The Primacy Project:

Making difficult Decisions in the Paediatric Intensive Care Unit (PICU)

Dawn Ritchie

Thesis submitted to the University of Nottingham for the degree of Doctor of Philosophy

August 2019

Abstract

The predominant end of life scenario within paediatric intensive care units (PICUs) in the developed world results from an active decision to withdraw life sustaining medical treatment. Consideration centres on the problematic concept of whether treatment being provided is no longer in the best interests of the child. The notion of best interests presupposes that there is, theoretically, a definitively right answer to the question "is this intervention in the best interests of the child?" Yet, when making clinical decisions, which have implications for life, quality of life, quality of death, and justification for actions sought, there might not be a single best option. Parents and medical staff are likely to have differing understandings of the child's condition and prognosis, together with varying interpretations of moral and ethical values and beliefs involved.

Aim of the study

This study aimed to explore how best interests was constructed and enacted when making difficult decisions to persevere with, withhold or withdraw life sustaining medical treatment in children.

Methodology

A qualitative methodology involving a twenty-one month case study of a single PICU was used. Data collection comprised ethnographic approaches of observations of care given to children, documentary analysis, interviews and informal discussions with parents and healthcare professionals directly involved in each of six embedded cases. Data were analysed using thematic analysis providing insight into both parents' and clinicians' understanding of the nature and construct of decisional processes.

Findings

Findings reflect the uncertainty and indeterminacy of clinical decision-making. Best interests emerges as an elastic notion used by clinicians and families who are struggling to validate and justify decisional processes in the effort to recognise ‘the best thing to do’ in highly emotional and clinical circumstances. Findings illuminate the complexity and shifting nature of negotiations, which underpin the co-production of decisions about best interests affecting critically ill children. The involvedness of lay and professional stakeholders characteristically results in multiple distinct understandings, permitting a range of reasonable outcomes. The multidimensional nature of shared decision-making, the complex interplay of motives and interests enabled the containment of disagreement and maintenance of relationships. Best interests as a PICU decision-making tool has been revealed to add little to the pre-existing repertoire of medical diagnosis and prognosis, and ethical considerations regarding sanctity and quality of life. Instead, it simply offers a different discursive frame for the same substantive quandaries and decisions of whether to continue to treat or not.

Conclusion

Best interests is presented as a concept that can be identified, managed and used to guide difficult decision making. Yet, it emerges as an elusive, ever-evolving construct generated within the uniqueness of each individual case. Frequently, it is used as a mechanism to validate and justify the reasoning process according to diverse and mutable perspectives amongst the complex network of involved parties. The potential for dispute, with differing understandings, varying values and beliefs is considerable. More remarkable, is that vast majority of best interest determinations are made without overt conflict or recourse to the legal system.

Acknowledgements

Firstly, thanks go to all the children, parents and professionals who participated in this study. I am truly indebted to you all. Your generosity, courage, candour and belief in the value of this project in times of adversity has amazed and inspired me.

To my supervisors, Professor Kristian Pollock and Professor Ralph Sandland, my sincere thanks and appreciation for your expertise and unfailing guidance. Throughout your unlimited patience, support and understanding, has instilled me with the confidence to believe this is possible. It has been my privilege work with you.

In particular, sincere thanks go to Dr Harish Vyas, Dr Simona Lampariella, Dr Patrick Davies, Jackie Browne and Sue Mager for supporting me in the field. My colleagues and friends who have provided me with time, plenty of cups of tea and encouragement throughout, I thank you. To Dr Carol Hall, Dr Joseph Manning and Lis O’Brien you have provided more support than I can ever thank you for.

To my Mum and brother, Gavin, thanks for always being there when I need you, quietly supporting. Lastly, to Duncan, your love has been constant, always encouraging, accepting and tolerating. How you have put up with me I will never know.

Scholarly outputs from this thesis

Oral Papers:

Ritchie, D., Pollock, K. & Sandland, R. Understanding the nature and construct of best interests when making difficult decisions in the Paediatric Intensive Care Unit (PICU). European Society of Paediatric and Neonatal Intensive Care (ESPNIC) Lisbon, Portugal. 8 June 2017

Ritchie D. Difficult decisions: supporting families. Paediatric Intensive Care Society (UK) Family Support Forum Conference, Nottingham. 24 January 2018

Poster Presentations

Ritchie, D. The primacy project: Decision making in the PICU. Children's Nursing Research Conference. Children's Nursing Research Unit, Alder Hey Children's Hospital, Liverpool, UK. 7 May 2013

Ritchie, D. The primacy project: The use of ethnography to explore difficult decision-making.1st International and multi-disciplinary children's critical care research summer school 26-27 August 2014 – (Awarded first prize for research in progress).

Ritchie, D., Pollock, K. & Sandland, R. The primacy project: making difficult decisions in the PICU e-Poster. Paediatric Intensive and Critical Care World Congress, Toronto 7 June 2016

Ritchie D., Pollock, K. & Sandland, R. Striving to do their best: health care professionals making difficult decisions in the Paediatric Intensive Care Unit. Nottingham Paediatric Research Showcase. 6 June 2019

Table of Contents

List of tables

Timelines

List of Figures

Glossary of terms and abbreviations

AICU	Adult Intensive Care Unit
EOL	End of life
FCC	Family Centred Care
HCP	Health Care Professional
ICP	Intra-Cranial Pressure
NHS	National Health Service
NICU	Neonatal Intensive Care Unit
MDT	Multi-Disciplinary Team
PIC	Paediatric Intensive Care: defines the care received whilst a child is critically ill, whether medically, surgically or trauma related. (Paediatric Intensive Care Society, 2010).
PICU	Paediatric Intensive Care Unit
QoL	Quality of Life
SDM	Shared Decision Making
WLSMT	Withdrawal of Life Sustaining Medical Treatment

Chapter One:

1. Introduction and Overview

1.1 Significance of the study:

Cutting-edge advances in science, paediatric critical care medicine and biomedical technology have generated the potential to prolong life. Nevertheless, it may not always be in the child's best interests to do so (Wellesley & Jenkins 2009). Paediatric Intensive Care Units[1] (PICUs) epitomise the quandary of modern healthcare, whereby the potential to achieve 'medically good' outcomes exists (Goh & Mok, 2001), but at what cost to the individual child, family, health care professionals (HCPs) and society?

Increasing numbers of children are being admitted to PICUs in England & Wales (Davis, Stutchfield, Evans et al., 2018). In an attempt to care for each child's complex healthcare needs during critical illness, specialist interventions including invasive monitoring, physiological system support and intensive therapeutic interventions are used and have resulted in a significant reduction in mortality (Paediatric Intensive Care Society, 2010; Department of Health, 2002, 2003; NHS Executive, 1997; Vemuri & Playfor, 2005; Goh & Mok, 2001). National audit data indicate that the vast majority of children will survive a PICU admission, 96% of children being discharged alive (Paediatric Intensive Care Audit Network, 2018). Even so, families and health care professionals (HCPs) in PICUs sometimes have to make extremely difficult and emotionally challenging decisions about a child's treatment and care.

Few issues in healthcare are as challenging or as complex as decisions involving continuation, withholding and/or withdrawal of treatment and within a paediatric intensive care setting decisions about end of life care

---

[1] Paediatric intensive care unit (PICU): a dedicated facility, providing specialised equipment and teams of staff who provide specialist intensive care to critically ill children (Paediatric Intensive Care Society, 2010)

are particularly difficult. HCPs have, since Hippocratic times, a primary duty of care to sustain life and prevent pain and suffering (RCPCH, 2004). It would be unlawful to sanction steps to terminate a life. However, not all children can, or will be, saved despite the primary function of PICUs being the preservation of life of the sickest, most unstable and technologically dependent children.

An increasing proportion of deaths in children, which occur in PICUs follow an active decision to withhold or withdraw treatment (Oberender & Tibballs, 2011; Sands, Manning, Vyas & Rashid 2009; McCallum, Byrne, & Bruera, 2000). There is growing recognition that such advances in care create moral, ethical and philosophical dilemmas for those directly involved in decision-making as well as the wider society. Continuing advances in care have moved debates away from whether a child can be 'saved', towards the ethical implications and practical/long term consequences of 'saving' the child. These decisions may be about whether a child should be resuscitated if their condition deteriorates, whether it is appropriate to continue intensive care therapies, or whether to withdraw intensive care therapies and provide palliative care. Ramnarayan, Craig, Petros & Pierce, (2007) suggest that parental and societal expectations, despite realising uncertain benefits to the child, support an increasingly aggressive approach towards the treatment of life threatening conditions. In particular, attention has focussed on the potential for medical treatment to be continued beyond the point at which it is perceived to offer any benefit to the child, medically inappropriate care, and even to needlessly prolong suffering, (Vemuri & Playfor, 2005; Goh & Mok, 2001). The delivery of potentially ineffective treatments brings with it a need for greater understanding of the socio-cultural, moral, ethical, legal and economic issues confronting the bedside management of these children and young people. Considerable concern exists that medical and scientific developments challenge the moral, ethical, social and legal standards by which we live (Schneiderman, 2011).

Families and HCPs in critical care settings sometimes have to make extremely difficult and emotionally challenging decisions about a child's treatment and care. These involve deep seated and strongly held values with the decision-making process being affected by feelings of anxiety, depression, grief and possibly guilt (Pochard, Azoulay, Chevret et al., 2001). Family centred care is a central tenet of child health care with participation of the parents in decision-making deemed fundamental (Smith and Coleman 2010; Butler, Copnell & Willetts, 2014). Correspondingly, there has been a growing emphasis on incorporating parental views in the decision-making process within the PICU, (Ramnarayan, Craig, Petros et al., 2007).

When making decisions about critically ill children there may not be an answer that is clearly 'right' or 'wrong,' (Brazier, 1987). Disputes may result from differing understandings of the child's condition and prognosis together with varying interpretations of moral and ethical values and beliefs (Birchley & Huxtable, 2014; Studdert, Burns, Mello et al., 2003). For the child and family this situation is unique, the process exceptional and the outcome decisive, whereas for HCPs and the courts the circumstances, whilst relatively rare, are not exceptional.

1.2 Personal reflections and motivation for the study

The nascent beginnings for this study developed while working as an experienced PIC nurse. I acquired experiential insight and skills through providing care to a small but significant number of parents who had faced the unimaginable situation that the treatment being provided to their child was no longer considered in their child's best interests. Each case I was involved with was unique. The emotional impact, moral distress and suffering incurred by all involved, the child, parents and the many HCPs, was immense.

These decisions about the point at which people believe that stopping intensive care therapies is for the best are among the most difficult choices parents and HPCs ever have to make. Debate and disagreement about how to manage these situations were frequent. In some instances, differences were seen to arise amongst the multi-disciplinary teams of

HCPs, with individuals questioning the benefits of continuing to provide treatments. At other times, it was parents who did not agree that technology should be withdrawn, the parents refusing to ‘give up’ on their child. Although not personally involved in a case which resulted in recourse to the law, media attention surrounding cases that came before the courts further reinforced questioning and contemplation as to what happens in these situations. I became increasingly intrigued as to why some cases became contentious and others not.

Having engaged with the literature, I became aware that a paucity of literature in PICU settings had prompted healthcare professionals to evaluate practices and extend opinions. On the few occasions where parents had been involved, studies had almost always been retrospective. A UK study looking at parental involvement in decisions about life sustaining medical therapies in critically ill children from a qualitative perspective had not been undertaken at the starting point for my PhD. With this study my aim was to contribute to this deficit in the knowledge base by illuminating and exploring how best interest decisions are constructed and enacted within real world clinical practice.

1.3 Clarification of terms

Within this thesis, a number of key terms are utilised. These require clarification and definition as they have multiple meanings, uses, and portrayals within the literature.

1.3.1 Child

The term child refers to those aged from 0 (birth), to someone who has not yet reached their 18th birthday.

1.3.2 Parent and parental responsibility

The term ‘parent’ is used in accordance with the definition outlined under section 576 of the Education Act 1996. This includes all biological parents, irrespective of marital status; any person who although not a biological parent, has parental responsibility for a child; and any person who although not a biological parent and who does not have parental responsibility, has care of a child.

In this thesis, I have focussed specifically upon parents and HCPs within the decision making process. This is despite being cognisant as to the extent which extended family members can be involved in the decision-making process. Whilst extended family member involvement is of interest for future research, it was beyond the scope of this thesis.

Parental responsibility is set out in section 3(1) Children Act 1989 as being

> "*all the rights, duties, powers, responsibilities and authority which by law a parent of a child has in relation to the child and his property*".

Additionally, where someone has the care of a child, but who does not have parental responsibility for them, they may still, subject to the provisions of the Children Act,

> "*do what is reasonable in all the circumstances of the case for the purpose of safeguarding or promoting the child's welfare*".

1.4 Thesis structure

Following this introductory chapter and in order to orientate the reader to the structure of the thesis, an outline of the chapters is detailed below.

Chapter 2 situates the study, providing a narrative review of the literature. Beginning with an overview of the nature of death in PICU, the chapter proceeds with an in-depth exploration of the medical and legal debates surrounding Withdrawal of Life Sustaining Medical Treatment (WLSMT) in PICU. These debates include the difficulties of defining futile or medically inappropriate care; exploration of the concept of best interests, including decisional responsibility; decision-making; and resource allocation. The chapter concludes with consideration of the knowledge gaps, providing robust rationale for this study

Chapter 3 presents the aims and objectives of this empirical study. A detailed justification of the research methodology and outline of the philosophical underpinnings is provided. This includes discussion of the use of a qualitative case study approach, definition and selection of cases, and specifics of study processes.

