either no-one wants to speak about it or, parents are not as involved as much as we would perceive that they should be.
J	Withholding of Information	Protecting teenagers Restriction of choice	Any instance with any participant or at any MDT where the withholding of information from the YP was noted, suggested or implied.	<p>JULIE TAYLOR: Because during his first-line treatment he often said I'd rather die than be doing this, and if it, if I, if this comes back I'm not doing it again. So I think if he was in a situation where cure was very unlikely –</p> <p>SOPHIA WRIGHT: But I – also, I –</p> <p>JULIE TAYLOR: - I would feel he had to be informed of that.</p> <p>SOPHIA WRIGHT: - ask myself that question, and I'd let my boys be treated. And I'd even let myself do that because how can you not –</p> <p>JOANNA CLARK: Because what's the – yeah, the option is -</p> <p>JULIE TAYLOR: Yeah, but –</p> <p>JOANNA CLARK: - a possibility or</p>

A –codes – Principles of Involvement

#	Codes	Subcodes	Definition	Illustrative Quote
				<p>absolutely you'll be dead within four weeks.</p> <p>JULIE TAYLOR: Yeah, but I still think some patients need that choice.</p>

I Codes – Practices

#	Category	Code	Definition	Illustrative Quote
1	HCP practices: acting on the care and treatment preferences of the teenager	HCP Note Importance of YP Opinion	Instances where the HCP vocalise to teenagers the importance of their opinion and preference regarding a decision.	CLAIRE TALBOT: Do you want to think about the two choices? Then you'll let us know? Yeah? I think what you're saying is very important –
2		HCP Warn of Bad Outcome	Instances where HCP warn teenagers of a potentially negative outcome if their advice is not followed	<p>CLAIRE TALBOT: So no to the PICC line and – we can't, we can't let you starve to death is the bottom line. Do you see what I mean? So I think the best thing is for you to have a tube today and it makes life really easier.</p> <p>ANWAR PASSI: Nah.</p>
3		Restriction of Choice	Instances where HCP restrict the choice or options available to teenagers and their	<p>ANWAR PASSI: I just don't want it at home.</p> <p>LINDSEY PHILIPS: If you had to have it at home?</p> <p>ANWAR PASSI: I don't</p>

#	Category	Code	Definition	Illustrative Quote
			families, either at the outset or gradually over the course of a consultation	<p>want it.</p> <p>LINDSEY PHILIPS: But if you had to have it at home?</p> <p>ANWAR PASSI: I don't.</p> <p>(pause)</p> <p>LINDSEY PHILIPS: Hm, but if we – the difficulty is, Anwar, you've been trying without it and you can't manage.</p> <p>(pause)</p> <p>LINDSEY PHILIPS: It would be a bad reason to keep you in hospital.</p> <p>MEGAN JONES: I suppose that's the question, isn't it, Anwar, would you rather stay here with it in or go home with it in – if, if, if you had to?</p> <p>[silence 00:23:23-00:23:35]</p> <p>ANWAR PASSI: Go home with it in.</p>
4		Bargaining	Instances where HCP bargain or negotiate with teenagers in an attempt to align them with a course of action.	<p>CLAIRE TALBOT: Yeah, you do – that's true. Well we could, we could come to a deal.</p> <p>ANWAR PASSI: Like?</p> <p>(laughter)</p> <p>CLAIRE TALBOT: Well, like, we could set you up with a Hickman - what if you have the tube today?</p>

#	Category	Code	Definition	Illustrative Quote
5		HCP seeking YP preference	Instances where the HCP seek the teenagers preference for a choice	MIA GARNER: Any thoughts? BECKY ALDEA: (hesitates) MIA GARNER: Do you wanna join the trial - no. [cross-talk 00:03:26] BECKY ALDEA: Oh, "any thoughts?" MIA GARNER: Yeah.
6		HCP Statement about YP Preference	Instances where HCP make a statement about the teenagers preference, either inferred, assumed or recalled	LINDSEY PHILIPS: Yeah, that's right – [inaudible 00:21:54]. You hate that catheter, don't you? ANWAR PASSI: No.
7		YP's Preference Put on Hold	Instances where HCP inform teenagers that they will return to the teenagers preference at a later date	GEORGE MIRZAEI: Moving onto the chemo. JOANNA CLARK: You found that – you think that would be a, a positive step? GEORGE MIRZAEI: Yeah. JOANNA CLARK: Okay. (laughing) Well I'm not gonna rush that –
8	Parent and family practices: acting on the care and treatment preferences of the teenager	Parent States YP Preference	Instances where parents of family members state the preference of	JASMINE MIRZAEI: I don't know. He wants to so much, as quickly as possible, get on with everything, go home, as quick as possible –

#	Category	Code	Definition	Illustrative Quote
			the teenager with regard to care and treatment.	
9	Teenagers practices: acting on the care and treatment preferences of the teenager	Teenager stating their preference	Instances where the teenager expresses a preference relating to care and treatment.	ANWAR PASSI: I want to go home.
10	HCP practices: Following prescribed clinical consensus	HCP Statement About Right Thing to do	Instances where HCP make a statement about the prescribed clinical consensus or the 'right thing to do'	JOANNA CLARK: You know, and I think the fairest thing is for him to sort of - really to be kept as comfortable as possible, and perhaps explore things in his own way with you guys if he wants to about what's happening, what he's afraid of. And he probably will open up to you. You know, he probably will open up to the nurses and he may open up – you know, in his own time, he may well open up and say...
11		HCP Presentation of Options	Instances where HCP present options regarding a care or treatment choice to a teenager and/or their family	ADAM NEW: Yes, so that one I think so, so, there's three all in, that one's now not there, and there's two others. I think, overall our feeling was that the one that would give you the best chance was the one in Sheffield but, because of this neuro-toxicity the company will not allow that so, we can't give that for safety reasons.

#	Category	Code	Definition	Illustrative Quote
				So, there are two other potential drugs...
12		Limited Options Available Physical Condition as Decision Maker	Instances where HCP make reference to the limited options available to the teenager and their family due to the restraints of the teenagers physical condition	<p>ADAM NEW: So the good things are that the – you know, as I said to you the other day, your leukaemia has gone into remission –</p> <p>HARRY BUKOSKI: Yeah.</p> <p>ADAM NEW: - which is good. The downside of it - obviously it's very strong and you get all these side effects.</p> <p>HARRY BUKOSKI: (sounds like approval)</p> <p>ADAM NEW: So I think you'll be in for a few weeks.</p> <p>HARRY BUKOSKI: (sounds like approval)</p>
13		HCP Statement that a Decision has Been Made	Instances where HCP refer to a decision that has been made with or without the teenagers and families input.	<p>RAUL ALDEA: Yeah, I know. What's happened with the chemotherapy?</p> <p>ADAM NEW: So –</p> <p>RAUL ALDEA: They stopped –</p> <p>ADAM NEW: - we, we stopped it. We may restart that in the middle of next week – only if you're well enough and if your blood count is okay. Alright?</p>
14	Parent and family practices: Following prescribed clinical	Parents Asking about Alternatives	Instances where parents or family members ask HCP about	ADRIAN BUKOSKI: Is there no other solution apart from leukaemia, apart from the marrow transplant? Do you know about any other

#	Category	Code	Definition	Illustrative Quote
	consensus		alternative options for care and treatment.	treatment? JOANNA CLARK: There are some novel drugs, there are some new drugs which are antibody drugs...
15		Parents seek HCP Preference	Instances where parents or family members seek the HCP preference or opinion on a course of action relating to the teenagers care and treatment.	SOPHIA WRIGHT: So even if you stay on the trial, there's a 25 percent chance to a 50 percent chance, you'd get the same, standard anyway. BECKY ALDEA: Yeah. (pause) RAUL ALDEA: Which one you think is better? SOPHIA WRIGHT: I don't know or I'd tell you – we'd be doing it. That's the thing, isn't it? RAUL ALDEA: But what – how do you explain this?
16	Teenagers Practices: Following prescribed clinical consensus	YP Seeking HCP Preference	Instances where the teenager seeks the HCP preference or opinion with regard to decisions about their care and treatment.	JOANNA CLARK: But you could probably do without the line if you wanted to stop the dalteparin. If you're happy on both – with both then we could hold fire for the moment. TOM STEPHENS: Well I, I'm really not too fussed. It doesn't bother me. Like – I mean, what do you reckon -
17	HCP Practices: Exchange and provision	Encouraging teenagers and parents to ask	Instances where HCP encourage families and	LINDSEY PHILIPS: I'll come back and see you next week. Is there

#	Category	Code	Definition	Illustrative Quote
	of information	questions	teenagers to ask them questions regarding information they have just received or upcoming care and treatment decisions	anything you wanted to ask me? (pause)
18		Encouraging parents to provide their child with information	Instances where HCP encourage parents or family members to have open discussions with their teenager regarding their care, treatment and upcoming decisions	SOPHIA WRIGHT: We, don't want him worrying, we don't want him scared, we don't want him hurting yeah? But sometimes, you know it's very difficult, you're his mother, you know but, you are also protecting him because you are his mum yeah? But, I don't think he will ask any of us because I think he may be too scared of the answer but, I don't want him to be scared, I want him to know we are going to look after him and... But, I think it is very difficult, they don't, these young people don't usually ask, they usually don't ask their mums and dads much either but, I think it must have been because we saw, you saw the doctors without him.
19		Information Holding	Instances where HCP hold information regarding the teenagers care and	NADIA CONTEH: Is it possible to have the publication or it's just for the doctors? JOANNA CLARK: No, no, it's not widespread. This

#	Category	Code	Definition	Illustrative Quote
			treatment without disclosing to the family and or teenager	has just – NADIA CONTEH: - just for the – JOANNA CLARK: - this has just been circulating within the lead clinicians within the, within the country. NADIA CONTEH: (sounds like approval) Okay.
20		Checking with teenagers they are happy to continue a discussion	Instances where HCP verbally check with teenagers whether they are happy to continue a conversation about their care, treatment, future life and/or death	CLAIRE TALBOT: And, are you - is it okay that we are talking about this? Because it's, it's hard to talk about these things isn't it? {Masood nods}
21		Talk away from teenager	Instances where HCP organise or facilitate talk away from the teenager with parents or family members regarding the teenagers care and treatment	JOANNA CLARK: It's always worth having a goal, but it's – yeah, it's gonna be a bit more hard work yet I think. Okay? So will I – do you want to examine him and do your bit and I'll leave you to – Mum, do you want to come and have a chat outside – JASMINE MIRZAEI: Sure. JOANNA CLARK: - and just sort of – (laughing) we can get a bit more technical with you, if you like. SOPHIA WRIGHT: Is that alright, George?