Chapter 4 details the ethnographic approaches used to generate data; techniques for data analysis; together with reflective discussion of relevant ethical considerations and quality assurance processes.

Chapter 5 serves to contextualise the study field and seeks to apprise the reader with the six embedded case studies derived from the ethnographic fieldwork. A synopsis of the case and time-line of events contextualises each child's admission to PICU, revealing key events and generating understanding of the phenomenon experienced. The specific themes and sub-themes, which emerged from within case analysis are detailed in diagrammatic representations.

Chapters 6 and Chapter 7 present the findings of the cross-case analysis. Insight is developed across instances and contexts, thereby illuminating convergence and divergence. Aggregation of the case findings identified two principal themes: decision-making and best interests. **Chapter 6** commences with a brief introduction to the findings. It explores how decision-making is constructed and experienced: specifically analysing relationships within and among professional actors and parents involved in decision-making: reviewing defining junctures within the process, together with consideration of how gaps in knowledge are managed.

Chapter 7 explores how difficult decisions within the PICU were guided by the concept of best interests. It builds upon previous chapters, providing insight as to how parents and professionals construct best interests in different ways according to the unique context of each case and individual perspective and values.

Chapter 8 provides a discussion of the core study findings with reference to the wider literature and **Chapter 9** provides a conclusion for the thesis and the overall contribution to understandings of how decisions to treat or not to treat are made.

Chapter 2:

2. Literature Review

This chapter presents a narrative review of the medical and legal debates surrounding withholding and withdrawal life sustaining medical treatment in the PICU. The review aims to identify and problematize attitudes and practices towards, and includes detailed deliberation of, the difficulties of defining futile or medically inappropriate care; exploration of the concept of best interests, including decisional responsibility; the difficulties of decision making between parents and HCPs in the PICU; and resource allocation. English case law is interwoven throughout. Case law review focused on significant cases during the last three decades where the courts had been asked to make decisions about medical treatment(s) having regard to the best interests of the child/patient. Cases primarily, but not exclusively, concentrated on children. The chapter culminates with consideration of the knowledge gaps, providing a robust rationale for this study.

PICUs epitomise the quandary of modern healthcare, generating debate as to whether treatments, which may feasibly support life should always be advanced (Miller-Smith, Wagner & Lantos, 2019; Larcher, Craig, Bhogal, Wilkinson & Brierley, 2015; Goh and Mok, 2005). The potential to achieve ‘good’ outcomes exists, but this may be at considerable cost, to the individual child, family, healthcare professionals and society. As Larcher et al (2015:s6) acknowledged when developing the current Royal College of Paediatrics and Child Health ethical and legal framework for making decisions to limit life-sustaining treatment, some therapies now available may “*neither restore health nor confer overall benefits to the child.*”

2.1 The nature of death in PICU

PICUs provide the starkest of alternatives, life and death. Whilst increased efficacy of interventions means the majority of children will survive a PICU admission, survivors may be discharged with new and increased morbidities (Manning, Hemingway & Redsell, 2013; Knoester, Bronner and Bos, 2008). The predominant end of life scenario within PICUs in the developed world is withdrawal of life-sustaining medical treatment (WLSMT), having replaced failed resuscitation (Meert, Keele, Morrison et al. 2016; Burns, Seller, Meyer et al. 2014). Sands et al's (2009) ten year retrospective analysis of deaths in a regional UK paediatric intensive care unit (PICU) established that managed withdrawal of life sustaining medical therapy (MWLST) accounted for 54.9% (n=112) of deaths with a further 9.8% (n=20) a consequence of an active decision not to escalate treatments. This pattern is consistent with the majority of literature from international studies with rates of between 43%-80% of deaths reported, (Burns, et al 2014; Lee, Tieves and Scanlon, 2010; McCallum et al, 2000). Oberender & Tibballs (2011), report greater worldwide variation exists between international regions following decisions to limit or actively withdraw life-sustaining medical treatment. North American, United Kingdom and Australian studies, report mortality rates of 60-78%, whereas rates of less than 50% were recorded in France and South America (Oberender & Tibballs, 2011; Sands, et al., 2009; Devictor & Nguyen, 2004; Lago, Piva, Garcia, et al., 2004; Garros, Rosychuk & Cox, 2003). These differences could reflect genuine differences in management and treatment of children, clinical practices and cultural norms, or they could relate to differences within access to intensive care resources and admission criteria whereby children with a poor prognosis may not be admitted to PICU's. Given the nature of WLSMT, it is neither feasible nor appropriate to undertake experimental designs such as RCTs. Available evidence is predominantly observational, thus providing descriptive data depicting clinical practice at that time. There is therefore a danger of ascribing meaning or misinterpretation when analysing findings.

Significantly, whilst the mode of death, WLSMT, has remained comparably similar from Sands et al's (2009) study, mortality rates have declined year on year (Hartman, Saeed, Bennett et al 2017; Burns et al 2014). Since PICANet commenced data collection in the UK in 2002 rates have fallen to an all-time low of between 2-3% (PICANet, 2018). Advancements in care whilst reducing overall mortality, in particular from acute illness, have however, resulted in increasing numbers of children with complex chronic conditions dying in the PICU following a decision to withhold or withdraw care (Rennick & Childerhose, 2015; Edwards, Houtrow, Vasilevskis, et al., 2012). These findings are similarly found in Roth, Rapoprt, Widger & Friedman's (2017) retrospective analysis of deaths in a Canadian tertiary care children's hospital, which also identified fewer deaths but increased consultations about limiting care and advanced planning.

Ethical debate and controversy has arisen about how advances in care, which may result in unnecessary suffering to children and their families, are balanced with consideration of the child's best interests (Miller-Smith et al, 2019; Larcher et al, 2015; Inwald, 2008; Vemuri & Playfor, 2005). This debate has been further fuelled by media exposure, feeding on public concerns not only about when care should be given or withdrawn, but also with whom the responsibility rests as to making difficult and complex decisions about resource allocation (Chen, Li, Laing et al 2018; Chen, Chen & Kao et al, 2014). Not all children can or will be saved despite the primary function of PICUs being the preservation of life of the sickest, most unstable and technologically dependent children. Considerable concern exists that medical and scientific developments have outpaced the moral, ethical, social and legal standards by which we live. Nonetheless, defining medically inappropriate care and determining which interventions are futile is fundamental in locating boundaries to a physician's duty to provide care.

2.2 Inappropriate or futile care

The term futility is not the sole preserve of medicine. Although its use is not in everyday vernacular, there is commonly an implicit assumption that it is inextricably linked with life sustaining treatments and this has perpetuated conceptual confusion. Chwang (2009) proposes that although the reasons a treatment may be futile are manifold, the focus should be on what the intended use of the treatment is, or ought to be, to determine usefulness. Contrary to Chwang's standpoint that defining utility is clear-cut and uncomplicated, a consensus definition of futility remains an elusive concept. Debate has continued within contemporary medicine for the last twenty-five years (Miller-Smith et al, 2019; Wilkinson & Savulescu, 2011). Attempts to differentiate between therapeutic and potentially clinically inappropriate care, non-beneficial treatments or medically inadvisable care are on-going (Larcher et al, 2015; GMC, 2010; Wilkinson & Savulescu, 2011). Yet, expressions of futility are relatively commonplace within health care settings such as "there is nothing more we can do", or "all we can do is keep him/her comfortable", (Gampel, 2006). Schneiderman (2011: 124), whilst acknowledging the debate itself is an ancient concept which can be traced back to the philosophical writings of Hippocrates and Plato, concurs that fundamentally the underpinning issues remain the same:

> *Should all treatments be undertaken, just because they are feasible? Should the desire for innovation and development mean that treatments unlikely to achieve the goals of medicine be attempted? What are the agreed goals of medicine? What happens when treatment does not achieve goals?* (Schneiderman, 2011:124).

Sokol (2013) suggests that, for physicians, tension exists as to how to balance their duty to benefit the patient (principle of beneficence), against their duty to do no harm (principle of non-maleficence). Skolol concedes that whilst any decision is underpinned by evaluation of available clinical evidence, when uncertainty exists, individual value judgements will be involved about what constitutes an acceptable risk and the benefits for the patient. However, by defining futility according to medical ideals, any decision-making ignores the social, psychological and spiritual dimensions of an individual's life.

2.2.1 Goals of treatment

Bailey (2004) suggests that establishing the patient's goals of treatment is vital and must occur prior to any consideration of futility. This requires a relationship between the family and HCPs to jointly discuss and determine treatment preferences based on the application of the principles of best interests, informed consent, substituted judgement, and possibly in the case of adults, advance directives (Miller et al, 2019; Larcher et al, 2015; Skolol, 2013; GMC 2010). The implications of the need for a broad and patient centered approach was also made explicit when the UK Supreme Court heard the case of *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC67. This case centred on an incapacitated adult patient who had endured a prolonged admission to ICU and whose treating physicians sought to limit treatment options on the grounds that such treatment was futile. The goal of medical treatment adopted by physicians was considered too high and narrow, when measured solely in terms of the prospect of curing or palliating the life threatening illness from which the patient was suffering. Lady Hale stated that consideration of the medical effects of the treatment were only part of the balancing of harms and benefits to the patient:

> " *decision-makers must look at his welfare in the widest sense, not just medical but social and psychological; they must consider the nature of the medical treatment in question, what it involves, the prospects of success; they must consider what the outcomes of the treatment for that patient is likely to be; and they must consult others who are looking after him or interested welfare, in particular for their view of what his attitude would be*." LJ Hale, *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC 67 para 39.

Furthermore, whilst a clear unambiguous plan of care should be negotiated, this needs as Lady Hale cautioned, to be sufficiently flexible to be modified according to the patient's condition.

2.2.2 Incidence of inappropriate or futile treatment

Debates about perceived futility or potentially inappropriate treatment are relatively common occurrences in the PICU. Breen, Abernethy, Abbott et al (2001) reported conflict in 48% of 102 adult ICU patients, the majority of conflict the result of disputes about the provision of life sustaining treatments. Studdert, et al (2003a) similarly reported that nearly half of 110 parents surveyed in an American PICU had experienced conflicts. Correspondingly, Forbat, Sayer, McNamee et al's (2016) report of conflict in a UK children's hospital, identified 136 individual episodes of conflict. The most common causes involved 'communication breakdown', 'disagreements about treatment' and 'unrealistic expectations'. Significantly, none of the above studies provided any statistics on the frequency of cases becoming intractable. Forbat et al (2016) and Larcher et al (2015) suggest that multi-partner dynamics may increase the scope for conflict in paediatrics. Yet, intractable disputes, with ostensibly irresolvable disagreement as to how to progress care, are seemingly rare. The majority of the time agreement about the best course of action is reached, with parents and professionals concurring (Miller-Smith et al, 2019; Birchley 2014). Nonetheless, if agreement cannot be secured, medical staff are neither legally nor ethically obligated to comply with patients' goals, and the courts will be asked to resolve the situation.

2.2.3 Attitudes towards technology and the concept of death

Radley (2002) acknowledged that the nature, diversity and pace of change in both health care delivery and society generally has altered how people think about not only their own health, but also others' health and, as a consequence, their expectations of health services and HCPs have been transformed. Clinical and technological advances in health care such as Extra-Corporeal Membranous Oxygenation (ECMO), High Frequency Oscillation Ventilation (HFOV), organ transplantation and gene therapy have brought about significant changes in people's views about the limits of health care and provoked thinking about moral and ethical aspects of such technologies. Zampretti, Bellomo, Dan & Ronco (2006) suggest that technology has effectively influenced every facet of the dying process, including frequently prolonging a death. Death is rarely unexpected in the PICU, technology enabling decisions and choices to be made in advance about how, when and where death occurs (Miller et al, 2019; Meert et al. 2016; Burns et al. 2014). Yet, whilst Zampretti et al (2006) state "*death is, and always will be, inevitable*" (p831), new technologies have cushioned the populace into believing that the goal of medicine is to defeat death.

Furthermore, exponential advances in internet and internet based technology, since commercialisation in the 1990s, has revolutionised access to information with parents and relatives actively seeking, evaluating and sharing experiences of health care (Thompson, 2016; Knapp, Madden , Marcu et al 2011; Wainstein, Sterling-Levis, Baker, et al 2006; Radley, 2002). Yardi, Caldwell, Barnes and Scott (2017) undertook a questionnaire survey to determine parents' online medical information-seeking behaviour in both in-patient and out-patient services at an Australian children's hospital. They identified that 90% of the 303 parents who responded, reported searching for information about their child's health. Of these, 96% accessed the internet, 63% using a smartphone. Yet, there is a very real danger that information on the internet can be biased towards more unusual or severe cases and therefore portrayals can be misleading and potentially alarming (Knapp et al, 2011). Strikingly, only 57% parents in Yardi et al's study ascertained whether an information source was reliable. No demographic data pertaining to the gender of participants in Yardi et al's study was provided, limiting insight as to any differences in maternal and paternal information seeking behaviours. Information about the patient is no longer the sole preserve of the health care professional and information proffered may not be accepted outright. Technology is transforming the delivery of health care and this has resulted in a change in the relationship dynamics between doctors and families (Chen et al 2018; Thompson, 2016) with relatives making more specific requests for, and on occasion demands, for treatments which HCPs may feel unable to provide (Miller-Smith et al 2019).