#	Category	Code	Definition	Illustrative Quote
				[George nods]
22	Parent and Family Practices: Exchange and provision of information	Parents and family members restricting information they received	Instances where a parent or family member either explicitly or implicitly restricts information from HCP regarding their teenagers care, treatment and future life or death	<p>JOANNA CLARK: Is there anything you wanted to ask?</p> <p>JASMINE MIRZAEI: If I ask more I will know more and it –</p> <p>SOPHIA WRIGHT: Yeah.</p> <p>JOANNA CLARK: Yeah, -</p> <p>[cross-talk 01:02:37]</p> <p>JASMINE MIRZAEI: - that just hurts more.</p>
23		Parents and family members seeking information	Instances where parents and family members seek additional information from HCP regarding their teenagers care and treatment	<p>RAUL ALDEA: How many weeks for this one?</p> <p>MIA GARNER: (hesitates) So this is 7-8 I think –</p> <p>RAUL ALDEA: No, no. You tell me, this one, how many weeks?</p> <p>MIA GARNER: Eight weeks.</p> <p>RAUL ALDEA: Eight? Eight, yeah? And next one?</p>
24	Teenagers Practices: Exchange and provision of information	Non-verbal responses	Instances where teenagers respond to information with HCP and parents with a non-verbal response (i.e. nod, shake	LINDSEY PHILIPS: Good morning, sir. How are you? Are you gonna talk to us this morning? (laughing) You gonna raise eyebrows at me – is that how you're gonna communicate?

#	Category	Code	Definition	Illustrative Quote
			head, shrug, make face)	
26		YP Asking Questions of HCP	Instances where teenagers ask HCP questions relating to their care and treatment.	<p>BECKY ALDEA: Yeah. Did you find out my bone marrow?</p> <p>SOPHIA WRIGHT: The bone marrow is the same as before. They haven't – they can't give exact numbers. But as long as it's less than 5 percent, we say in remission anyway. So I don't think -</p> <p>BECKY ALDEA: What – what do you mean "the same"? So it's still 3 percent?</p>
27		YP Defer to Parent for Answer	Instances where the teenager defers to their parent or family member to answer a question posed by the HCP.	<p>CLAIRE TALBOT: What did the people in Bristol say about the trial?</p> <p>MASOOD FARRAN: Mum?</p>
28	HCP practices: Responsibility and Role Designation	Implicit designation of roles	Instances where HCP imply roles for teenagers, parents and themselves during consultations.	<p>ADRIAN BUKOSKI: How can we help our child?</p> <p>JOANNA CLARK: Just support him. We'll, we'll do the other side of things, the medical side of things.</p>
29		Assign responsibility to teenager	Instances where HCP inform	MIA GARNER: Yeah, so two weeks and then – then

#	Category	Code	Definition	Illustrative Quote
			teenagers that they have responsibility for a decision or a course of action taken.	either way, whichever you decide is absolutely fine. But yeah, by the, by the bone marrow we need to make a decision. BECKY ALDEA: Yeah. MIA GARNER: And, you know, up to you entirely which way you go.
30		Assign responsibility to other HCP	Instances where HCP assign responsibility for a decision to other HCP, either in their team or in a different specialist team.	JOANNA CLARK: So the heart valves – we’re waiting for the heart doctors. They’re having a special meeting this morning to discuss that today and they’ll come back to us about what we need to do.
31	Parents and family practices: Responsibility and Role Designation	Explicitly assigning responsibility to HCP	Instances where parents or family members explicitly verbalise to HCP that a decision or treatment plan is the responsibility of the HCP.	JOANNA CLARK: But we do our best. Sometimes it’s just not good enough, is it? TAALIA ROSSI: It’s just because we really trust, trusted you and –
32	Teenagers practices: Responsibility and Role Designation	Accepting responsibility	Instances where teenagers verbalise an acceptance of their responsibility with regard to their care and treatment	TOM STEPHENS: Yeah, I think I’ve been eating quite well. JANE STEPHENS: Yeah – TOM STEPHENS: I mean the other night – sometimes I just didn’t fancy anything and then I’d obviously try and eat something else,

#	Category	Code	Definition	Illustrative Quote
				rather than just go without –

V. Guidance on Participants Loss of Capacity and Withdrawal

Extracted from Principles in Practice Research Protocol

12.0 Ethical considerations

The study will be conducted in accordance with UK research governance policies and procedures (including submission to local R&D, NHS REC approval, and the CAG) and conform to established procedures for ensuring confidentiality when working with patient and health professional populations. Informed consent will be sought from clinicians and parents and young people. The relevant R&D departments at both [names removed] will be consulted. The project will undergo review by the Applied Health Research in Cancer Governance Group active at the primary Teenage and Young Adult Cancer Centre as well as review by MCRN Pain and Palliative Care Portfolio Group.

12.1 Consenting to participate

Clinicians

Formal consent will be sought from all participants in the study. Clinicians' consent will be sought prior to data collection so as to minimise the disruption once the study has begun recruiting young people and families. Phase 1 of the research as mentioned earlier will firstly serve as an opportunity to obtain the written consent from as many eligible clinicians as possible. We are aware that not everyone will be consented during this period due to absences, holidays and rotations. For those that are not consented at the outset, written consent will be obtained as soon as possible. Consent forms and information sheets will be distributed to the clinical team in MDTs and via email. Clinicians interested in participating will have opportunities to meet with a member of the research team and discuss the study in more detail in a place of their choosing before deciding on whether to participate. Clinicians who elect to participate will be asked to sign a consent form. They will be provided with a copy and the original will be stored in a secure location at the university.

Parents, guardians and other adult family members

Parents and young people will also be formally consented as part of their recruitment into the study. See recruitment pathway for young people and families. Consenting young people and parents will be the responsibility of the researcher alone. Clinicians will not be responsible for providing detailed information about the project or for obtaining consent for inclusion. It is understood that both parents and young people may want numerous meetings before agreeing to take part in the study and the researcher will be responsive to this. In line with [name removed] consent policy on research participation, consent will be understood as a 'process that continues throughout the life of the study' [reference removed for confidentiality]

Parents will first be introduced to the researcher during a consultation, ward round, or informal bedside visit with a clinician. If the parents agree for the researcher to remain, after the meeting the researcher will arrange a suitable time and place to provide parents with more information including the study information sheets. They will be given opportunities to discuss the study further and then inform the researcher if they wish to participate. To minimise the time burden on parents and so as not to create a sense of duty for the parent the researcher will be available to speak at their next hospital appointment or to talk on the phone, via email or post, whichever parents find most acceptable. Parents who elect to participate will be asked to sign the study consent form. Parents with children under the age of 16 will also be required to sign consent on behalf of their child; discussed in detail below.

Young People

Due to the observational nature of the study and the focus on how young people are involved in decision-making in practice, it is important that young people are all willing to consent/assent to the study. Therefore In line with clinical and research practice at the site, the researcher will offer the young person an information sheet of his/her own. Age group stratification and consent procedures for young people are broken down below. General Medical Council guidance on assessing capacity to consent 0-18 year olds (GMC, 2007) has been referred to, to incorporate procedures supported at a national level.

The procedures are also compliant with site consent policy for research participation (Braveman, 2010), as well as with trust-wide policy for obtaining clinical consent (Mundy, 2013). In addition, the clinical lead for the largest teenage cancer service in the UK, has reviewed the consent procedures for this project and deems them appropriate for consenting young people [sentence removed for confidentiality] into this research project.

Young people are likely to first see a researcher during a clinical consultation, ward round or informal bedside visit when their parents are also present. If the researcher has permission to remain in the meeting, following the meeting and guided by the young person's parents, information may be given to the young person about study participation then or at a later time. As with parents the researcher will provide initial information about the study and then follow up with the young person in a way that is acceptable to them and their parents. Therefore, the researcher will be available to speak at their next hospital appointment or to talk on the phone, via email or post, whichever the young person finds most acceptable. Young people who elect to participate will be asked to sign the study consent/assent form.

13-15 years – young people aged 13-15 years who wish to participate will be encouraged to sign an assent form, acknowledging their participation in the study and allowing their medical records to be accessed by the researcher. Their parents will be asked to sign the consent form for their child's participation and granting permission for the researcher to access their child's medical records.

13-15 year olds who are deemed Gillick Competent can legally consent on their own; however, [sentence removed to maintain confidentiality] (Mundy, 2013); we will encourage young people to agree to parental involvement. Due to the observational nature of this research, consent from parents will be required if 13-15 year olds are to be included in the study.

On the recommendation of the clinical lead for the service, in the instance that a 13-15 year old provides consent and their parent does not, every effort will be made to negotiate with the family and reach a consensus.

16-17 years – People above the age of 16 are generally assumed to have capacity to consent for themselves (Braveman, 2010). Therefore 16-17 year olds who wish to participate will be asked to sign a consent form for them to participate, and to grant permission for the researcher to access their medical records. Their parents will not be required to sign to consent for their child’s participation unless the young person lacks capacity. [Sentence removed to maintain confidentiality] we will encourage young people to agree to parental involvement.

On the recommendation of the clinical lead for the service, in the instance that a 16-17 year old provides consent to participate and their parent states they are unhappy with their child’s participation, every effort will be made to negotiate with the family and reach a consensus.

For 16-17 year olds who the clinical team deem to lack capacity, the consent process for 13-15 year olds will be followed.

18-19 years – 18-19 year olds are recognised as adult participants, therefore those who wish to participate will be asked to sign a consent form for their participation in the research, and to grant permission for the researcher to access their medical records. While parents have no formal role in consenting for their child, in line with Dr XXX’s recommendation and the policy outlined by XXX we will encourage young people to agree to parental involvement and negotiate should there be a divergence of opinion regarding consent in the family.

Table.1 – Consenting to participate - Young People 13-19

	13-15 year old provides assent	13-15 old does not provide assent	16-17 year old provides consent	16-17 year old does not provide consent	18-19 year old provides consent	18-19 year old does not provide consent
Parents’ consent on	Included	Negotiate to reach consensus	Included	Negotiate to reach consensus	Included	Not included

behalf of their child (13-17 years) Parent's do not consent on behalf of their child (13-17 years)		on inclusion If this is not possible - not included		on inclusion If this is not possible - not included		
	Negotiate to reach consensus on inclusion If this is not possible - not included	Not included	Negotiate to reach consensus on inclusion If this is not possible - not included	Not included	Included	Not included

12.2 Loss of capacity to consent

Below is a description of how we will handle loss of capacity to consent in for each participant group:

Clinicians - Should a clinician lose capacity to consent we will retain data collected to date, but the clinician will be withdrawn from the study.

Parent's - Should a parent lose capacity to consent we will retain data collected to date, but the parent will be withdrawn from the study.

13-19 year olds - Here we are refereeing to a young person who had capacity at the beginning of the study but as a result of treatment over the course of the illness loses mental capacity such that researchers and clinicians conclude that the young person no longer has the capacity to consent. Unless the young person gave indications that he/she was uncomfortable with the researchers' presence or interaction with them, that young person would remain in the study. If there were indications that the researchers' presence or conduct, which formerly had been accepted, had become felt as intrusive or burdensome by

the young person, the young person would be withdrawn from the study. In such circumstances, unless parents object, data collected would be retained and used in the study. If it were determined that a young person had lost the capacity to consent we would seek consent from the parents for the young person to continue participating.