2.3 Defining futile treatment

2.3.1 Quantitative futility

Quantitative futility occurs where the likelihood that an intervention will be of benefit to the patient is extremely poor and therefore does not warrant attempting the intervention (Schneiderman, 2011; Gampel, 2006). This is not a value free or objective definition, since it is not proposing that there is absolute certainty, rather that it almost certainly not going to work. In 2015, a consensus statement issued by five American critical care societies, concluded that ‘futile’ should only be applied “*in the rare circumstances that an intervention … cannot accomplish the intended physiologic goal*” (Bosslet, Pope, Rubenfeld et al. 2015:1319), and that clinicians should not provide futile interventions. Concerns have been expressed about the status and quality of evidence used to make judgements. Unequivocal outcome data is, as Bailey (2004) recognises, generally unavailable resulting in HCPs frequently using experience to make decisions. Even when data are available, interpretation of findings is necessary, thus subjectivity is incurred. The implication of a futile treatment is that there is no longer a duty on the physician to provide treatment that is deemed futile. The question which then must be asked is how many times does an intervention have to fail, or how low the probability of success, before there is consensus that an intervention can be deemed futile?

Schneiderman and Jecker (1990) proposed that a quantitative threshold analogous to statistical evaluation is utilised whereby a value of either p=0.05 or p=0.01 is adopted, that is either a 5 in 100, or 1 in a 100 chance of treatment being beneficial. Although superficially persuasive, since 95% certainty may appear a high level of certainty, this is not without controversy since it highlights anxieties about being wrong 5% of the time and additionally how evidence accrued to support judgments is made (Bailey 2004). McCrary and Swanson (1994) reflected on the lack of consensus regarding the level a threshold for the percentage of probability of success should be set. The majority of doctors proposing anywhere between 1-10% coining the phrase “the elastic boundary of medical futility" (McCrary and Swanson, 1994). Setting a threshold unavoidably encompasses a value judgement about risk taking. As Miller-Smith et al (2019) acknowledge, there is a very fine balance between too narrow a definition, which only applies to a nominal number of cases, and too expansive a definition, which encompasses cases where treatment may not be completely ineffective. Unequivocal outcome data of ineffective treatment is rarely accessible in paediatrics. There is a paucity of high quality outcome studies undertaken, with Chwang (2009) identifying that if the converse argument of demonstrating that treatments are efficacious and indicated is applied to medicine, then it still would not be possible to tell which treatments are indicated.

HCPs' perceptions about the effectiveness of interventions are normally based upon clinical experience. Yet, it must be questioned as to whether these can be used to determine futility when high quality research studies are not available. Bailey (2004) cautions against relying solely on experience, given the widespread recognition that there is a tendency for staff to remember those who die following interventions and forget those that may have benefitted. Decisions could be challenged, as potentially being unilateral and founded on assertion. It is generally assumed that it will be HCPs involved in the patient's care, in particular physicians, who will make these decisions. Nonetheless, it must be contended as to whether they are the best qualified to decide. Two other possibilities emerge which will be discussed in greater depth in section 2.5: letting the patient or their surrogate decide; or letting society set the parameters.

2.3.2 Qualitative futility

Qualitative futility also encompasses the benefit to the patient. However, in this instance, the issue is not about the probability that a treatment may be effective, but that the intervention is harmful to the patient without a compensating benefit. In this situation life may be sustained, but there may well be medical consensus that there is no chance of recovery and that no meaningful goals can be accomplished (Schneiderman, 2011). For example, an infant with a terminal congenital syndrome, such as

Edward's syndrome. The use of medically inappropriate or potentially inappropriate treatment remains ambiguous. The American critical care societies consensus description acknowledges that there may be some chance of "*accomplishing the effect sought by the patient but clinicians believe … competing ethical considerations justify not providing them*" (Bosslet et al. 2015: 1319). The fundamental question then, is who has the authority to determine the harm/benefit ratio, whether a patient's life is worth living and on what grounds? In the majority of instances, agreement is secured between the health care team and the parents/surrogate decision maker (Miller-Smith et al 2019; Larcher et al 2015). However the question remains as to who has definitive judgement when conflict exists.

There are intrinsic weaknesses and dangers in allowing physicians the authority to make such evaluations since it infers that they have expertise in and an ability to make such judgements (Miller-Smith et al 2019; Veatch 2005). Questions must be raised as to what extent the physician's own values and beliefs will impinge on decisions made. What happens if their values and belief conflict with those of patients or surrogates? Undertaking a treatment considered by the individual clinician to be futile may contravene their professional integrity. Therefore, whether a patient receives treatment or not may be dependent upon who is treating them and result in a lottery of care. Additionally, this practice potentially leads to insidious misuse and discrimination. Would treatment be restricted depending upon sex, colour, religion, ethnicity, pre-existing illness, economic advantage/disadvantage? Many HCPs already perceive that they are responsible for rationing life-saving/life sustaining treatments (Bailey, 2004) and in this situation, covert rationing would be likely to occur. Initiation of futile interventions could be considered an imprudent use of finite health resources. Similarly, innovative and experimental treatments may not be able to be developed since without proven benefits they may be automatically referred to as futile.

The inherent difficulty with qualitative futility is that it is based on value judgments and/or on moral judgments. Therefore, some people may not consider interventions in such instances are futile. Unanimous agreement is impossible, different viewpoints exist on the sanctity and value of life both across and within groups defined by race, ethnicity, socio-economic status, religion, age etc. For individuals who disagree with HCPs, their unique circumstances and values need to be respected and accommodated. The difficulty however, lies in recognition of the limits of medicine. Not all treatments can or should be provided. The challenge is how to prevent what appear to be arbitrary decisions being made. Approaching futility in a non-paternalistic way may result in patients interpreting that their right to refuse treatment also suggests an entitlement to receive any treatment that they request (Bagheri, 2008). Although laudable, it is fundamentally flawed, since medical staff are neither ethically nor legally obliged to comply with a patient's wishes and therefore treatment can be withheld. An absolute right to treatment does not exist.

2.3.3 Vitalist interpretation of futility

Another definition relates to prolonging life whereby HCPs cannot declare a treatment futile as long as it is extending life, regardless of the quality of that life (Schneiderman, 2011). This vitalist perspective does not reflect the findings of Jacobs and Taylor (2005), who suggest, there is a 'line' that some people are not prepared to cross. If by prolonging life, an individual is unable to achieve a standard or quality of life (QoL) that the individual deems worth living, they would not choose that option: the inviolability of life. Prior to the contemporary era, it is doubtful that anyone could have postulated that the development of technologies could create states considered between life and death. Adopting the position that no action should be taken to shorten human life, irrespective of circumstances and condition, is at odds with traditional philosophical thinking and contravenes the Hippocratic Oath "*to restore health and alleviate suffering*" and the so called natural cycles of life and death. It also resonates with the relatively modern fear of being kept artificially alive through the use of technology which emerged during the medicalization discourse from the 1950s through the 1970s (Seymour, 1999). The increased use of advanced medical technologies has been portrayed as inappropriate, censured for the inhumane and undignified nature of contemporary death, (Moller 1990, 1996, Illich 1974, Kastenbaum, 1969). Yet, withdrawal of technological support has been suggested to imitate the gradual decline, which occurs during 'natural' death (Timmermans 1998; Seymour, 1997; Harvey 1997).

Attempts at defining futility within contemporary medical literature remain unsuccessful; quantitative futility exposes the debate surrounding the scientific status of evidence whereas qualitative futility is based on value judgments subject to pluralistic values and societal heterogeneity, (Miller-Smith et al 2019; Wellesley & Jenkins, 2009; Bailey, 2004).

2.4 Background principles

2.4.1 The function of law

Given the increasing complexity of decision-making in paediatric critical care settings, it is unsurprising that in a very small minority of cases the courts are asked to adjudicate when disputes arise between the family and HCPs. The English legal system is however intricate and complex. Primary legislation or statute is enacted by parliament. Although, when parliament elected to join the European Union it passed the power to make laws for the UK in certain defined areas such as free trade, market regulation and the free movement of workers. Case law comes from decisions made by the courts. It is implausible for primary legislation to encompass the nuanced complexity and variations in situations involving the withdrawal of treatment so courts interpret statute and apply precedents used to determine prior cases. Where case law and legislation conflict, legislation will take primacy.

English and European law uphold the principle of family privacy and parental autonomy. The law presumes the capacity and recognises the authority of adults to parent their children in accordance with their own preferences, beliefs and lifestyles (Human Rights Act, 1998 and Articles 5 & 18, UN Convention on the Rights of the Child, 1992). The supposition is that parents are best qualified to decide how to meet the needs of their children and how to protect their best interests. Usually, parents are invested legally with the proxy power by virtue of parental responsibilities to consent or refuse consent to medical treatment on behalf of their child (Children Act, 1989). Parents, with parental responsibility, have a duty in law as dictated by the 1933 Children and Young Persons Act to provide proper medical care for their child/children. Yet, this decision making power is only a partial power since parents can only consent to treatment that is in their child's best interests. While parents may choose to refuse treatment, they are likely to be overruled if refusal is not in the best interest of the child. As Heywood (2012) advances, the court retains a paternalistic protective approach to children's best interests enabling their own judgment to be substituted for that of the parent.

Non-legal communications, including paediatricians' opinions as to the right course of treatment, or economic perspectives about the cost effectiveness of interventions, or political or religious statements, may be referred to, and may influence, legal decisions. Nonetheless, these concepts must be recreated in a manner that allows them to make sense as law: that is, in ways that make the concept comprehensible as either lawful/unlawful. To do otherwise would result in an abandonment of legal criteria of whether a decision is legally valid. Such expert opinion may be introduced into the legal reasoning of the decision. Similarly, the legal communications produced inform society about what is lawful or unlawful and these can either be direct through judgments, or indirect. Indirect communications occur through reproductions by other systems, such as medicine, or the media, in ways that have meaning for them.

2.4.2 Presumption in favour of prolonging life

The sanctity of life is not disputed, since as established in *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 W.L.R. 1421 it would be unlawful to sanction steps to terminate a life; the court is only concerned with circumstances in which steps should not be taken to prolong life. This case involved a new-born Down's syndrome baby diagnosed with a life threatening intestinal obstruction, which could be cured by simple surgical intervention. The parents refused consent for surgery arguing the baby should be allowed to die, rather than live as a person with mental and physical disabilities. The Court of Appeal held that the life of a Down's syndrome child was such that the baby should not be allowed to die and the baby should have surgery and expect to live a normal span of life for a Down's syndrome person. There exists a predilection in favour for the preservation of life. This has more recently been reinforced within the case of *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC67 (Section 2.2.1, p11). Whilst the focus of this judgement relates to how to determine what is in a patient's best interests, Lady Hale held that the basis for determination is the strong presumption that it is in a person's best interests to remain alive. However, Lady Hale acknowledged that, from that starting point, every case is distinctive and different and must be considered uniquely.

2.4.3 Best interests standard

The law imposes an obligation to act with the sole purpose of advancing the child's interests. The Children Act 1989 s1 (1) states that "*the child's welfare is the court's paramount consideration*". Best interests is a term frequently applied, but not exclusively, to medical situations when clinical decision making may have implications for life, quality of life and death, and justification for actions may be sought (Woods, 2008). Lord Donaldson, in *Re J (A minor) (Wardship: Medical Treatment)* [1991] Fam. 33; [1991] 2 W.L.R. 140; [1990] 3 All E.R. 930, held that the role of the judge is to perform a balancing exercise when deciding whether to give or withhold consent, affording presumption in favour of prolonging life (the desire to survive), but also taking into account the child's pain, suffering, quality of life and the burdens of proposed treatment. The court considers the sanctity of life from the perspective of the child and not from the point of view of the parent/decision maker. This allows consideration of a quality of life which others may find intolerable, *Re T* [1992] 3 W.L.R. 782 [1993] Fam. 95 per Lord Donaldson at [1993] Fam. 95, 112, F-G.

> "*I consider the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment and decide whether in all circumstances such a life would be so*

> *afflicted as to be intolerable to that child. I say 'to that child' because the test should not be whether the life would be intolerable to the decider. The test must be whether the child in question, if capable of exercising sound judgment, would consider the life tolerable*" Taylor LJ in *Re J (A minor) (Wardship: Medical Treatment)* [1991] Fam. 33 p55

In practice, things are less clear and practically indeterminate, because how can we ever know in these incredibly complex and rarefied situations what the child would decide. Nonetheless, there is increasing recognition that children with complex care needs are capable of participating meaningfully in advance decision making, but their expressions may not always be effectively interpreted (Carnevale, Teachman & Bogassain 2017; Earle et al 2006) How capable are the judiciary or clinicians or parents of representing a viewpoint? There is an assumption that the best interests of a child can be recognized (Huxtable, 2018). As Goldstein (1994) observes, medical staff can, as a consequence of their training, make recommendations about preferred treatments and signpost about possible outcomes. However, this does not qualify them, or correspondingly judges, to impose their preferred value choice about what is appropriate and beneficial for the child and their family. HCPs and the courts frequently have uncertain knowledge of possible outcomes and probability of outcome underlining both the subjective and objective elements.

Intensive care interventions can and do inflict burdens on persons (Pollack, Holubkov, Funai et al 2014; Knoester, Bronner and Bos, 2008), that some may rationally decline. Consideration of withdrawal of treatment necessitates a qualitative judgment, involving quality of life issues pertaining to the burdens of treatment. There has been growing concern about the iatrogenic harm of medical interventions in paediatric intensive care medicine. Increasingly, contemporary research has broadened in focus to incorporate minimizing physical and psychological morbidity (Manning, Neethi, Rennick et al., 2018; Ong, Lee, Leow et al., 2016; Pollack et al 2014; Colville & Pierce, 2012). It also highlights the question at what point in the scale of suffering and disability does the best interests of the child result in bringing to an end treatment.