Without parental consent, under these changed circumstances the young person would be withdrawn. The parents would, again, be given the option to allow data collected thus far to remain in the project or have it destroyed. If a young person is withdrawn from the study for reasons relating to loss of capacity parents will be assured that the event will have no effect on the young person's care and treatment going forward.

VI. Participant Information Sheets and Recruitment Pathways

Who are we?



I am Emma, a PhD student studying at the Institute of Child Health working with the doctors and nurses at [NAMES REMOVED].



Myra Bluebond-Langner and Louise Jones are my supervisors. They have carried out lots of research with young people with illnesses and their families.

Thank you for taking the time to read and consider participating in this project. We hope to understand what decision making is like for young people like you, so we can develop guidance for doctors, nurses and families to help everyone when decisions need to be made.



Contact us

Please contact me if you have any questions about the study

Researcher: Emma Day

Institute of Child Health,
University College London, 30
Guildford Street
London WC1N 1EH

Mobile: 07523 055647

Email: e.day.12@ucl.ac.uk

Decision Making with Teenagers, Parents and Clinicians



This leaflet tells you about our research study and **how you can get involved**. Please feel free to ask us any questions you may have.

Oct 22ndth 2014

Version no. 2

What is the project about?

This project is about understanding what it is like for young people, parents, doctors and nurses and parents to make decisions about care and treatment. With a better understanding of everyone's views and experiences, we plan to develop guidance that will be helpful to doctors, nurses, parents and young people when decisions need to be made.

Who has checked the study?

Before research is allowed to happen it has to be checked by a committee of people who make sure that the project is fair and ethical. This research has been checked by the Bloomsbury Research Ethics Committee.

What does taking part in the project involve?

The project has two parts.

1. I would like to come to the meetings you and your parents have with the doctors and nurses about your treatment.

If it's ok with you and your parents i would like to sit in on meetings, appointments and rounds taking notes about what people say and do, and taking an audio recording of the meeting. Some of these meetings might be in hospital, or in clinic or at home.

If there is time I'd like to have a short chat with you and parents before and after the meeting to find out how you are and see if the meeting went well.

2. I would also like to have a longer chat with you about your care and treatment, the decisions that have been made and what that is like for you.

This can happen wherever you like!

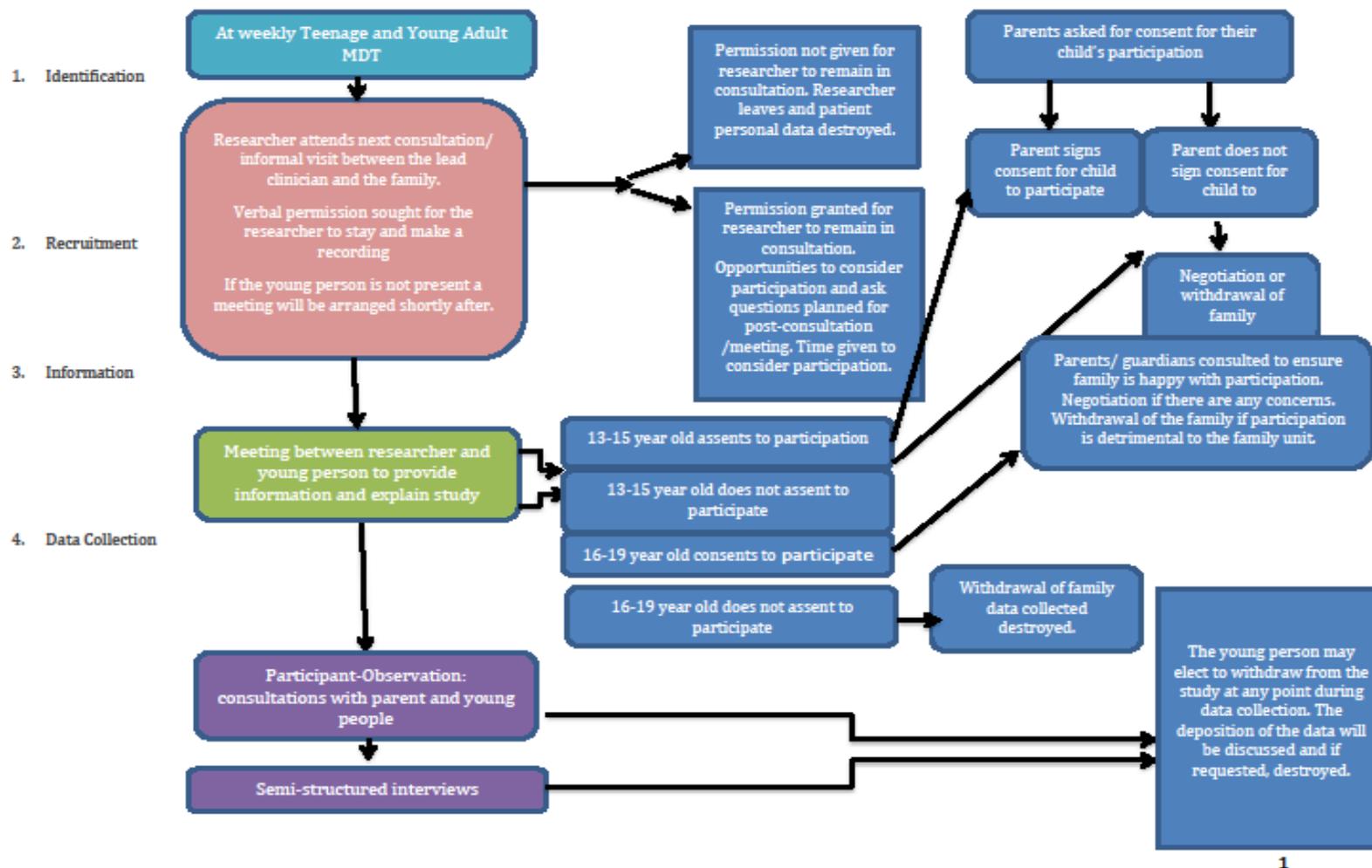
What happens to the information?

Any information we collect is kept confidential. You'll be given a study number to protect your identity. The only time we would talk to someone outside the research team is if we felt you or someone else was in danger.

Do I have to take part?

You can choose whether you want to join the study or not. If you do decide to take part, we will ask you to sign a form so we both have a record of you deciding to join. If you say yes at the start you can change your mind at any time without having to give a reason. Children and teenagers who have taken part in studies like this before have reported that they were pleased to have their views listened to. If you agree to participate, we hope you will as well.

Research pathway for young people 13-19



Clinician Information Sheet

Project title: Principles and practices in medical decision-making for young people, parents and health care professionals: A prospective ethnographic study to inform policy and practice

Short title: Decision-making with Teenagers, Parents and Clinicians

Researcher: Emma Day

We would like to invite you to be part of this research study to help better understand how teenagers (13-19 years old), families and health care professionals' view and experience participation in decision-making regarding care and treatment.

Last summer we conducted the first phase of this research by observing team meetings and conducting interviews with key members of the team. This research is the second phase and will build on the findings of this work. We would like to focus on young people aged 13-19 years diagnosed with AML and relapse ALL receiving their care and treatment in the UK. There has been limited work to date on the views and experience of young people themselves, and less still exploring the process of interaction between young people, parents and clinicians when decisions regarding care and treatment are made. This participant-observation study aims to fill this gap in the literature by providing an account from all three perspectives.

Objective: To understand the complex process of decision-making that takes place between health care professionals, families and young people independently, and as a collective, when decisions regarding the young person's care and treatment need to be made.

- a. Investigate how participation in decision-making is understood in principle and enacted in practice by all three parties
- b. Document the decision-making process between three parties at key decision points

Overview: The study will have two components. Firstly we will focus on the consultations that you will have with your colleagues, parents and teenagers with leukaemia, about care and treatment. It will involve a researcher being present to take notes and audio record at consultations, meetings and ward rounds. The researcher would also chat with you before and after the consultations to understand better your views about the consultation. Secondly, we would like to interview you about your experiences treating and caring for teenagers with leukaemia and their families and the decisions involved in this work. We will also be interviewing parents and teenagers about their experience of decision-making. We would be happy to provide you with copies of any of the recordings we make of your discussions with us and the parents. Parents will also be provided recordings on request. During the course of the study we will also be reviewing the medical records of the teenagers who participate in the study.

All information collected over the course of the study will be kept strictly confidential unless anything is discussed or observed which may raise serious concerns about the safety of a child, family member or professional. The recordings and other data used in our study will be assigned a study code to ensure that your information and comments are anonymous. No identifying names or details of specific individuals will be included in any reports, presentations or articles. Quotations from the data may be used in these but these will not be traceable to specific individuals. All information will be held securely, including any electronic data on encrypted computer files. If you decide to withdraw from the study and ask us to do so, we shall destroy these records.

Our conversations with you and the interviews will take place wherever it is best for you. The design of this study is to understand how decisions are made in clinical practice and therefore the role of the researcher is to observe and record this as it would usually occur and not to alter or interrupt the day to day work of clinical staff. We expect the conversations before and after the consultation with parents (and teenagers) to be short lasting about five to ten minutes, and the single interview about 40-60 minutes, but may take longer if you wish. If you were interviewed last summer as part of the first phase research you will not be asked to attend another interview unless you feel you would like to.

You do not have to join the project. Participation is voluntary; a decision not to take part at any time will not affect your employment or professional standing at {NAMES REMOVED} You can stop at any time during a conversation or interview or ask that the researcher not be present at a consultation, or be present and not tape record. You can also withdraw from the study completely. If you decide to stop taking part we will ask you if we may still keep the information you have provided up to that point in the study. If you would prefer us not to use it we will not.

We recognise the sensitive nature of the discussions we are asking to be present at and talk with you about. However, clinicians and parents who have taken part in studies of this kind have reported that they were pleased to have their views listened to. If you agree to participate, we would hope you will as well.

There are no direct benefits to participation in this study. However your participation may be of benefit to clinicians, parents and children in the future.

This project has been approved by NHS ethics and has received approval from the sites research and development team. All parents, health care professionals and young people will be required to consent before inclusion in the study, and can withdraw at any point without their care/ employment being effected.

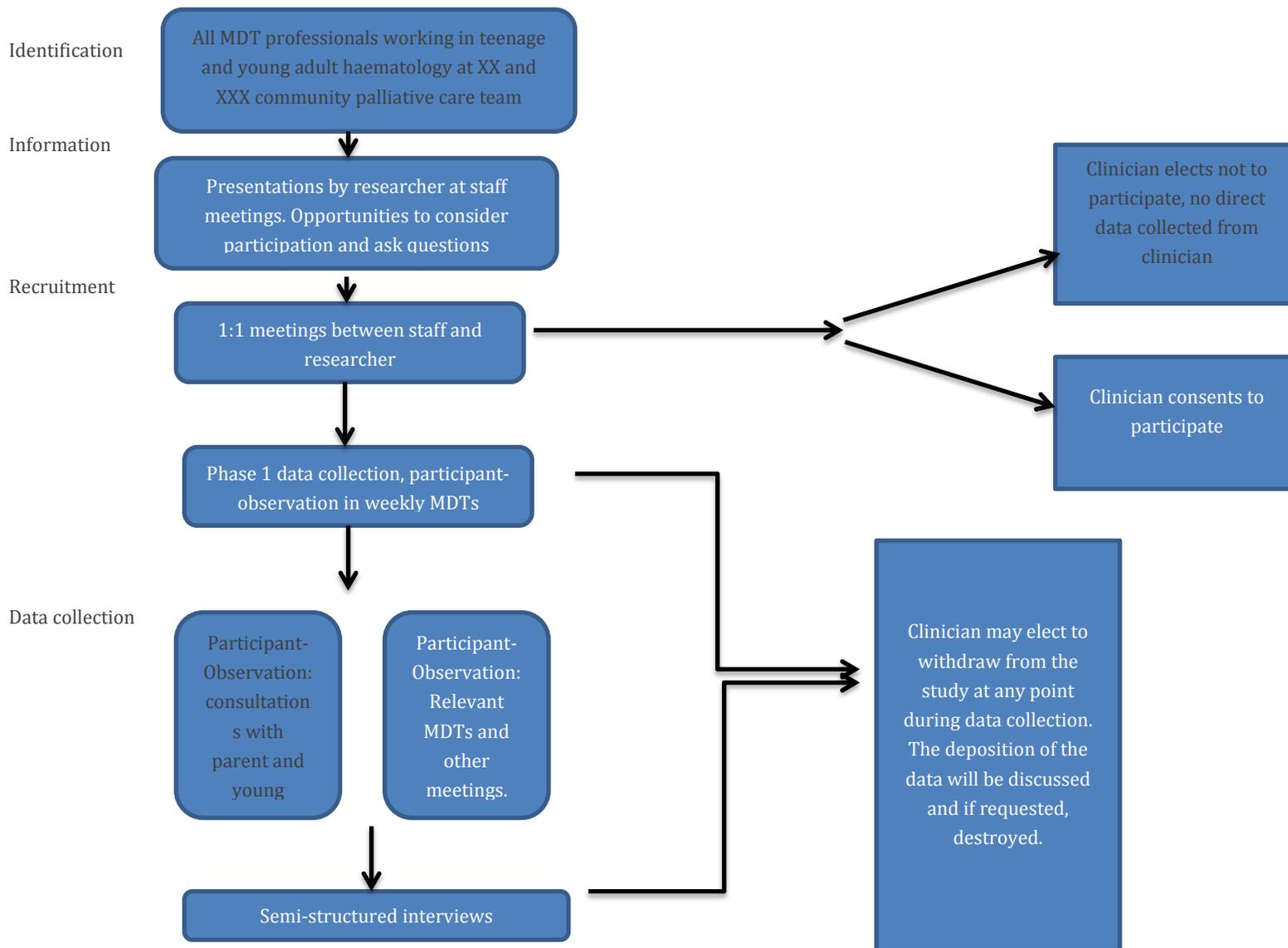
Contact: If you have any questions about the research please contact Emma Day on 07523055647 or e.day.12@ucl.ac.uk

If you have any concerns about the conduct of the research please contact Professor Myra Bluebond-Langner on 0207 905 2781 or bluebond@ucl.ac.uk.

Professor Bluebond-Langner is Emma's supervisor and therefore has overall responsibility for the project.

Thank you for taking the time to read this and giving consideration to participate in the study.

Research Pathway for Clinicians



Parent/ Guardian Information Sheet

Study: **Decision-making with Teenagers, Parents and Clinicians**

Researcher: Emma Day

Dear Parent/Guardian

We would like to invite you to be part of a research project to help us to better understand young people's involvement in medical decision-making regarding their care and treatment. We would like this project to inform policy and practice to support young people, parents and clinicians making decisions regarding care and treatment in the future.

The Project

We want to learn how parents, young people and clinicians, make decisions about care and treatment. We also want to understand how parents, young people and clinicians view the involvement of young people in decision-making in principle and what the differences are in practice.

The Researcher

Emma Day is the main researcher on this project; she has been studying at UCL and preparing this research project since 2012. She is interested in the psychological, social and practical impact of illness on children and young people, with particular focus on the role of young people in medical settings. She believes in producing research that can be applied in practice and can be of benefit to patients, parents and staff.

What the project involves

The project will focus on the conversations that you will have with your child and their doctors about their care and treatment. It will involve a researcher being present to take notes and audio record consultations, ward rounds and informal conversations you have about your child's care and treatment. The researcher would also chat with you before and after the consultations to better understand your views about the consultation. We would also like to interview you about your experiences caring for your child and the choices you have had to make over the course of their illness. We would be happy to provide you with copies

of any of the recordings we make of your discussions with the clinicians and us.

Over the course of the project we would also like to look at your child's medical records to collect basic information about your child's illness and to see how information about decisions is recorded there.

Confidentiality

All information collected in the study will be kept strictly confidential unless something is discussed or observed which may raise serious concerns about the safety of a child, family member or professional. The recordings and other data used in our study will be assigned a study code, to ensure that your information and comments are anonymous. No individual names or details that would identify specific individuals will be included in any of the reports, presentations or articles. Quotations from the data may be used in these but these will not be traceable to specific individuals. All of this information will be held securely, including encryption of computer files. If you decide to withdraw from the study and ask us to do so, we shall destroy these research records, and confirm to you that we have done so.

Interview location

Our conversations and interviews with you will take place wherever it is best for you. They can be in your home, the hospital or another place of your choosing. We expect the conversations before and after the consultation to be short, lasting about five to ten minutes, and the single interview about 40-60 minutes, but each may be longer if you wish to speak further.

Participation

You do not have to join the project. Participation is voluntary; a decision not to take part at any time will not affect your child's care in any way. You may participate in as much or as little of the project as you wish. You can stop at any time during a conversation or interview or ask that the researcher not be present at a consultation, or be present and not tape record. You can also withdraw from the study completely.

We recognise the sensitive nature of the discussions we are asking to be present at and talk with you about. However, parents and young people who have taken part in studies of this kind have reported that they were pleased to

have their views listened to. If you agree to participate, we hope you would also benefit in this way.

There are no direct benefits for your family for participating in this study. However your participation may be of benefit to parents, children and clinicians in the future. We hope that by researching how care and treatment decisions are made with teenagers we will be able to make suggestions to improve practice for young people, families and clinicians in the future.

Ethics approval

Before we are allowed to conduct any research in the NHS, it must undergo review by a committee who certify that the project is fair and ethical. We have been given approval to conduct this study from two agencies: the Research and Development department at your hospital trust, and the Research Ethics Committee for Bloomsbury which looks after the ethical aspects of our proposals. If you have any complaints about the study, please let us or one of the staff members know.

Contact details

Before making up your mind about participation, you may wish to discuss this study with your partner, and other family members and friends. If you have any questions or concerns please contact Emma Day the main researcher for this project or Professor Myra Bluebond-Langner the supervisor for this project.

Emma Day

Email: e.day.12@ucl.ac.uk

Mobile: 07523 055647

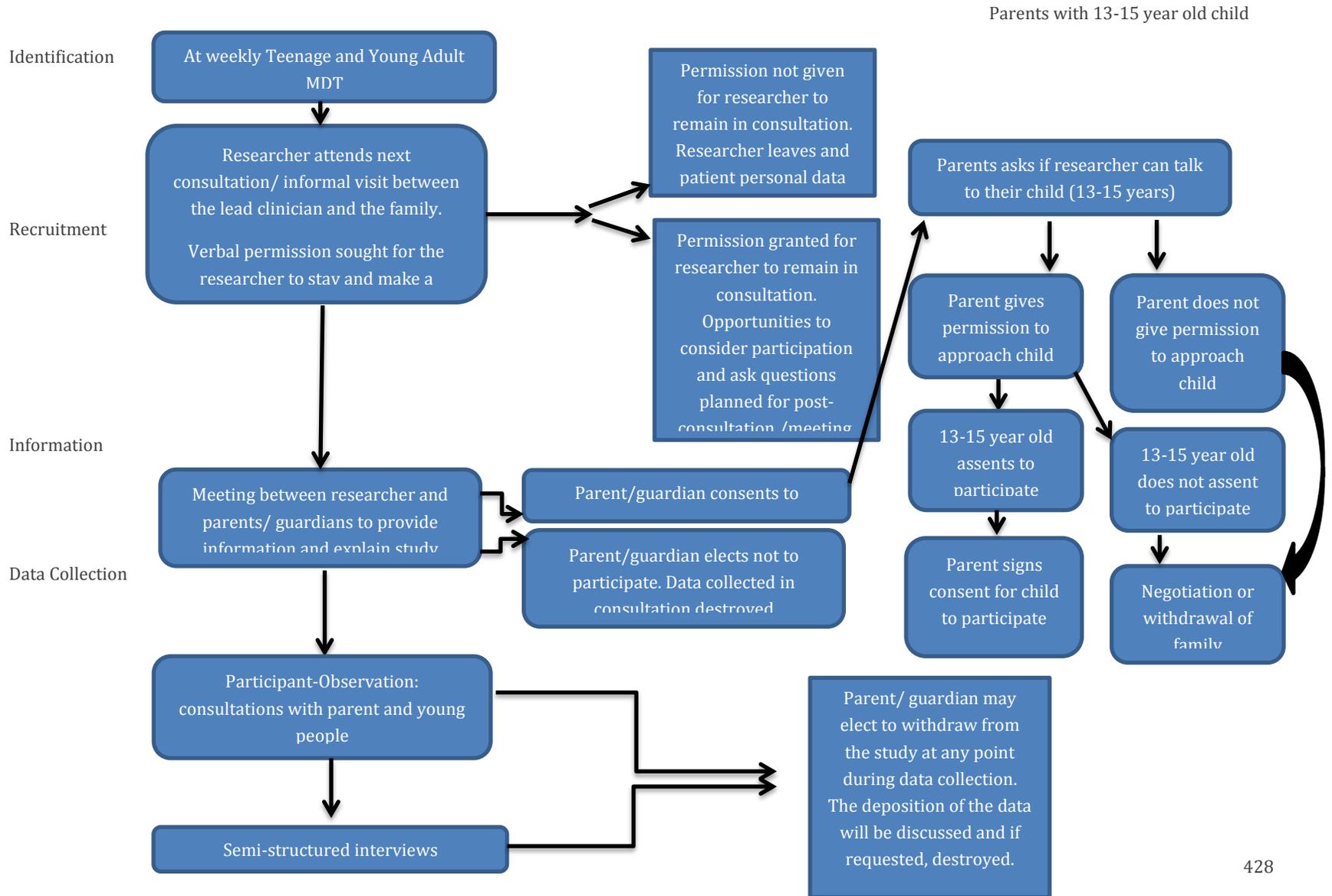
Myra Bluebond-Langner

Email: bluebond@ucl.ac.uk

Telephone: 0207 905 2781

Thank you for taking the time to read this information. We wish you and your family all the very best

Research pathway for parents/ guardians



Information Sheet for Extended Family

Study: Decision-making with Teenagers, Parents and Clinicians

Researcher: Emma Day

Dear family member

We would like to invite you to be part of a research project to help us to better understand young people's involvement in medical decision-making regarding their care and treatment. We would like this project to inform policy and practice to support young people, parents and clinicians making decisions regarding care and treatment in the future.