The concept of intolerability and 'best interests' test was further scrutinized by Dame Butler-Sloss LJ in the case of *L (A Child) (Medical Treatment: Benefit)* Re [2004] EWHC 2713 (Fam); [2005] 1 F.L.R. 491. L, aged 9 months, was born with trisonomy 18, Edwards Syndrome. As a result of this, he suffered with multiple cardiac defects, chronic respiratory failure, gastroesophageal reflux, severe developmental delay, epilepsy and hypertonia. L had remained in hospital since birth and suffered cardiac and respiratory arrests on numerous occasions and lesser episodes of oxygen desaturation on an almost daily basis. Medical consensus was that his condition was incurable. Children with Edwards Syndrome seldom live beyond one year (Wu, Springett & Morris 2013). L's mother did not wish the possibility of mechanical ventilation to be excluded in an emergency. The mother and NHSTrust were unable to agree and the High Court therefore was asked to decide. Butler-Sloss LJ asserted the test of 'best interests' should be the test invoked and that 'best interests' includes not only medical interests but also emotional and other factors. The advantages and disadvantages of giving or not giving potential treatment(s) weighed against wider aspects of the overall welfare of the child. Dame Butler-Sloss in *Re L* chose to focus on best interests, rather than intolerability, although recognising that the latter may be encompassed within the former. The Court of Appeal in *Portsmouth NHS Trust v Wyatt* [2005] EWCA Civ. 1181; [2005] 1 W.L.R. 3995 approved Dame Butler-Sloss's decision having revisited *Re B* and *Re J*. It was concluded that,

> "*a best interests 'test' based on the intolerability of the child's quality of life has its origins in (1) extempore dicta in Re B not approved by the majority in Re J and (2) in only one of the three judgments in Re J. In our view, this supports the proposition that Hedley J was right to observe the concept of 'intolerable to the child' should not be seen as a gloss on, much less a supplementary test to, best interests. It is as the judge observed,*

> *a valuable guide in the search for best interests in this kind of case.*" LJ Wall: Para76

The best interests test is further developed in *Re Wyatt*. Charlotte Wyatt was born at 26 weeks gestation weighing 458g. As a consequence of her prematurity, she developed chronic respiratory and kidney problems together with profound brain damage that left her blind, deaf and incapable of voluntary response or movement. Unanimous medical opinion was that should her condition deteriorate, that it would not be in Charlotte's best interests to provide artificial ventilation. The legal case focused on what should happen if Charlotte's condition deteriorated and was unable to be treated without the use of mechanical ventilation. *Re Wyatt* further expands upon Lord Donaldson's original mention of best interests being a balancing exercise, by recommending the use of a balance sheet of benefits and dis-benefits to judge the quality of life a child would have to endure. Such a balancing exercise is inevitably an intangible and subjective concept. Interests are seldom perceived as positive or negative, rather more or less significant. Of particular note is Dame Butler Sloss's reference to Thorpe LJ at *Re A (Male Sterilisation)* [2000] FLR 549 at 560, "*only if the account is in relatively significant credit will the judge conclude that the application is likely to advance the best interests of the claimant*." This intimates that it is not simply a balancing exercise, also inferring that there is a presumption in favour of the continuation of life. However, this presumption is not unambiguous since best interests may be the best outcome for the child in light of what is presented and available.

2.5 Autonomy in decision making

Autonomy derives from the Greek auto (self) and nomos (governance) and described the right of Greek city states to be self-governing. While this thesis is concerned with autonomy in the limited sphere of decisions about treatment within the PICU setting, the principle of autonomy is based primarily upon respect for an individual who has decision-making capacity to be free to make decisions regarding their care. Beauchamp and Childress (2013) advise that autonomy requires both liberty (independence from controlling influences such as coercion, persuasion and manipulation) and agency (capacity for intentional action). The futility debate has emphasised the changing relationship between healthcare professionals and patients. Medicine has undergone a paradigm shift. Until relatively recently, the late 1970s, early 1980s, the vast majority of medical decisions were undertaken by physicians acting with beneficent intent (Bagheri, 2008). It was accepted that doctors would utilise their specialist knowledge and skills, including making unilateral decisions, for the benefit of the individual patient (Chin, 2002). Pilnick & Dingwall (2011) acknowledge that Western countries are no longer accepting of such a paternalistic[2] approach, increasing attribution of the value of patient autonomy and self-determination, within both the legal system and society as a whole, having overshadowed medical benevolence. Patient autonomy is about creating the conditions to enable individuals to control the care situation by providing information to enable informed choices and respecting decisions made. Patient-centred care and autonomy can be simplistically portrayed, as counter to medical paternalism, whereas in clinical practice the choice may not be about the adoption of either approach but seeking a balance that enables successful information exchange and decision-making. Nevertheless, the intrinsic nature of the relationship remains fiduciary. Fiduciary applies to any situation whereby a person's lack of knowledge forces them to justifiably place confidence and trust in someone else, in this context the HCP, and seeks that person's help or advice. Therefore, it must be questioned whether medical paternalism does serve the best interest of the patient, especially when the patient is a child.

2.5.1 Parental autonomy

Preferences regarding the degree of involvement in a care situation are highly individual and variable (Gillam and Sullivan, 2011, McHaffie 2001;

---

[2] Paternalism in this context is framed as involving an interference with the autonomy of the person subject to the paternalism, i.e. the patient or surrogate who is involved in making these difficult health care decisions. This interference is done without the knowledge of the person, but is undertaken with the intention of benefitting the person interfered with.

Anspach 1993). As Swenson et al (2004) acknowledge, some may be active participants whilst others may be content to allow doctors to make decisions on their behalf. Individual differences may vary according to age, gender, culture, level of education, experience of illness and severity of the illness/disease (Ryan & Sisko, 2007). Paternalism, whilst often depicted as undesirable asymmetry in doctor/patient interactions (Pilnick & Dingwall, 2011; Lee & Lin, 2010; Perakyla, 2006), is argued by Horne et al (2005) to be fundamental to the NHS or any health care system where access is controlled and justified by recourse to the public good. Horne postulates that the accountability renders the potential for patients to influence treatment inevitably limited.

It can be argued that some parents are less well equipped to understand complex medical issues. This does not however mean that they are incapable of understanding and participating in decision-making (Madrigal, Carroll, Hexem et al, 2012). Likewise, they may hear selectively when given bad news. Butler-Sloss LJ in *L (A Child) (Medical Treatment: Benefit)* Re [2004] EWHC 2713 (Fam); [2005] 1 F.L.R. 491 while acknowledging the case has brought a mother into conflict with professional teams, states:

> "*the mother must accept the clinical judgment of the doctors who are caring for her child…. It is the duty of the mother, for the sake of L., to reduce those areas of conflict to a minimum, and to listen to what is proposed by those who have a great deal of medical and nursing experience*." Para 31

Similarly, the case of *An NHS Trust V MB* [2006] EWHC 507 (Fam) additionally emphasises the very real difficulty parents face in accepting the inevitability and need to withdraw life sustaining treatments.

2.5.2 Parents making tragic choices

Botti Orfali and Iyengar (2009) questioned whether it is preferable for parents or medical staff to make decisions about end of life care. They undertook 19 qualitative in-depth interviews with American and French parents who had infants in Neonatal Intensive Care Units. Of the 19 parents interviewed, 17 interviews were undertaken solely with mothers, 9 in the USA and 8 in France. Only 2 interviews in France, were conducted jointly with both mother and father thus limiting generalisation across genders. Parental experiences, predominantly drawn from this maternal perspective, were similar, the participants being confronted by choices of whether to continue or interrupt their babies' life sustaining treatment, resulting in the baby dying. The decision model in both countries varies; France where the paternalistic model, with decisions made by physicians on behalf of the parents, continues to dominate and America where a more autonomous model, with parents actively involved in the decision-making is adopted.

Findings from the qualitative studies found that mothers who made choices were confident that the best decisions had been made. However, in spite of this higher confidence, they also expressed more negative emotions than those who did not choose. American mothers wished they had not experienced the psychological burden of choosing, while for French parents the lack of active choice appeared to lessen psychological anguish. Of particular significance is that both groups were ambivalent towards decision autonomy. Botti et al. identify, that whilst parents wished to be involved in decision-making, they did not wish to have the burden of choosing to withdraw LSMT. This predilection for relinquishing decision making to doctors appears to conflict with the prevailing perception for increased patient autonomy[3]. The desire to be an active participant may not extend to highly consequential choices, which involve perceived responsibility and potential feelings of guilt and regret. Nonetheless, the lack of paternal participation may have skewed this finding.

Botti et al. additionally undertook experiments with 177 university undergraduates, using a vignette analogous to the real life context

---

[3] It is acknowledged that in this context autonomy is parental autonomy, which is the displaced autonomy of the child. The Children Act 1989 gives parents parental responsibility for their child. This enables parents to take decisions on behalf of their child until the child gains sufficient maturity and understanding to be able to make decisions for themselves.

described in the interviews. Findings from the experiments were similar to the in-depth analysis of the interviews. Those not having to make a decision experienced a less affective response, whereas those required to choose expressed more confidence about the decision made. Participants again were ambivalent towards decision autonomy, disliking having to make decisions but also not wanting to relinquish decisions to the medical staff. Significantly, when withdrawal of treatment was proposed as the “right thing to do” participants were able to distance themselves from the choice and experienced fewer emotional affects.

Findings from both the qualitative and experimental studies have ramifications in terms of participatory and shared decision making within the critical care context. Autonomy in decision-making may not be beneficial for the lay population as a whole with greater involvement potentially resulting in increased psychological burdens for some. Fuedtner, Schall & Hill (2018) postulate that parental involvement in difficult decision-making is oversimplified with decisions presented as discrete singular acts, whereas the reality in the critical care setting is a series of decisions. Decision-making being recurrent and sequential. Each new decision predicated by choices previously made.

It is known that the emotional stress of admission to PICU detrimentally impairs parental capacity to participate in decision-making and the lack of a clear trajectory can be confusing (Butler, Hall, and Copnell, 2018; Ames, Renwick & Baillargeon, 2013; Madrigal et al, 2012). Decisional involvement is not static and can fluctuate, throughout the course of an illness (Popejoy, Pollock, Almack et al, 2017; Madrigal & Patterson, 2018). Weiss, Barg, Cook, et al (2016) identified that parents in NICU demonstrated a preference to delegate decision making when there was high degree of urgency and a high level of medical expertise required. Notably, although these studies refer to parents preferences, analysis of demographic data demonstrates that maternal perspectives predominate throughout the literature. Maternal participation rates varied from 70% of all respondents in Butler et al’s and Ames et al’s studies to 83% in Weiss et al’s study. Limited paternal participation may mean that the decision delegation may be unrepresentative, further exploration of paternal perspectives warranted.

There is a strong argument to support the final decision being made by the parents, since they have to live with the consequences. No judge or doctor has to assume personal responsibility for the day-to-day care the child may require as a consequence of their personal preference for a style of living. The experience of being involved in caring for a child who has had treatment withheld and or withdrawn has been demonstrated to have deleterious effects on family members general and mental health and well-being (Aspesberro, Mangione-Smith and Zimmerman, 2015; Knoester, Grootenhuis, Bos, 2007; McHaffie, 2001). Some families do prefer a more passive role ‘following the path of least resistance’ and will not wish to make the decision (Madrigal & Patterson, 2018). Yet, one of the strongest drivers for the provision of futile care is purported to be HCPs following the ‘path of least resistance’ perhaps out of respect for the family’s wishes, or it may be driven by a fear of litigation either malpractice or common law challenge to the medical assessment of futility (0’Connor et al, 2011).

Additionally, society has changed with the advent of internet technologies, parents are becoming more vocal and involved in resolving these dilemmas (Thompson, 2016; McKlindon, Jacobson & Nathanson, 2016). The core issue is how HCPs move to a shared or negotiated decision-making approach, thus correcting perceived imbalance of power. Acting in the best interests of the patient must regardless remain paramount, since the rise of enhanced autonomy must be balanced against the known harm that can arise from futile care.

2.5.3 HCPs’ autonomy

As previously alluded to, a central tenet of medicine is a belief in beneficence. It is accepted that healthcare professionals must act in the best interests of their patients, with the welfare of the child paramount.

The difficulty is that there are at least two interpretations of best interests within the context of paediatric critical care, the doctors’ and the parents’.

This may well result in different perceptions and possible conflict about what are the best interests of the child. Where HCPs believe that they know what is in the best interests of the child, there is a very real danger that they may override the parents by withholding information, thus preventing them from effectively participating in decision-making. Although presumptively wrong, but possibly not always actually wrong, the question of whether or not to tell the truth is shrouded in uncertainty as to what is the truth. As previously explicated, diagnosis and prognosis cannot be made with absolute certitude, at times being little more than educated guesses.