The Project

We want to learn how parents, young people and clinicians, make decisions about care and treatment. We also want to understand how parents, young people and clinicians view the involvement of young people in decision-making in principle and what the differences are in practice.

The Researcher

Emma Day is the main researcher on this project; she has been studying at UCL and preparing this research project since 2012. She is interested in the psychological, social and practical impact of illness on children and young people, with particular focus on the role of young people in medical settings. She believes in producing research that can be applied in practice and can be of benefit to patients, parents and staff.

What the project involves

The project will focus on the conversations that you will have with **{Name of Child}** and their doctors about their care and treatment. It will involve a researcher being present to take notes and audio record consultations, ward rounds and informal conversations you have about **{Name of Child}** care and treatment. The researcher would also chat with you before and after the consultations to better understand your views about the consultation. We would also like to interview you about your experiences caring for **{Name of Child}**

and the choices you have had to make over the course of their illness. We would be happy to provide you with copies of any of the recordings we make of your discussions with the clinicians and us.

Over the course of the project we would also like to look at **{Name of Child}** medical records to collect basic information about their illness and to see how information about decisions is recorded there.

Confidentiality

All information collected in the study will be kept strictly confidential unless something is discussed or observed which may raise serious concerns about the safety of a child, family member or professional. The recordings and other data used in our study will be assigned a study code, to ensure that your information and comments are anonymous. No individual names or details that would identify specific individuals will be included in any of the reports, presentations or articles. Quotations from the data may be used in these but these will not be traceable to specific individuals. All of this information will be held securely, including encryption of computer files. If you decide to withdraw from the study and ask us to do so, we shall destroy these research records, and confirm to you that we have done so.

Interview location

Our conversations and interviews with you will take place wherever it is best for you. They can be in your home, the hospital or another place of your choosing. We expect the conversations before and after the consultation to be short; lasting about five to ten minutes, and the single interview about 40-60 minutes, but each may be longer if you wish to speak further.

Participation

You do not have to join the project. Participation is voluntary; a decision not to take part at any time will not affect **{Name of Child}** care in any way. You may participate in as much or as little of the project as you wish. You can stop at any time during a conversation or interview or ask that the researcher not be present at a consultation, or be present and not tape record. You can also withdraw from the study completely.

We recognise the sensitive nature of the discussions we are asking to be

present at and talk with you about. However, parents and young people who have taken part in studies of this kind have reported that they were pleased to have their views listened to. If you agree to participate, we hope you would also benefit in this way.

There are no direct benefits for your family for participating in this study. However your participation may be of benefit to parents, children and clinicians in the future. We hope that by researching how care and treatment decisions are made with teenagers we will be able to make suggestions to improve practice for young people, families and clinicians in the future.

Ethics approval

Before we are allowed to conduct any research in the NHS, it must undergo review by a committee who certify that the project is fair and ethical. We have been given approval to conduct this study from two agencies: the Research and Development department at your hospital trust, and the Research Ethics Committee for Bloomsbury which looks after the ethical aspects of our proposals. If you have any complaints about the study, please let us or one of the staff members know.

Contact details

Before making up your mind about participation, you may wish to discuss this study with your family members and friends. If you have any questions or concerns please contact Emma Day the main researcher for this project or Professor Myra Bluebond-Langner the supervisor for this project.

Emma Day

Email: e.day.12@ucl.ac.uk

Mobile: 07523 055647

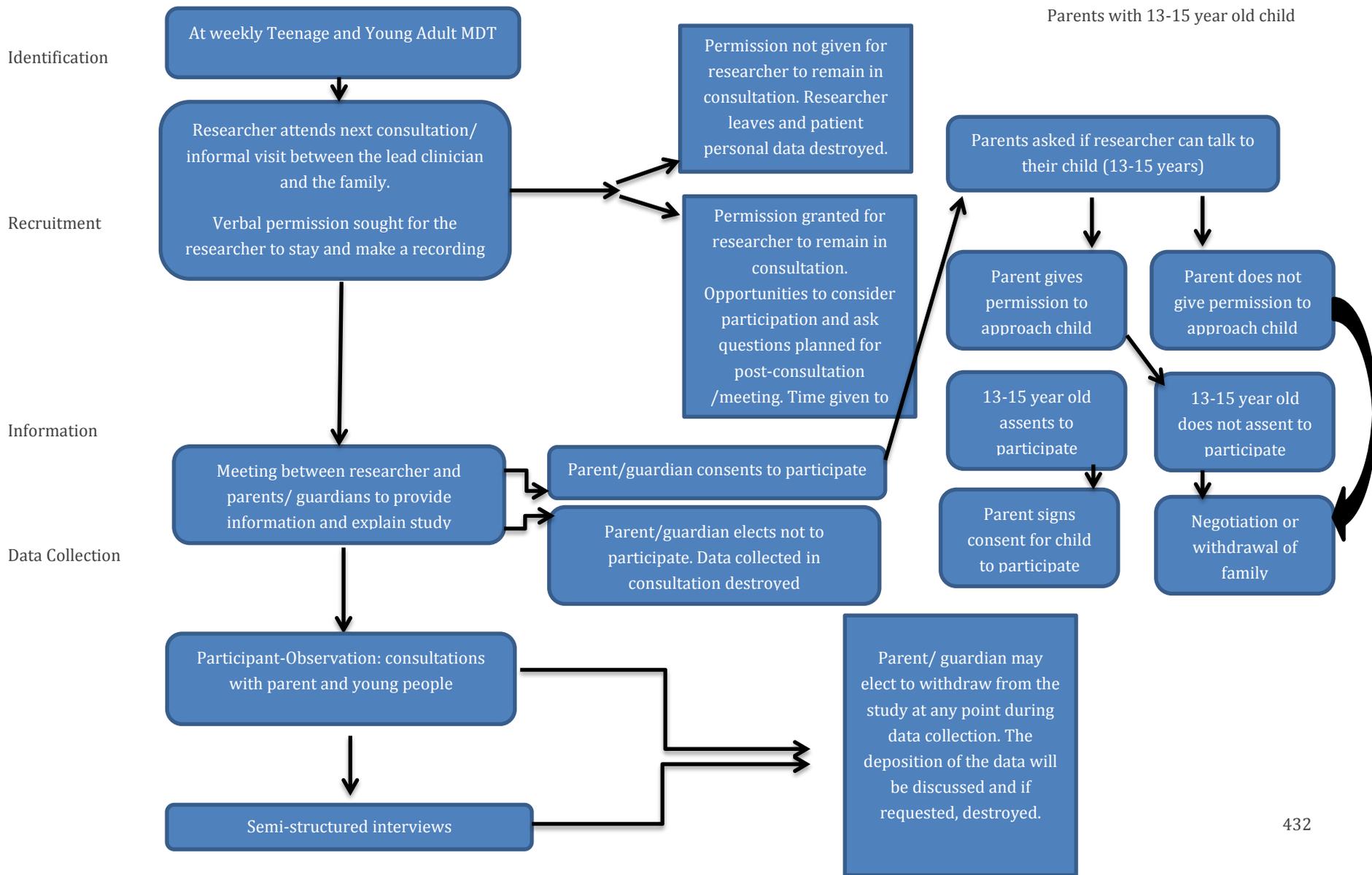
Myra Bluebond-Langner

Email: bluebond@ucl.ac.uk

Telephone: 0207 905 2781

Thank you for taking the time to read this information. We wish you and your family all the very best.

Research pathway for parents/ guardians/ extended family



VII. Personal Reflections

Prior to accepting this studentship and starting this research I had completed a BSc in Social Science and an MSc in Health Psychology. Though I had completed a placement in an adult neuro-palliative care service for my MSc, and had experience with teenagers and adults in an acute health care setting this project was to be my first experience with teenagers diagnosed with life-threatening cancer for whom cure was not guaranteed. Similarly, this work was my first experience of ethnography and participant-observation, and my first experience working longitudinally as part of a clinical team. This lack of prior experience in the field meant that I started the project with nothing more than a basic understanding of teenager cancer and end of life and an uninformed belief in what the involvement of teenagers in medical decision-making should look like. As someone who learns most effectively through direct experience I was keen to integrate myself with ward life and people receiving care and treatment as soon as possible. With the cooperation of the clinical team I was able to shadow ward rounds and meetings for a year prior to data collection. This period on the wards enabled me to practically, logistically and emotionally prepare myself for the data collection phase.

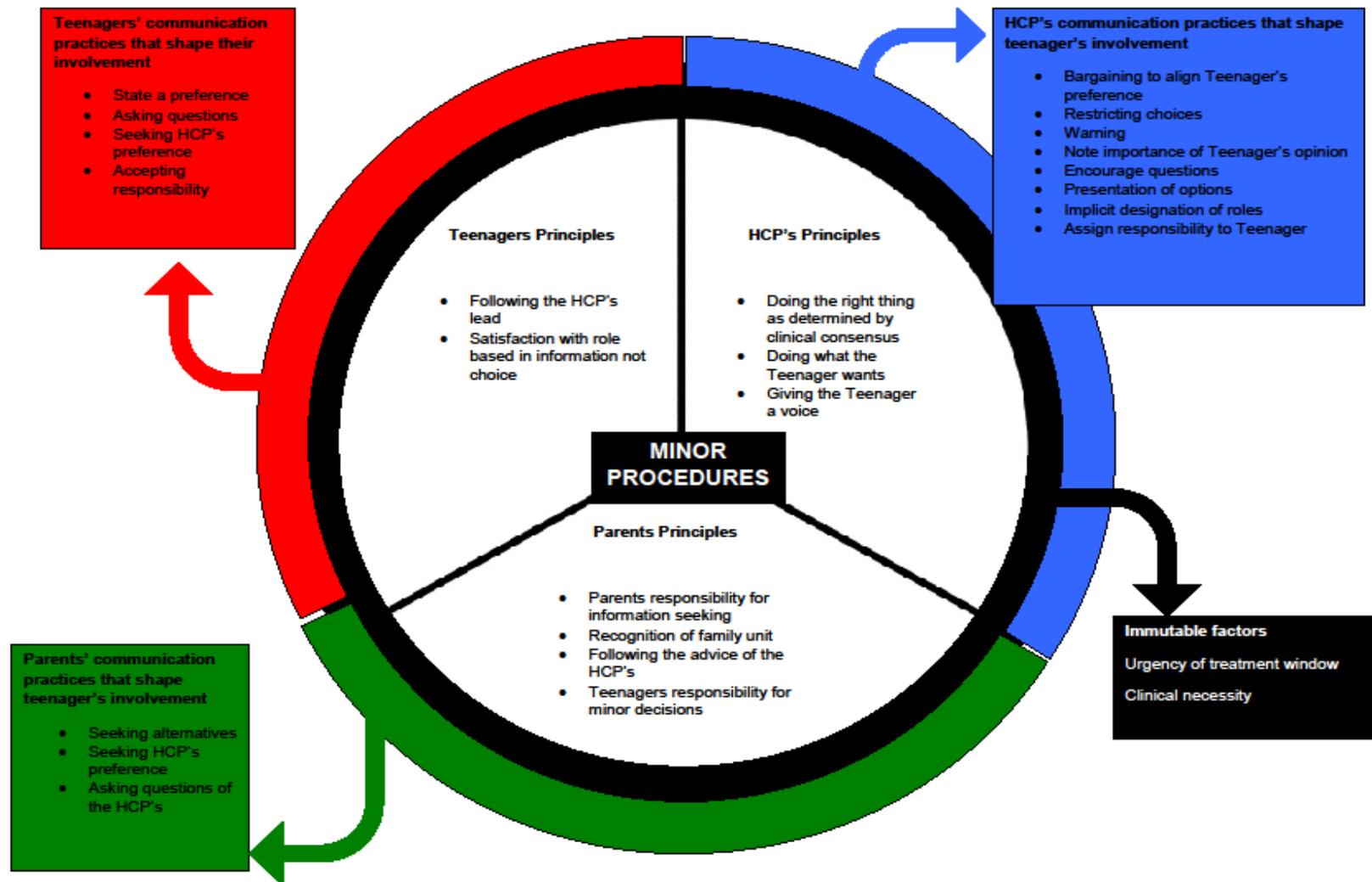
Starting the project shortly after my 22nd birthday influenced how I viewed the patient group I was to work with as I sat in the age bracket that the clinical team cared for and treated. Discussions were had about people my age and older about how they would be involved in care and treatment decisions. Relating to these teenagers was inescapable as they discussed exams and university choices, the importance of which I had felt so keenly just a few years earlier. I, perhaps wrongly, aligned myself with these teenagers and saw similarities between them, my friends and myself.

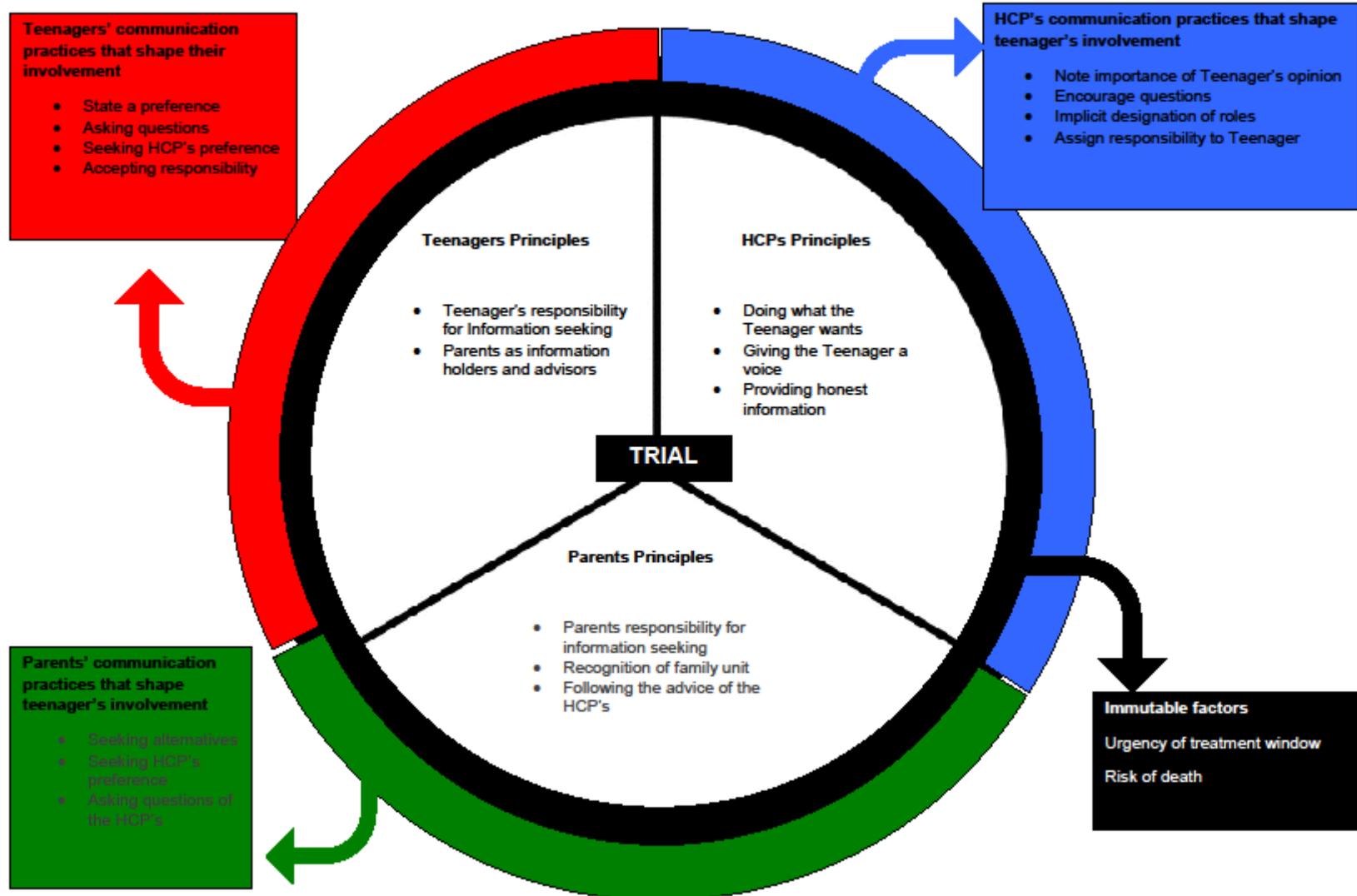
Throughout the 9 months I got to know these teenagers and families I experienced the highs and lows of the disease trajectory alongside them.

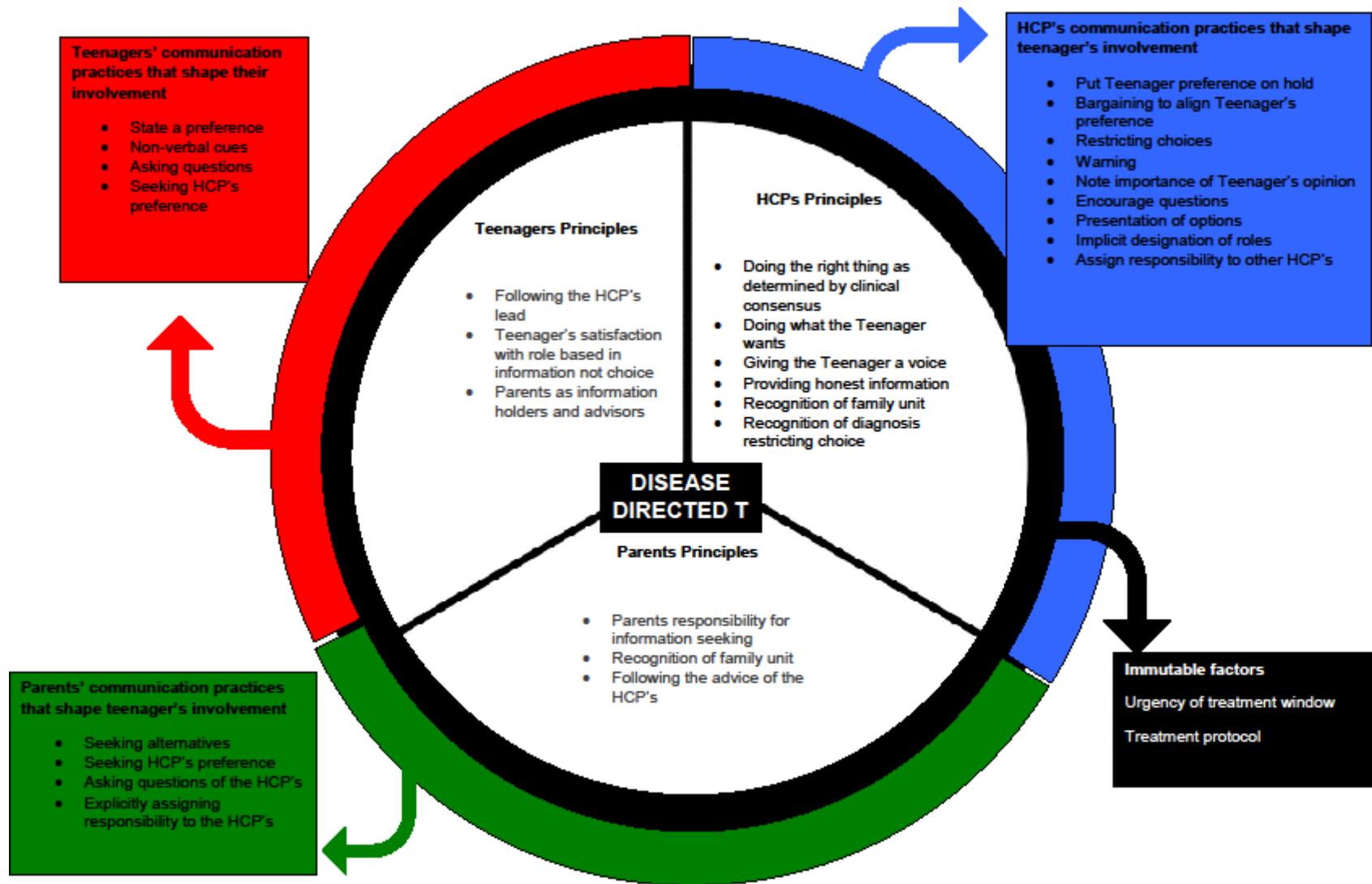
Celebrating remissions and hospital discharges with some while experiencing the heartbreak of families as they faced relapse and death. The project had an undeniable impact on me and I faced situations I would never have envisaged. At times returning to the field was a challenge; I felt I was walking in and out of someone else's nightmare, a witness to the worst day a family had experienced to return to my life where such tragedy was thankfully unknown. The necessity of confidentiality meant that I would participate in deeply upsetting moments, to walk away and not discuss them, to try, unsuccessfully, to forget what I had seen and heard. The nature of the research also meant that I had to relive these moments repeatedly, through audio-recordings and transcripts. I did not have the ability to reconstruct an event, to create a less traumatic narrative for my own benefit; the audio recording laid bare the 'reality' of the interaction, capturing the emotion, the conversations and the heart-breaking silences.