Similarly, whilst Heywood (2012) suggests the majority of parent's views pertaining to care and treatment are respected, parents may be led into making this decision through a process of "guided paternalism" (Shaw, Stokoe, Gallagher et al, 2016; deVos, Bos, Plotz et al 2015; Quill & Brody, 1996). Whilst the intention of medical staff may be to encourage patient autonomy, the final decision resting with the parents, the medical staff may assist the outcome by discussing not only what choices are available but also by offering opinion as to what should be done (Geoghegan, Oulton, Bull et al, 2016a; Shaw et al 2016; Shudy et al, 2006; Quill & Brody, 1996). Still, it is the parents who will ultimately have to either accept or delegate responsibility for the choice and live with the consequences of the decision. HCPs in this situation may seek approval from the courts for actions. Continued judicial deference to medical opinion (Birchley, 2010; Quigley, 2008) may further create an asymmetry in the balance of power between parents, medical staff and the courts thus limiting application of this criterion. Though, in the case of *Re T (A minor) (Wardship: Medical Treatment)* [1997] 1 WLR 242 the parents of a young child with a diagnosis of biliary atresia refused a liver transplant, as they felt it was not in the child's best interests. Health professionals caring for the child made attempts to persuade the parents to consent to surgery. This included seeking an independent second opinion from a consultant paediatrician. Despite medical opinion being unanimously in favour of surgery, the Court of Appeal accepted the parent's argument.

This is a distinctive case, not replicated in the ensuing twenty plus years, of the courts siding with the parents. It highlights, as cited by the Judges, the fact specific uniqueness of each case and the need for parents to be provided with full information.

The concept of enhanced autonomy is built on the principles of doctor-patient/surrogate dialogue, exchange of views and negotiation of differences for the purpose of acting in the best interests of the child. There needs to be recognition that HCPs can and do provide informed advice whilst respecting the family's wishes. In the case of *OT, Re* [2009] EWHC 633 (Fam) OT, aged ten months, suffered from a genetic mitochondrial disorder and had been ventilator dependent since admission to hospital aged three weeks. He had sustained severe and irreparable brain damage which prevented him from breathing spontaneously and he also suffered from fits and abnormal movements. The unanimous medical evidence presented was that OT was likely to suffer further strokes, which would further damage and destroy parts of his brain. OT was clearly distressed and experienced pain as a consequence of medical interventions, namely frequent airway suctioning. It had become apparent in January 2009 that the medical staff views of treatment conflicted with parents, OT's father having made explicit that the parents would not agree to any withdrawal of artificial ventilation. The parents had previously rejected the findings of three independent consultants not involved in OT's care and who concurred with his medical team that his condition was serious, progressive and decline inevitable. Although the parents were offered opportunity to seek second opinions for themselves, no reports were ever submitted to the court. It was determined that the parents had opportunity to seek additional medical opinions both before and during the court case.

In some respects, it could be argued that medical staff are better placed than the courts to make such decisions since they have the benefit of clinical experience, are likely to have built relationships, and understand the context of decisions. HCPs, like judges, should be able to take into account all necessary factors when considering a decision. Whether the judiciary is better able to determine the best course of treatment is open to contention. However, it could equally be argued that judges review the facts of the case as it appears before them and do not merely accept medical staff opinion. Doubts nonetheless persist as to just how deeply the courts seek substantiation outside medical evidence (Heywood, 2012). Quigley (2008) suggests that while the judiciary is less deferential to the health professions than previously it is vital to protect against shifting power solely from medical professionals to the judiciary. To do so may result in a narrow interpretation of best interests and a danger that the role of doctors is to put forward a range of options for the courts to decide which is the best option.

2.5.4 Determining the extent to which the law should supervene parental rights and obligations.

Generally, HCPs will defer to parental wishes and medical staff must obtain the consent of a person with parental responsibility if treatment is to be provided. However, the choices of parents may come into conflict with HCPs. There may be disagreement about what truly is in the child's best interests, or there may be a conflict of principles, or there may be a lack of resources. If consent is withheld the doctor must not perform a procedure since to do so would constitute a trespass and unlawful assault upon the child. Nevertheless, this power must be exercised reasonably in the best interests of their child. Where HCPs consider that the best interests of the child are not being upheld the courts may be involved. Similarly, whenever there is any serious disagreement about how the best interests of a child are upheld the law has a role. Nonetheless, it must be remembered that the vast majority of 'best interest' determinations occur not in the courts, but in PICU and they are made as Foster (2005:1241) states "*not by detached judges, but by harassed clinicians and distraught parents*." Birchley, Gooberman-Hill, Deans, Fraser and Huxtable's (2017) study exploring decision-making in the PICU identified that professionals had little experience of escalating disputes about best interests to the courts. They found that professionals avoided doing so, due to perceptions of the arbitrary nature of judicial review. Additionally, as Huxtable (2018) highlights the costs for all parties, including financial, emotional, and ongoing professional and parental relationships can be immense and may further explain reluctance to seek recourse to the courts.

Whenever it is called upon to intervene, the role of the court must be explicit. Lord Donaldson defined the relationship between the court, the doctors, the child and the parents in *Re J (A minor) (Wardship: Medical Treatment)* [1990] 3 All E.R. 930. Lord Donaldson held:

> "*The Doctors owe the child a duty to care for it in accordance with good medical practice recognised as appropriate by a competent body of professional opinion (Bolam v. Friern Hospital Management Committee [1957] 1 W.L.R. 582. This duty, is however, subject to the qualification that, if time permits, they must obtain the consent of the parents before undertaking serious invasive treatment.*
>
> *The parents owe the child a duty to give or withhold consent in the best interests of the child and without regard to their own interests.*
>
> *The courts when exercising the parens patriae jurisdiction takes over the rights and duties of parents, although this is not to say that the parents will be excluded from the decision making process.*" p41C&D

However, the ultimate responsibility to give or withhold consent lies with the court alone. The only difference for a child who is a ward of court is that it is the court, as opposed to the parents, provides or withholds consent. The child should be treated medically exactly the same as one who is not. Although this provides clarification about the role of the court, it nonetheless must be questioned as to when and under what conditions should the state have the right to intervene and itself become the 'parent'? Under what circumstances should parental decisions about a child's health and medical care be examined? And, what conditions permit the courts to replace parental rights and autonomy?

As has already been established, there is a lack of consensus about what constitutes futile treatment, what interventions or therapies are appropriate. The role of law has been clarified in the Supreme Court, *Aintree University Hospitals NHS Foundation Trust v James* [2013] UKSC67. Lady Hale demonstrated clear judicial recognition of the importance of decisions being taken through a broad and patient-centred understanding of best interests and futility, as opposed to paternalistic perspectives or for reasons of practical expediency. There is nonetheless, no societal consensus about what constitutes “a life worth living”. Consequently, the state generally operates a policy of minimum intervention. The legal system has neither the reserves nor the responsiveness to be an adequate substitute for all parents whose child may be subject to decisions about the withdrawal or withholding of treatment (Goldstein, 1994). Even if this were not the case, there is nothing to suggest that judgments would be any better, or in actual fact as good, as those decisions made by parents. It can however be postulated that judges involved in making decisions about the withdrawal of treatment in children do amass considerable experience and expertise. Therefore, they are presumably better able, with considerable medical input in the form of evidence before the court, to review individual cases objectively.

When conflict arises between parents and healthcare professionals there is a real danger that the legal system is perceived within modern society to be omnipotent and possessing the power to make a ‘right’ decision. Whilst the legal system itself may recognize that there may not necessarily be a ‘right’ answer, what the courts are obliged to establish is a lawful decision, which can then be implemented. Nonetheless, as King (2000:542) identifies going to the courts for dispute resolution offers no guarantee that the legally right decision will be what is best for that child and that legal decisions are “*notoriously prone to the personal predilections of judges*.” The judicial system is an adversarial system, where judges are provided with facts to make decisions. However, there exists a very real danger that parents may be overwhelmed and unable to assert their position due to a lack of both legal and medical knowledge.

2.5.5 Legal best interest versus family's best interests.

The Courts when making a decision focus on the best interests of the child. The test of best interests appears to be structured in such a manner that it tends to deny that the interests of those inextricably linked to the child, the child's parents and siblings, need to be taken into consideration in case law. Brazier (2003:109) doubts whether it is "*ever possible to divorce the interests of the individual from the interests of the carer*," underlining the need for more explicit discussion. Although superficially only taking the child's interests into question is child-centred, it must be contended that the interests of the child are intimately connected to parental interests (Birchley, 2010). Parents may suffer economic hardships as a consequence of a decision and similarly if parents have other children, their relationships and situation may also suffer. Adoption of a more relational view of interrelated interests would acknowledge parents as being essential to any calculation of best interests (Carnevale, Teachman & Bogassian, 2017; Heywood, 2012). Carnevale et al (2017) propose that a relational ethics framework to decision making should be adopted enabling all viewpoints to be recognized and listened to. By sharing ethically relevant concerns, greater understanding of the complexity of what is at stake for all involved is facilitated, misunderstandings can be clarified, differences in perspectives bridged and agreement of how to advance care secured (Carnevale et al, 2017). This process of rapprochement may, by considering the complex relational processes, avert conflict through a partnership approach to decision-making.

The Children Act 1989, identifies a range of statutory criteria, which must be considered by decision makers. These include the requirement to consult with those involved in the care of the young person and anyone interested in their welfare. Although parents are involved and able to express their wishes, with a shared decision-making approach advocated by the General Medial Council (2010), RCPCH (Larcher et al.

2015) and the courts in Re J (a minor) (wardship: medical treatment) [1991] Fam 33, they possess no legal authority to demand treatment. The limits of parental rights and responsibility, which relies on the best interest principle, has been recently challenged in both the Charlie Gard and Alfie Evans cases. The UK Supreme Court in *Re Charlie Gard (Permission to appeal)* Supreme Court Hearing, 19 June 2017 and European Court of Human Rights, *Gard v United Kingdom (Admissibility)* (39793/17) [2017] 6 WLUK 575; [2017] 2 F.L.R. 773; (2017) 157 B.M.L.R. 59; (2017) 65 E.H.R.R. SE9, rejected parental requests to appeal, reiterating that in all decisions concerning children, the child's interests must be paramount. The Gard case related to the rights of parents to take their son who had been diagnosed with a rare genetic disorder, that had caused progressive and irreversible brain damage, to the USA for treatment. Alfie Evans similarly, had suffered irreversible brain damage, having been diagnosed with a degenerative neurological disorder shortly after birth. The Alfie Evans case also concerned parents wanting to take their child abroad for treatment also went to the Court of Appeal *Re E (A Child)* [2018] EWCA Civ 550; [2018] 3 WLUK 120 whereby the High Court decision not to treat Alfie was upheld. Permission to appeal was sought on the grounds of a failure to weigh parental views in the best interest decision, argued as a consequential breach of Articles 8 and 14 of European Convention Human Rights. The Court of Appeal upheld the High Court judgement, that the decision not to provide treatment did not contravene parental rights to have their own views in the best interests decision. This too was followed by refusal to allow an appeal by the *Supreme Court Evans v Alder Hey Children's NHS Foundation Trust* [2018] EWCA Civ 984; [2018] 4 WLUK 432 which reiterated the supremacy of the best interest approach.

2.5.6 The right to demand treatment

In *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 W.L.R. 1421 Lord Donaldson commented that neither parents, nor the court can insist upon doctors adopting treatment "*which they could not conscientiously administer*" i.e. against their professional judgment. The interpretation is that treatment cannot be dictated but should be jointly determined between the doctors and parents or the court. However, the extent to which this is or can be a joint decision is limited by the above veto Lord Donaldson afforded doctors. This could be interpreted that doctors' decisions are protected by the courts, however, the requirement by the courts for the paramount consideration to be the best interests of the child undermines such.

The issue of courts mandating treatment also arose in R*e J (A Minor) (Child in Care: Medical Treatment)* [1992] 3 W.L.R. 507. Lord Donaldson, at the appellate court hearing, could not envisage any circumstances in which the court would require a doctor to administer treatment which in the bona fide clinical judgment of the practitioner is contra-indicated as not being in the best interest of the patient going so far as to say that this would be

> "*an abuse of power as directly or indirectly requiring the practitioner to act contrary to the fundamental duty which he owes to his patient. This, subject to obtaining any necessary consent, is to treat the patient in accordance with his own best clinical judgment, notwithstanding that other practitioners who are not called upon to treat the child may have formed quite a different judgment or that the court, acting on expert evidence, may disagree with him*". p27A

Although the legal principle is to accept variation in practice, agreement between different members of a complex network of care may be hard to secure. The law nonetheless insists on a minimum standard of care, and if doing one's best does not meet this standard, there will be liability as determined in *Wilsher v Essex Area Health Authority* [1986] 3 All ER 801. In this case, a premature neonate, during the course of admission was subject to medical procedures where a breach of duty occurred. As Leggatt LJ iterated, the courts have not given doctors a new right, merely the court has chosen not to deprive them of the power of clinical judgment. This potentially makes it incredibly difficult for parents to challenge professional opinion and brings into question the role of medical evidence and use of expert witnesses.

In the case of *R v Cambridge HA ex parte B* [1995] 1 WLR 898, F.L.R. 1055, 2 All E.R. 129 Bingham MR reiterates that the courts are:

> "*not arbiters as to the merits of cases of this kind. Were we to express opinions as to the likelihood of the effectiveness of medical treatment, or as to the merits of medical judgment, then we would be straying from the sphere under which our constitution is accorded to us*". p905B

This case, which involved a ten year old girl, who was suffering from leukaemia, highlights the difficulty of making rational and reasoned choices involving clinical effectiveness particularly when the media becomes involved. The child, B, had originally been diagnosed with acute lymphoblastic leukaemia aged five years and received a bone marrow transplant. She relapsed with acute myeloid leukaemia aged ten years and her father was advised she had a matter of weeks to live. NHS consultants did not consider intensive treatment with a third course of chemotherapy and second bone marrow transplant to be in her best interests, due to the very poor likelihood of success and the unpleasant nature of the treatment. The case drew attention to the individualistic nature of professional opinions and the conundrum of how to manage differences between professionals and the issue of whether it was in Child B's best interests to rely on the overwhelming medical opinion of the day. The case underlines the involvedness courts face in unravelling professional autonomy and the role of clinical judgment vs parents. It also underscores an obligation on the part of courts to resist the temptation of upholding an individual doctor's personal preference. The case highlights the difficulties when medical opinions differ as to clinical effectiveness and therapeutic benefits of proposed treatments especially when undertaking treatment of an experimental nature. It additionally highlights the dilemmas in terms of cost to the patient and allocation of finite resources. Moreover, the apparent reluctance of the law to intervene and impose treatments can give the impression to the general public that the courts act in collusion with medicine. Increasingly commonly in these terribly difficult circumstances, when there is disagreement between parents and clinicians, treating doctors together with the legal system have been subject to “trial by public opinion” on a global level (Hammond Browning, 2017: Wilkinson, 2016). Whilst there is a need for public debate of some of the ethical issues raised within Charlie Gard and Alfie Evans cases, including access to experimental treatments and rationing of healthcare, the manner in which it has been conducted has generated concern. The use of media reporting, especially targeted social media campaigns, interventions by religious and political leaders have all challenged the role of the law as an arbiter in ensuing that a child’s best interests remain the paramount concern (Wilkinson, 2017). Nevertheless, the need for openness and transparency in decision-making in these difficult and sometimes controversial cases is vital.

2.6 Making the decision

Difficult decision making within the PICU is a truly complex endeavour comprising a multiplicity of involved participants, parents and HCPs trying to secure agreement. Decision-making is multifaceted and influenced by the entire clinical encounter. Whilst theories of decision-making may not provide adequate explanation for choices made, an overview of some of the main theories of decision-making are explored to provide insight into how individuals may choose different courses of action.

2.6.1 Dual process theory

Individuals are highly selective about what information is useful and can be attended to, especially within high stress environments such as the PICU (Meert, Eggly, Pollack et al, 2008). Extensive research, emerging from studies into human psychology during the 1970’s and 1980’s postulated that there are two distinct systems involved in decision-making with a clear distinction made between intuitive and deliberative processes (Frankish, 2010). System 1 decisions are described as fast, automatic, intuitive (emotive decisions) whereas system 2 decisions are rule-based, analytical, deliberative or reflective (conscious) decisions (Stanovich & West, 2000). Chen & Chaiken (1999) suggested that system 1 heuristic decisions are made first, but if this fails to provide a ‘good enough’ decision then system 2 information-processing will be adopted. However, rather than a unitary system of decision-making, current thinking proposes a dynamic interaction between the two systems along a continuum (Mukherjee 2010; Hammond 1996). Complex thinking is influenced by many factors including the options being proposed, risks involved, time pressures, individual values attitudes and beliefs, access to information, and any conflict between the two systems. The implications of heuristic influences on decision making within the context of the PICU are that for some personalities, more information and more choice may not always be better or helpful. Empirical evidence exists that for some parents, they are better able to cope when presented with a restricted selection of options (Stivers et al 2005). Chen & Chaiken (1999) posited that people may adopt a satisficing approach to decision-making, decisions made under the principle of ‘least effort’. Once, a ‘good enough’ decision has been identified which satisfies relevant purposes, then the search for alternatives is suspended.

2.6.2 Decision making in conditions of uncertainty: prospect theory.

Tversky and Kahneman (1972,1992) conceived and refined prospect theory, which sought to describe how people make decisions when experiencing conditions of uncertainty and risk. They suggested that when faced with a decision people make a mental representation or model of the problem, subconsciously and uniquely framing information received together with their own distinct contextual interpretation of the decision to be made. This means that decisions or choices made about the same problem may be paradoxical, varying according to how each individual perceives, shapes and interprets information (Soman 2004; Kahnemann and Tversky, 1982). Whilst framing is a subconscious process, it can be manipulated, either intentionally or unintentionally. Manipulation can occur by the way the problem is portrayed and how information about options, including advantages and disadvantages are presented (Richards Starks, O'Connor et al. et al 2018; Shaw et al 2016). Tversky and Kahneman propose that people make optimal decisions in real world settings by evaluating potential losses and gains, as opposed to the final outcome of the decision. The effects of emotion may well be separate and incompatible with assessments of value and balancing or weighing choices. They further suggest people will take greater risks to avoid loss. Beresford & Sloper (2008) suggest that this can result in a reluctance to make choices or decisions between options. Decision avoidance may mean that loss can be avoided, albeit temporarily, and could provide explanation for seemingly irrational decisions. Given the nature of the emotion-laden choices facing parents and professionals it is hardly surprising that decision avoidance may ensue (Payne & Bettman, 2004).

2.6.3 Clinical decision making

A central tenet of medicine is clinical or professional judgment which extends into assessment, diagnosis, treatment and decision-making, (Thornton, 2009). However, professional judgment is notoriously susceptible to error and bias, its reputation having come under increased scrutiny over recent years (Kienle and Kiene, 2011). All decision-making is to varying extents an uncertain business and even in areas of vagueness, such as determining futile treatment, some decisions are clearly better than others. Traditionally, decision-making has been the role of the medical professional (Heywood, 2012; Goethals et al 2010; Coombs and Ersser 2004), consultants in charge of patients' care being legally accountable for treatment. Doctors, having built relationships with the child and family, make clinical judgments based on knowledge and experience of the child and family's individual circumstances and background. Historically, both the validity and opinions of the medical profession have rarely been contested. Yet during the 1980s and 1990s as the study of bioethics gained momentum public scrutiny descended on autonomy in decision-making (Kuhse and Singer, 1985).

2.6.4 Professional judgement

Professional judgment relates to the proficiency and reasoning that individual clinicians acquire through clinical experience and practice. Sackett et al (1996) contend that professional judgment on its own is insufficient and that it must be used in conjunction with evidence based practice (EBP). EBP is defined as the conscientious, explicit and judicious use of best evidence in making decisions about the individual care of patients (Sackett et al 1996). The rise of EBP has played down the role of professional judgment in favour of technical rationality, based upon scientific principles and research methodologies (Lotz et al 2016: deVos et al 2015). This has resulted in the development of clinical guidelines and protocols (Thornton 2009). However, medical use of EBP does not consider how medicine is actually practiced and how decisions are made. Considerable variation exists across multiple individual decisions. Bate et al (2012), suggest that clinicians have access to so much potentially germane information that it is impossible to manage and therefore typically only a limited amount of information is utilised within the decision making process to enable a good enough decision to be made, an approach branded as ‘satisficing’. An integral element of such an approach is the use of tacit knowledge developed through custom and practice, personal experience and observation of others involving the development of internalized guidelines (Gabbay and Le May, 2004). As Kienle and Kiene (2011) acknowledge, clinicians make countless decisions using non-scientific knowledge for which they cannot provide adequate criteria or rationale. Professional judgment is non-objectifiable and consequently appears to have fallen into disrepute. Nevertheless, prudent use of a combination of evidence and clinical expertise, together with the needs and wishes of the patient are key to making better decisions.

2.6.5 Evidence based practice and the use of clinical guidelines

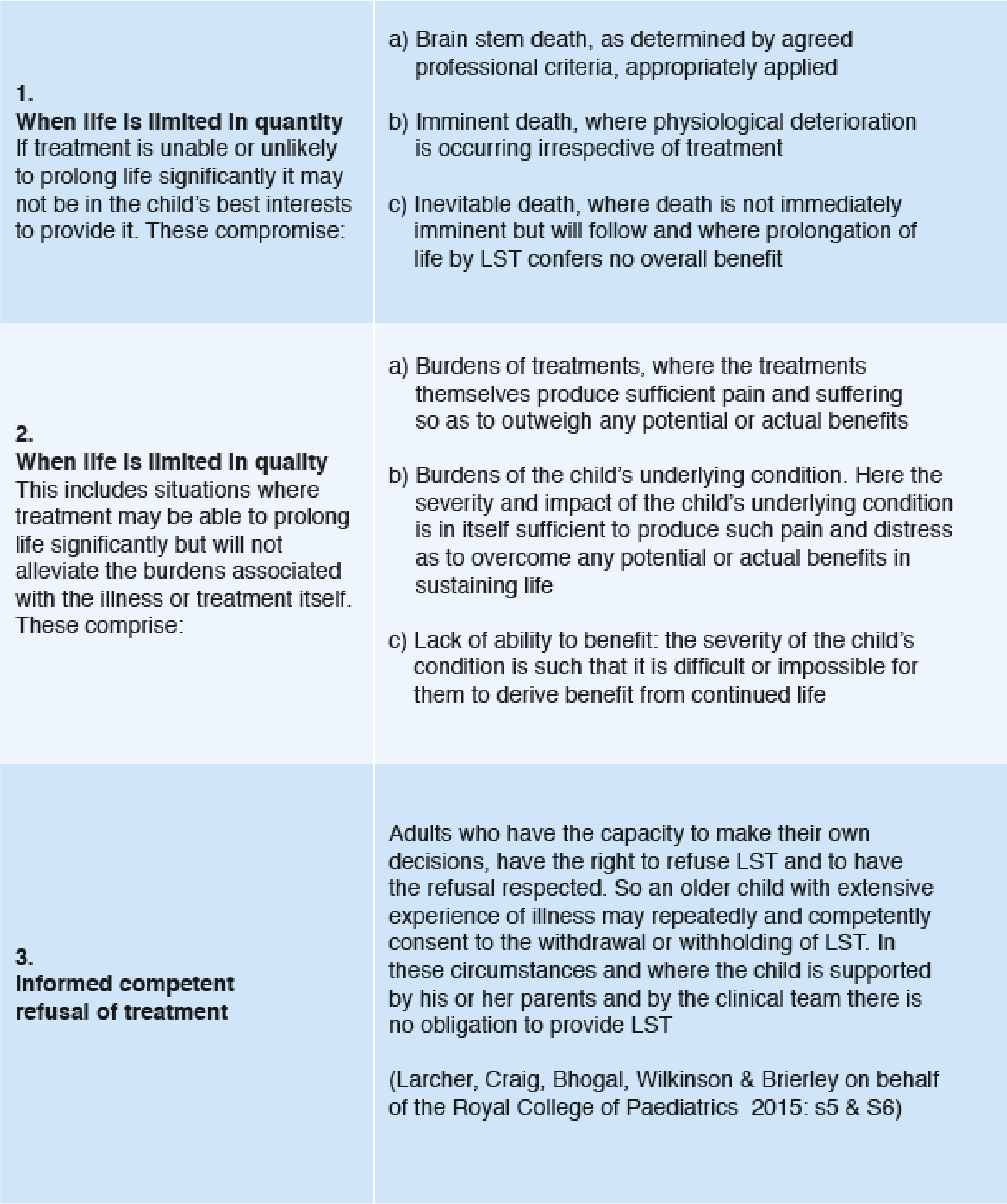
The debate surrounding futility has progressed from academic discussion and into public policy with the publication of practice guidelines. Clinical guidelines aim to reduce the problems of individual variation in clinical decision making by standardising care and formulating best practice (Eccles, Grimshaw, Shekelle et al. 2012; Timmermans, 2005). They are defined as systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances (Field and Lohr, 1990). Whilst consensus remains elusive, guidelines can establish standards for practice aimed at resolving conflicts and influencing judicial thinking.

The Royal College of Paediatrics and Child Health first published guidance on withholding or withdrawing life sustaining treatment in children practice in 1997, updated with a second edition in 2004. The latest guidance, in the form of a framework for practice was published in 2015 (Larcher et al. 2015). It is intended to provide clinicians with practical assistance, being based upon existing legislation and upholding the concept of the rights of the child about when it may be ethically permissible to withdraw or withhold treatment. The RCPCH considers that there are three sets of circumstances when treatment limitation can be considered, fully detailed in figure 1.

1. When life is limited in quantity
2. When life is limited in quality
3. Informed competent refusal of treatment. (Larcher et al 2015:s5 & S6).

Larcher et al (2015) outline that the framework is not intended as a narrow, rigid, inflexible tool. But they equally acknowledge that it is not feasible for a framework to capture all the nuances and idiosyncrasies that may occur. There remains a requirement to recognise the individuality of every patient and to acknowledge that guidelines are just guidelines, as opposed to criteria to be applied in every circumstance.