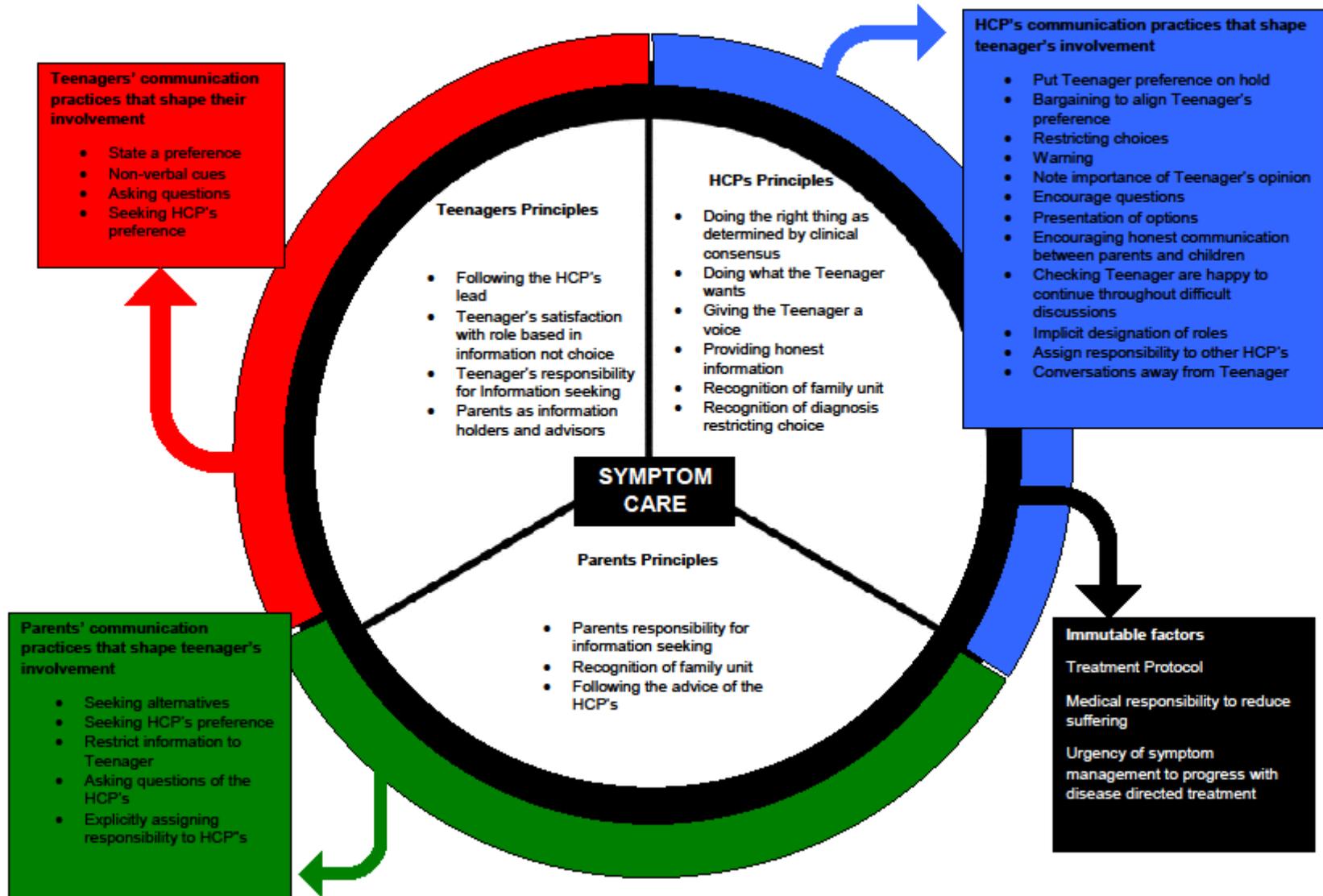
I draw this experience to a close with profound respect for the health care professionals who care for these teenagers and their families every day. Switching seamlessly between delivering good news and bad news, moving from room to room and responding to whatever they encounter. The ability to maintain a positive outlook and a unique sense of humour in the face of such emotionally and practically demanding work is to be commended. Whilst this thesis presents recommendations for improving clinical practice, it has been written following extensive reflection, analysis, objectivity and distance. My intention is to take nothing away from the responsive care and treatment provided by health care professionals in the moment.

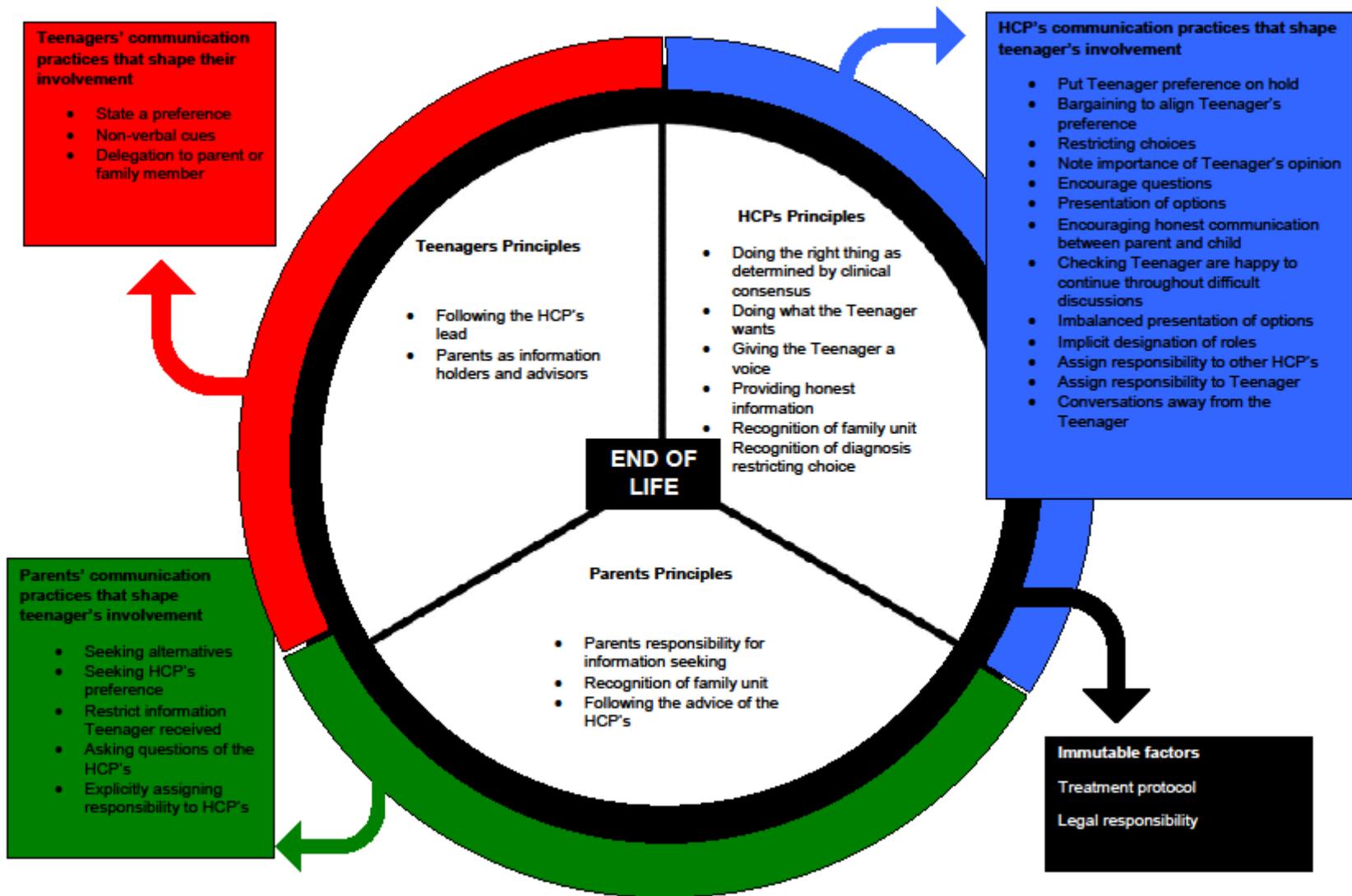
VIII. Principles in Practice by Decision