What the guidelines offer is an overarching framework, encompassing the professional, legal and ethical theories and principles including duty of care and partnership, legal duty, and respect for children’s rights. The guidelines are intended to enable HCPs to make more objective decisions. The utility of the RCPCH framework document is open to question. The 2015 guidelines explicitly acknowledge that ongoing audit



1. **When life is limited in quantity** If treatment is unable or unlikely to prolong life significantly it may not be in the child's best interests to provide it. These compromise:	a) Brain stem death, as determined by agreed professional criteria, appropriately applied b) Imminent death, where physiological deterioration is occurring irrespective of treatment c) Inevitable death, where death is not immediately imminent but will follow and where prolongation of life by LST confers no overall benefit
2. **When life is limited in quality** This includes situations where treatment may be able to prolong life significantly but will not alleviate the burdens associated with the illness or treatment itself. These comprise:	a) Burdens of treatments, where the treatments themselves produce sufficient pain and suffering so as to outweigh any potential or actual benefits b) Burdens of the child's underlying condition. Here the severity and impact of the child's underlying condition is in itself sufficient to produce such pain and distress as to overcome any potential or actual benefits in sustaining life c) Lack of ability to benefit: the severity of the child's condition is such that it is difficult or impossible for them to derive benefit from continued life
3. **Informed competent refusal of treatment**	Adults who have the capacity to make their own decisions, have the right to refuse LST and to have the refusal respected. So an older child with extensive experience of illness may repeatedly and competently consent to the withdrawal or withholding of LST. In these circumstances and where the child is supported by his or her parents and by the clinical team there is no obligation to provide LST (Larcher, Craig, Bhogal, Wilkinson & Brierley on behalf of the Royal College of Paediatrics 2015: s5 & S6)

Figure 1: The three set of circumstances which the RCPCH detail it is legal and ethical to consider treatment limitation (Larcher et al., 2015: s5 & s6).

of process is necessary to ensure that the physical and emotional needs of families considering decisions to limit LST are met. Street, Ashcroft, Henderson et al. (2000) identified during an audit study undertaken at a

Bristol Royal Hospital for Sick Children between January – July 1998, that although 17 out of 18 medical staff involved in making decisions about WLSMT were aware of the existence of the RCPCH (1997) guidelines only 12 had actually read them. Of those, four stated they were useful. Similarly, 8 out of 22 nursing respondents were aware of the RCPCH guidelines, but only two had read them, one stating they were useful in managing a specific case (Street et al. 2000). This connects with Timmerman's (2009) supposition that awareness of guidelines is poor and even when known there is little evidence to suggest that behaviours are changed, with individual clinical autonomy still taking precedence over clinical guidelines.

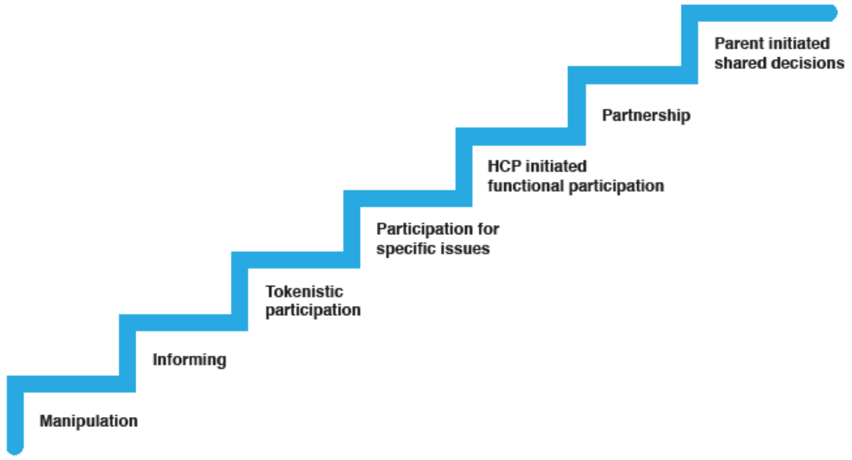
2.6.6 Shared decision making

Current thinking favours a shared decision making (SDM) model balancing patient autonomy with physician autonomy, a procedural approach vs empirical basis to decision making (Madrigal et al 2018; Birchley, 2014; Stewart, 2011; Sandman & Munthe 2010). Yet, while the ideologies of SDM are frequently espoused, application in practice remains ill-defined and subject to contention (Park & Choi, 2018; Munthe, Sandman & Cutas 2012; Birchley et al. 2017; Birchley 2014).

2.6.6.1 Parental participation in SDM

Traditionally, parental participation in SDM has been viewed as hierarchical according to the degree or amount of power transferred. Hart's ladder of participation (1995) whilst designed to reflect how authority and control is shared between adults and children, illustrates how participation is separated into eight different levels. The first four levels - manipulation, passive participation, participation by consultation, participation for specific issues - are effectually practices of non-participation. The later levels - HCP initiated functional participation, interactive participation and parent initiated shared decisions - allow progressive progression towards attaining full autonomy, with the HCPs present only in a supportive capacity. Repeated studies have demonstrated that while the majority of parents in PIC and neonatal critical care settings do wish to be involved in decision making, this can encompass a broad continuum of roles from autonomy to decision delegation (deVos et al 2015; Madrigal, Carroll, Hexem etal. 2012; Gillam& Sullivan 2011; McHaffie 2001; Anspach 1993). Parental capacity to participate in SDM to allow WLSMT requires knowledge, power to influence, reciprocity and mutuality, all at a time when their ability to think and function may well be distorted (Miller-Smith et al, 2019; Carnevale et al 2016; Latour, Van Goudever, Duivenvoorden et al 2011; Needle, O'Riordan & Smith 2009). In situations where there is uncertainty in determining treatment goals, proponents of SDM suggest that if the parents are able to participate then a decision that aligns with their personal preferences and goals can be achieved, although limited empirical evidence exists to support this (Madrigal et al. 2012).) Ineffective engagement and communication have been reported to result in greater dissatisfaction with care and increased allegations of malpractice across neonatal and PIC settings, (Clarke-Pounder, Boss & Roter 2015; Latour et al, 2011; Meyer et al 2009).

Figure 2: Adaptation of Hart's (1995) Ladder of Participation demonstrating levels of parental participation in decision-making



Parental involvement in SDM is intrinsically linked to how information is communicated (Carnevale et al 2016, 2012, 2007 & 2006; Latour, van Goudoever, & Hazelzet, 2008; McPherson, Sachdeva & Jeferson 2005; Meert, et al., 2008;). Knowledge in this context refers to information about the specific treatments and options available together with personal preferences and wants. It is also inextricably linked to the ability to influence the decision making process. Communication within the environs of PICU is challenging with the content of information complex and time often constrained. These together with multiple individual HCP voices, and the cyclical and recursive nature of decision-making, all increase stress for parents and HCPs alike (Austin, Kelecevic, Goble et al 2009; Weiss Zoffman & Egerod 2015).

Feudtner et al (2018) argue models of decision-making require a broader conceptualization, including recognition of social pressures, including how the need to be a ‘good parent’ impacts upon participation. Parents described that ‘being a good parent’ includes anticipating how others, including HCPs, may judge them for decisions made, if they are perceived to give up hope for their child, make the ‘wrong’ decision or challenge too much (Madrigal & Patterson 2018; October, Fisher & Feudtner, 2014; deVos, Seeber, Gevers et al. 2015; Joseph-Williams, Elwyn and Edwin, 2014). Miller-Smith et al (2019) recognises parents are in an untenable position, wanting openness and transparency whilst simultaneously having hope maintained. Consideration must be given to the detrimental effect of SDM on parents and families. Nonetheless, this does not mean that a paternalistic approach should be adopted. Instead it reinforces the challenges HCPs face in meeting the unique and differing needs for information and participation in making treatment choices. Full participation may not necessarily be appropriate in every situation and should be assessed according to individual circumstances. The challenge for HCPs is to negotiate this complex process of engagement between paternalism and unrestricted parental autonomy, within this heterogeneous population (Richards et al. 2018; Morrison and Madrigal, 2012).

2.6.6.2 SDM: a staged process

Decision making cannot be viewed in isolation, it is part of the multifaceted phenomena of the admission and is inextricably linked with what precedes and what follows the decision. Within the context of adult, neonatal and PIC care, decision-making has been exposed to occur as a staged process. The first stage entails HCPs coming together to agree to a unified viewpoint which is then shared with parents (Power, 2012; Sorenson and Iedema, 2008; Wirtz et al, 2006: Whitney 2003; McHaffie et al 2001; Seymour 2001). Feasibly, the desire for a collective approach reflects the need for certainty in these difficult and irrevocable decisions.

Information is then shared with parents, usually during a formal meeting or family conference[4] (Michelson, Emmanuel, Carter et al 2011). Much existing literature focuses on how information is communicated to enable a shared approach. Studies have indicated that a course of action may be strongly recommended, (Shaw et al 2016; Boss et al. 2016, de Vos et al. 2015; McHaffie 2001, Anspach 1993). Anspach (1993:98) suggests recommendation creates passive acceptance and is akin to achieving parental assent due to the invocation of “a moral precept with which most parents would find it hard to disagree.” The second strategy is listing of options. While potentially promoting parental interaction and participation, option listing nevertheless does not preclude the use of persuasion when presenting information (Shaw et al 2016; Power 2012). HCPs need to be aware that their personal partialities may influence recommendations to parents (Needle, Mularski, Nguyen et al. 2012). Furthermore findings from Boss, Donohue, Larson et al’s. (2016) prospective study exploring communication dynamics and delivery in a single centre PICU demonstrated complex biomedical physician input dominated interactions, with parents afforded limited opportunity to contribute or voice questions. Within the discourse of SDM in critical care settings a power imbalance remains, knowledge alone not necessarily resulting in SDM (Linney, Hain, Wilkinson et al., 2019).

Birchley’s (2014) comprehensive analysis of best interests and shared decision making in the PICU, furthermore acknowledges that, while

---

[4] A family conference is defined as planned meeting involving parents, HCPs (such as intensivists, specialist physicians, nurses, social workers, chaplains etc), and sometimes others providing support to the parents (such as extended family members, friends, etc). The purpose of a family conference is to enable communication between parents and HCPs and provide support to the parents

shared decision making has become an accepted convention, insufficient consideration has been given as to its application including the benefits and risks to the interests of the child. The requirement for further consideration of the interface has also been highlighted by UK Supreme Court case, *Montgomery v Lanarkshire Health Board* [2015] SC 11 [2015] 1 AC 1430. *Re Montgomery* represents a significant shift in the duty of care of HCPs, redefining the standard for informed content and disclosure of information (Herring, Fulford, Dunn and Handa 2017; Heywood and Miola, 2017). The relationship between HCPs and the patient is recognized to be founded on personal autonomy and the duty to disclose. Whilst this mirrors GMC good practice guidance (2010), Heywood and Miola (2017) question whether the decision of the Supreme Court will result in increased judicial involvement when making decisions about WLSMT.

2.6.7 Resolving difference in opinions

It is proposed that the best approach to making decisions about medically inappropriate treatment is when there is a procedure to ensure fairness, including an appeals and review process, 'players' are knowledgeable, and the decision is based on clinical consensus (Stewart, 2011). Initially a futility determination would be made by HCPs involved in the care of the patient. However, if once the decision was communicated to the family, the family disagreed or were unhappy with the decision they would have the right for the decision to be reviewed. Recourse to the law imposes its own limitations (Huxtable, 2018; Brazier 2005) and, as Birchley et al's (2017) study identified tends to be avoided by HCPs.

Resolution of different opinions through the use of mediation is emphasized by both the courts, in *Great Ormond Street Hospital v Yates [*2017] EWHC 1909 (Fam) and professional bodies (Huxtable 2018; Larcher et al 2015; GMC 2010; Nuffield Council on Bioethics, 2006; Brazier 2003). Whilst mediation may enable greater understanding of actors' positions, there is a lack of research into whether it is able to effectively address the nuances of these ethically intricate cases (Huxtable, 2018; MacLean 2007).

Clinical ethics committees, are designed to resolve ethical dilemmas and conflicts and multi-disciplinary in composition (Huxtable, 2018; Larcher et al 2015; Lachman, 2010). However, much of the published literature on clinical ethics committees focuses on their consultative function. Considerable variation in practices are highlighted even within countries e.g. Australia and USA (Slowther, McClimans and Price 2012; Pederson, Akre and Ford, 2009; McGee, Spanogle, Caplan et al 2002). Conferring a binding decision making role upon ethics committees in the case of a futility determination could potentially cause confusion and inconsistency, with the committee's function shifting between advisory and facilitative to authoritative and governing. An appeal could nonetheless be made to a legal body if the family still disagreed with the decision. Critics of ethics committees challenge that they will result in delays in decisions, particularly with the requirement for an appeals process and additionally may struggle to act independently from healthcare organisations (Huxtable, 2018; McLean 2015). Equally, the obligation to continue provision of futile treatment in the interim may result in harm to the patient and conflicts with professional obligations, especially if the determination is in favour of futility.

Whether a procedural approach and the adoption of clinical ethics committees is a fair approach is questionable. The balance of power is still likely to remain with professionals since committees are likely to be staffed by medical professionals (Huxtable, 2018; MacLean 2007). Therefore, it could be asserted that they are likely to share similar values and beliefs as treating HCPs. Within the relatively small and distinct paediatric discipline of PIC, impartiality and neutrality must be questioned since it is likely that experts would know each other. Pederson et al's (2009) qualitative study exploring the barriers and challenges facing clinical ethics committee consultations reported that tendencies to side-step and avoid discussing conflicts with 'outsiders' persisted. There remains a sense of professional loyalty within the medical profession and a reluctance to speak out against colleagues. Pederson et al (2009) reported that there remained a continued reluctance for openness, even though there was recognition that such a barrier was untenable and counterproductive within modern health care. Establishment of a UK Clinical Ethics Network has nonetheless provided a forum for knowledge and practice exchange (Larcher et al 2015).

2.7 Resource allocation

Increasingly decisions for allocation of resources occurs at a local Trust level. These have some degree of responsibility and accountability to the strategic health authority (LETBs) and ultimately secretary of state for health. However, as unelected bodies this is limited. It raises the concern as to whether people can be confident, even where there is universal provision, as in the NHS, that they will have access to good quality health care and will not be subjected to a lottery of provision. There is recognition of the difficulties inherent in measuring outcomes using tools such as quality adjusted life years (QALYs) and disability adjusted life years (DALYs) which are acknowledged as imprecise and imperfect measures (Baily, 2011: Burns & Mitchell, 2011). Nevertheless, it begs the question as to how just, fair and reasonable rationing rules are determined? Successive governments whilst unable to produce a blank cheque to fund health care have lacked the political will to become embroiled in a contentious political debate about allocating health resources and health care rationing. However, governments by potentially saving themselves embarrassing and unpleasant open debate, force HCPs to make decisions in an underhand and deceitful manner. As Gampel (2006) cautions there is a very real need for ”*a democratic process to find reasonable and public rationing criteria*”. Although there are inherent difficulties in conveying the issues to the general public, by failing to do so government is also culpable of acting in a paternalistic manner (Baily, 2011).