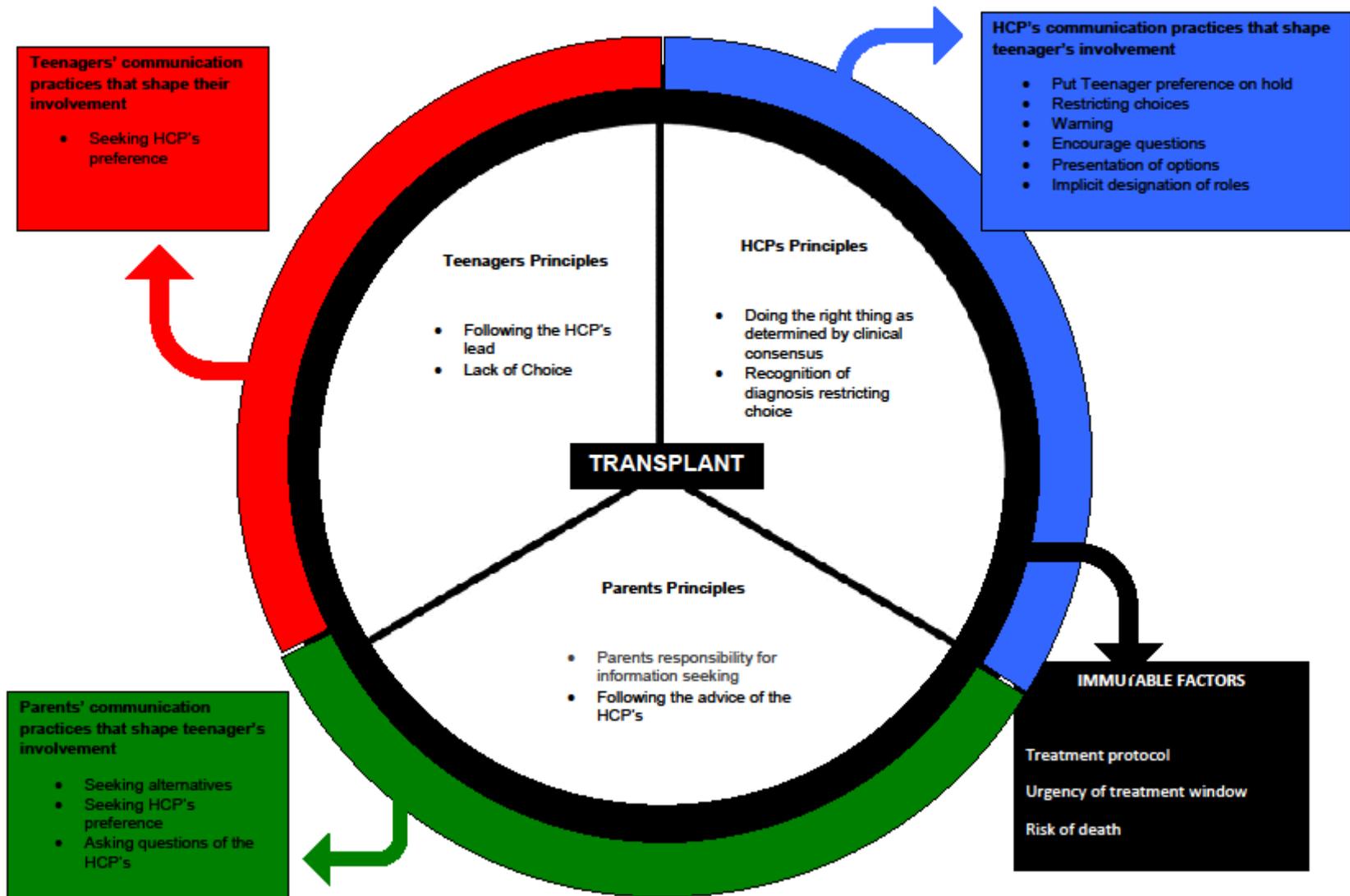


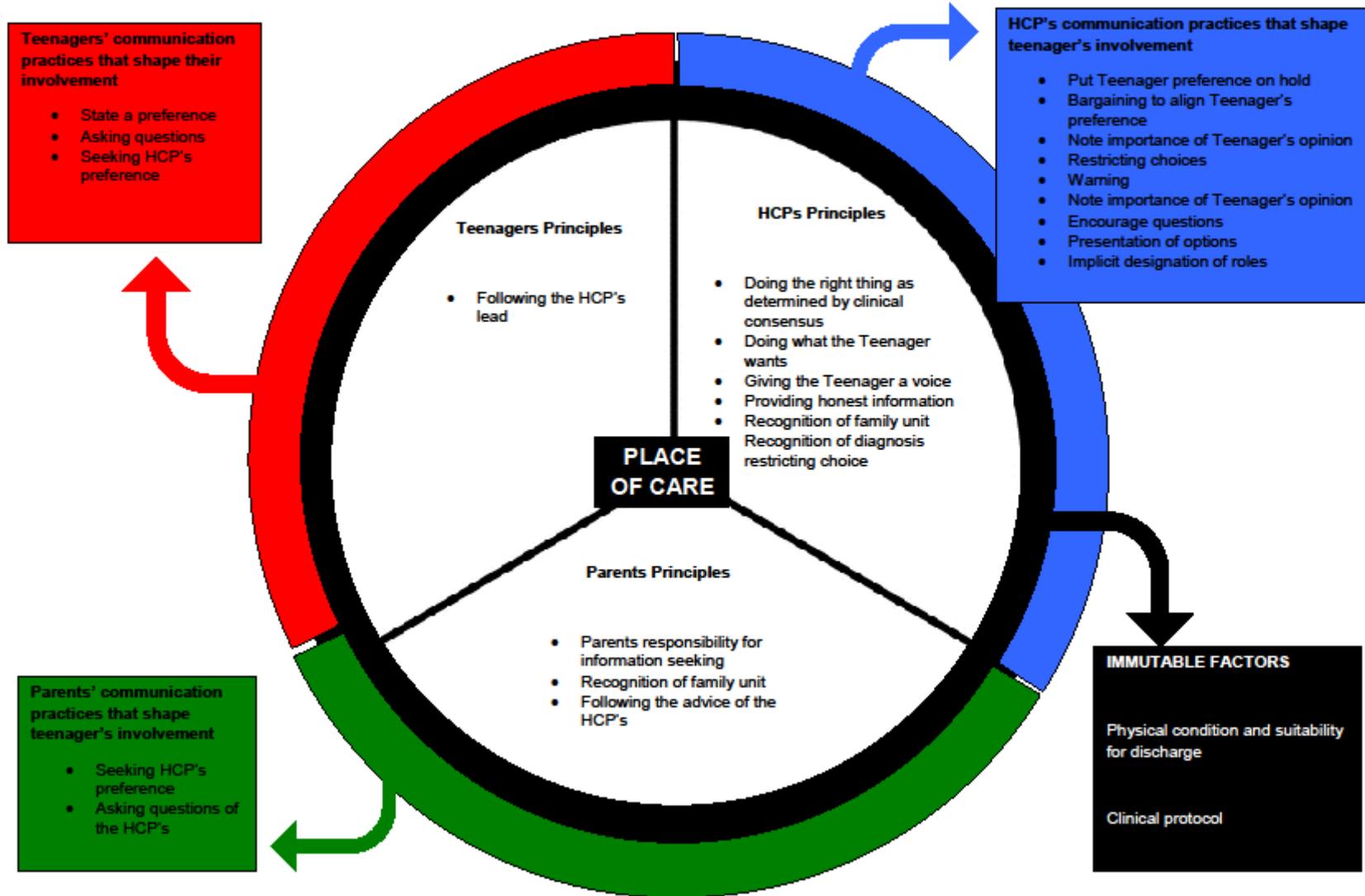


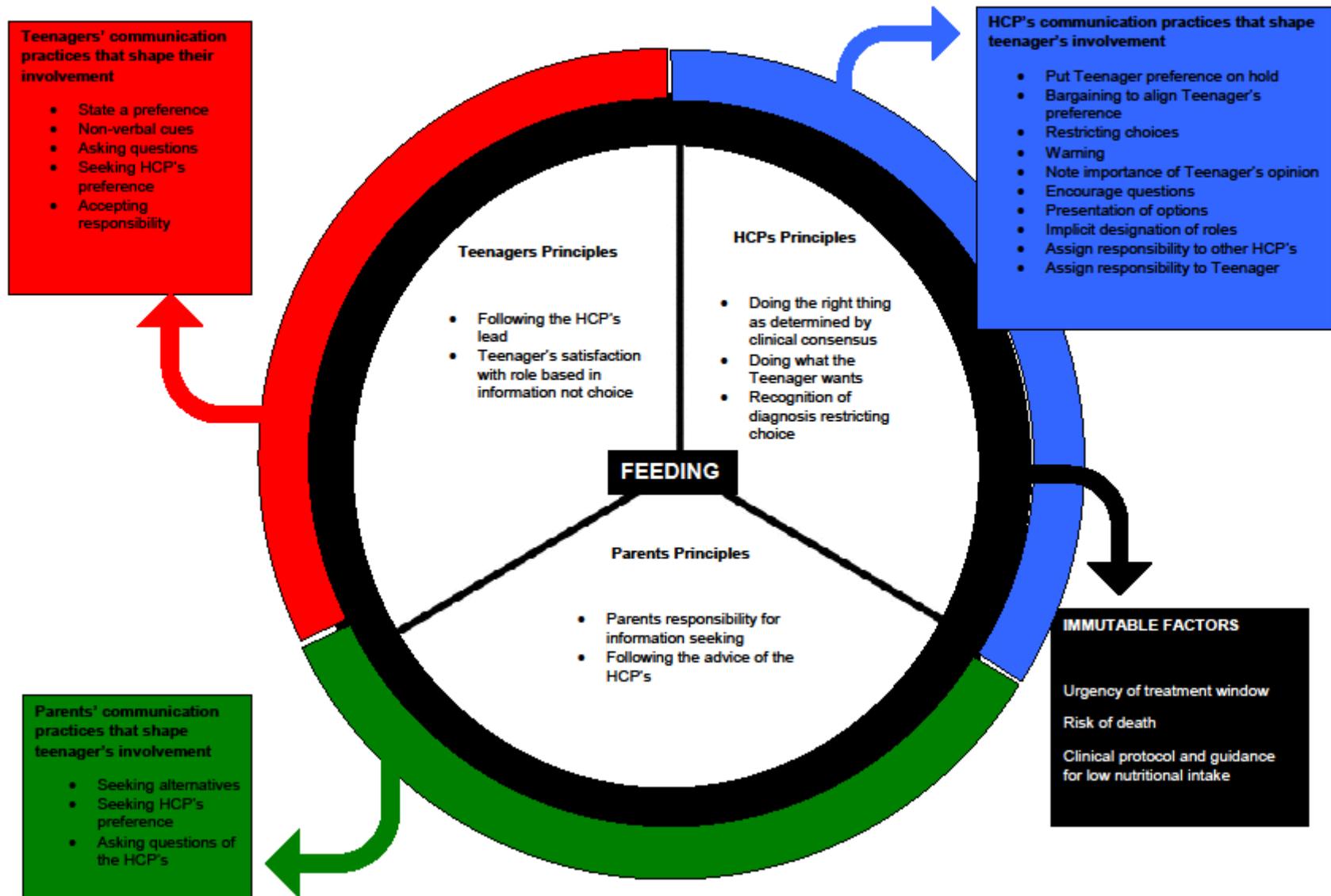












XVI. List of Tables and Figures

Tables

- I. Descriptive Characteristics of Included Studies
- II. Origin of Research Included in Narrative Systematic Review
- III. Observations over 9 Months of Data Collection
- IV. *Informal encounters and interviews over 9 months data collection*
- V. Study Recruitment Figures
- VI. Overview of Recruited Teenagers and Families
- VII. Overview of Health Care Professionals Referenced in this Thesis
- VIII. Contribution of Each Family to the Overall Data Set
- IX. Overview of Health Care Professionals' Principles and Occurrences Across the Data Set
- X. Data Source Table – Health Care Professionals
- XI. Overview of Parents and Family Members' Principles and Occurrences Across the Data Set
- XII. Data Source Table – Parents and Family Members
- XIII. Overview of Teenagers Principles and Occurrences Across the Data Set
- XIV. Data Source Table – Teenagers
- XV. Informal Conversations by Teenager
- XVI. Teenagers, HCP and Parents Principles of Involvement as Identified in Preceding Chapters Categorised into Four Distinct Groups
- XVII. Data Source Table – Consultations
- XVIII. Percentage of Speech During Consultations by Age of the Teenager
- XIX. Practices Employed by Each Party to Enact Principles of Acting on the care and treatment preferences of the teenager
- XX. Number of Discussions had in Consultations for Each Decision
- XXI. Number of times HCP Sought the Teenagers' Preference for Each Decision
- XXII. Number of Times Teenagers Stated a Preference for Each Decision
- XXIII. Number of Times when the Teenagers' Preference Diverged from the HCP Plan or Advice for Each Decision
- XXIV. Number of Times when the Teenagers Divergent Preference was Acted on by HCP for Each Decision
- XXV. Practices Employed by Each Party to Enact Principles of Doing the Right Thing as Determined by Clinical Consensus
- XXVI. Practices Employed by Each Party to the Enact Principles Relating to the Provision and Exchange of Information
- XXVII. Practices Employed by Each Party to Enact Principles Relating to Responsibility and Role Designation

Figures

- I. PRISMA Diagram
- II. ALL 5 Year Survival Rate
- III. AML 5 year Survival Rate
- IV. Simplified typical treatment trajectory for teenagers diagnosed with ALL
- V. Simplified typical treatment trajectory for teenagers diagnosed with AML

- VI. Overview of the Dataset
- VII. Principles in Practice
- VIII. Conceptual Model – Decisions of Serious Consequence
- IX. Conceptual Model – Decisions of Minimal Consequence

Appendix

- Table - Glossary
- Table - Code Book
- Figure – Principles in Practice By Decision