The right to refuse treatment is sometimes misconstrued as an entitlement to receive treatment even when this is contrary to medical opinion (Schneiderman & Capron, 2000). Gampel (2006) states that the objection is in the form of a *reductio,* that unless HCPs are allowed to exercise professional judgment and refuse some patient demands, there would be an infinite and unsustainable demand on healthcare. The General Medical Council in Treatment and Care Towards the End of Life: Good Practice in Decision Making (2010:12) warns that doctors have a responsibility to make the care of their patients their primary concern:

> "*there is no absolute obligation to prolong life irrespective of the consequences for the patient, and irrespective of the patient's views, if they are known or can be found out.*"

As has already been alluded to, the outcomes of prolonging life with technology are unknown and could result in more harm and suffering, the oxymoron of resisting providing futile treatment and providing a good death (O'Connor et al, 2011).

In the case of Alfie Evans, there was an appeal to the Supreme Court that the standard of care, significant harm, should be the criteria which is applied. This was phrased that rather than best interests test being applied the courts should have allowed Alfie to be transferred to another PICU for treatment, providing that the transfer was safe. Potentially this would allow parents greater latitude in pursuing other treatments (Miller-Smith et al 2019; Elliston 2007; Dresser 2003). The harm threshold as defined by Diekema (2011) suggests that the threshold for state intervention is only justified when parental actions place the child at serious risk of harm. Nonetheless, the indeterminacy and pejorative nature of the harm threshold in these ethically complex cases renders it inadequate (Birchley 2016a, 2016b: McDougall & Notini, 2013; Skolol 2013). The absolute dominance of best interests principle in this area was revealed in Lady Hale's justification for not granting permission to appeal:

> *“we held that Alfie’s best interests were the ‘gold standard’ against which decisions about him has to be made.” Evans v Alder Hey Children’s NHS Foundation Trust* [2018] 3 WLUK 483 para 4

Inextricably intertwined within the on-going futility debate are considerations of resource limitation or rationing (Rubin & Truog, 2017). HCPs are required to work within professional boundaries which include making decisions about the goals and limits of medicine, standards of care and appropriate use of resources (Wightman, Largent, Del Becarro et al. 2017 Baily, 2011). This suggests that rather than the futility debate pertaining exclusively to the appropriateness of treatment for the individual patient, it is ultimately about the allocation of scarce and expensive resources. Rationing infers that a treatment which may offer benefit may be refused, the key issue being how to allocate limited resources beneficially and equitably (Rubin & Truog 2017; Schneiderman, 2011). This bioethical conflict opposes the interests of the individual against those of society (Rubin & Truog 2017; Baily 2011; Moratti, 2009). Yet, there must be recognition that health care operates within economic constraints; resources are finite. Health care also functions within a political context and whilst the NHS was founded on the principles to fund health care for all, the original philosophy of the NHS was that demand would be curtailed by the health of the population as a whole improving. Furthermore, the nature and expanse of technological advances were not anticipated.

2.7.1 The scale of the problem

As previously alluded to, the provision of futile care is economically challenging. Health care delivery is constrained by the imposition of external constraints and medical futility judgments do not occur independently of political considerations. There has been recognition amongst adult ICU providers that limiting provision of futile and inappropriate treatment has resulted in significant cost savings

(Esserman et al, 1994; Atkinson et al, 1994). There exists a tendency to generalise these findings to paediatrics. Yet, the provision of futile treatments is reportedly rare in PICU accounting for only a very small proportion of PICU expenditure (Goh & Mok 2001; Vemuri & Playfor 2005). Goh & Mok's (2001) prospective evaluation of 662 consecutive admissions to a 20 bedded multi-disciplinary PICU over a nine month time period identified a total of 104 bed days (3%) were utilised by patients who fulfilled at least one criteria for futility. Futility criteria used included imminent demise futility (those with a mortality risk greater than 90% using the PRISM II score); lethal condition futility, that is those patients with conditions incompatible with long-term survival; and qualitative futility, those with unacceptable quality of life and high morbidity defined as persistent vegetative state before and during stay on PICU and brain death. This study, whilst limited to one PICU, does bring into contention whether findings from adult PICUs pertaining to the economics of treatments are readily transferrable to the PICU setting. If futile treatments are rare, and are not usually offered or disputed and only account for a small proportion of PICU expenditure then it could be postulated that, for this reason, policies regarding futile care are not likely to be very useful.

Vemuri & Playfor's (2005) prospective cross-sectional survey mailed to all PICU directors in the UK differs from Goh and Mok's finding. In Vemuri & Playfor's study respondents were asked to complete data for one specific day, including biographical details, reason for admission, pre-existing conditions and also conduct an assessment of whether care being provided in each case was, in their opinion, appropriate, futile, or inappropriate. This study had a response rate of 68% with care considered futile in 8% (n=9) of cases. Of particular note is that the care being provided was considered inappropriate in a further 13% (n=14) cases. Futile treatment was defined as care being provided which would not have the desired outcome or accomplish its intended goals. Inappropriate treatment was defined as extremely unlikely to confer benefit, extremely costly or of uncertain benefit. Whilst the high prevalence of 21% of cases in this study of futile and inappropriate care conflicts with Goh & Mok's (2001) findings, it highlights the need for a longitudinal study of medical futility in PICUs in the UK. There is an increasing need to accurately assess the impact of such resource consumption on the provision of this service to enable resources to be targeted towards patients who are most likely to survive and survive with minimal impairment.

The danger of extrapolating and applying findings to different populations is shown with Lantos and Meadow's (2011) comparison of adult and neonatal intensive care. They identified that adult ICU's most expensive patients were those who have the longest stay, whereas the converse is true in NICU. Similarly, when comparing length of stay, for AICU patients the prognosis is worse after 3 days, whereas it works the opposite way in NICU, where the most expensive patients are most cost effective. The paper emphasises that issues of economics and ethics are different. However, the paper also raises the very pertinent issue that if HCPs are better able to predict which patients are likely to die and which survivors would be severely impaired then this would allow resources to be more accurately targeted. It again reinforces the need for longitudinal data and better prognostication tools to reduce value judgements. Gampel (2006) cautions that families may be misled into believing treatments have no chance of sustaining life whereas physicians may be thinking that a remote chance of success does not legitimize cost expenditure.

2.8 Chapter summary

The literature review has provided the context to the study. It has drawn attention to what is currently known about these agonisingly difficult decisions about whether to continue, withhold or withdraw intensive care treatments and the conflicts that can sometimes arise in the PICU. The changing trajectory of how children die in PICUs has been explored together with consideration of how medical technology has blurred the boundaries between life and death. The conflicts that can surround assessment of a child’s best interests have been informed by the body of evidence pertaining to debates around the concepts of futility, autonomy, decision making best interests and resource allocation. The study has also been informed by wider consideration of how the substantial body of English case law, primarily, but not exclusively, relating to children has addressed these issues.

Prospective research investigating the relational and temporal nature of difficult decision-making in the PICU is lacking. The experiences of all parents in the PICU setting are individual and distinctive because social, cultural, spiritual, emotional and psychological issues shape the context of their life and experience. Nevertheless, this complexity at the commencement of the PhD remained to be explored in the UK. Factors that have influenced both HCPs and parents in North America and Europe may or may not be consistent with those influencing parents in the UK. Existing literature highlighted a preponderance of maternal viewpoints conveyed as parental perspectives. This made the proposed study unique and essential. Although a number of UK neonatal studies have been undertaken, caution must be taken when extrapolating findings to the paediatric critical care setting. Neonates are a distinct population with very different needs and issues and correlations are limited.

Within contemporary healthcare, there is growing recognition and emphasis on working in partnership to secure an agreed decision. Yet, the methods which have been used to investigate difficult decision making to date have recognised deficits. Retrospective collection of data mean that the intricacies and complexities of the phenomenon are lacking detail. Allowing time to have passed to allow parents to come to terms with what has happened prior to seeking their experiences does mean that parents’ accounts are reflective and may differ from their responses at the time. This study aimed to explore the immediacy of the decision-making process as it happens.

Furthermore, by undertaking a multi-perspectival inquiry, a comprehensive understanding of all actors' involvement in the process of construction of a decision will be illuminated. Michelson et al (2009) have undertaken a qualitative prospective study and McHaffie et al's (2001) neonatal survey demonstrates the feasibility of collecting sensitive information at this extremely emotive and vulnerable time in parents' lives. Well researched information about parental and health care professionals' views and preferences regarding their role in decision-making will aid paediatric intensive care practitioners in sensitively approaching and assisting families who face decisions about withdrawing life sustaining medical therapies.

Chapter Three

3. Methodology and Methods

This chapter presents the methodological approaches taken to explore difficult decision making within the context of the PICU setting.

The chapter commences by detailing the specific aim and objectives for this research inquiry. A detailed account of the underlying methodological and philosophical assumptions of the inquiry follows. In-depth critique demonstrates that ethnographic approaches were selected for their suitability in addressing the research questions developed from deficits in existing literature (section 2.5 page 54). Specific consideration is given to the relationship of the researcher with the researched and experiences of researching in a field in which the researcher has also worked as a professional, and the issues around insider research.

3.1 Study aims and objectives

The overarching aim of this study was to explore how the construct of best interests is understood when making difficult decisions to persevere with, withhold or withdraw life sustaining medical treatment in children by:

- Exploring what is meant by the concept of ‘best interests’ and how it is perceived, described and experienced by parents and HCPs.
- To review how decisions to persevere, withdraw and/or withhold treatments in critically ill children are reached and the context surrounding them.
- To consider the roles of parents and HCPs in interpreting and applying best interests for surrogate decision making in the PICU.
- To identify issues arising from the study that can help to inform policy and development of clinical guidelines.

3.2 Methodology

3.2.1 The qualitative research paradigm

In developing a research strategy, crucial choices are required to be made as to what kind of knowledge is being sought and selecting the most appropriate method is vital in achieving desired results (Crotty, 2009; Starks and Trinidad, 2007). The literature review identified a dearth of research exploring the decision-making process, resulting in a lack of understanding of the phenomena in question. The study sought to explore and understand the nature and construct of difficult decision making within the context of a PICU. A qualitative research approach was selected because this allowed for in depth exploration of parents and HCPs' experiences and emotions, examination of accepted organisational and societal practices and consideration of obstacles and catalysts to change. Such complex interactions involving the interplay of values and emotions would be difficult to elicit using positivist approaches (Holloway and Wheeler, 2010).

3.2.2 Philosophical perspective

Positivism and with it the philosophy that empirical science should be the foundation for all factual knowledge (Avis 2003), was an inappropriate epistemology since the purpose of the inquiry was to reveal an understanding of the inter-relationships between individual beliefs, cultural norms and social rules. A positivist epistemology is based on the supposition that knowledge is not arrived at speculatively but is grounded in something which has been observed through scientific observation (Crotty, 2009) and a belief that scientific knowledge is accurate, reliable and reproducible (Ellis, 2010; Avis, 2003). Positivism assumes the social world can be investigated in the same way as the natural world and commonly incorporates any approach that uses a scientific or quantifiable method (Neuman, 2006). Quantitative research is deductive, starts with knowledge and assumptions within the specific area, and aims to confirm or refute the original hypothesis following empirical testing (Neuman, 2006). Positivism is acknowledged as a useful approach in nursing enquiry (Winters and Ballou 2004) and survey data has been used effectively to measure characteristics of the proposed population (Ramnarayan, et al. 2007). Nonetheless, although these data are informative, they do not provide understanding of what happens in practice. Generating such measurement orientated and reproducible data with a single enduring truth is incompatible with the complexity of the individual human experience (Koch, 1999). Dilthey (2003) suggests that it is only by studying the ‘meanings’ humans construct through their use of language and interactions that the social world can be understood.

Intepretivist approaches attempt to understand and explain the human and social reality, allowing in depth exploration of organisational and societal practices and establishing obstacles and catalysts to change (Crotty, 2009). Originally conceived in response to the abiding debate about whether social sciences can or should be scientific, they are linked to the works of Weber and Dilthey, who proposed that human sciences were concerned with understanding of the everyday lived experience of people in specific settings (Neuman, 2006). This contrasts with the explicative approach focussed on causality found in the natural sciences.

Interpretivism embraces an inductive style of reasoning with the emphasis upon the identification and presentation of experiences and coding of data to discover themes or construct theories (Pope & Mays, 1993). Inferences made are descriptive, recognising the value of the individual subjective experience within which there may be multiple and complex ‘knowledges’ co-existing (Creswell, 2007). Within the complexity of the PICU environment, interpretivist approaches can be used to gain insights into the complexity of organisational, social and cultural issues and advance understanding of processes of health care delivery and communication.

3.2.3 Determining the methodology

A number of qualitative strategies of inquiry could be considered for use in this study (i.e. grounded theory, phenomenology, narrative study, case studies). However, Creswell (2009) proposes that the strategy should be driven by the philosophical standpoint and research purpose.

3.2.4 Ethnography

Detailed consideration of study objectives, which centred on gaining an understanding of decision-making when active treatment was being withdrawn in PICUs, established that a prospective extended case study of a single PICU using an ethnographic approach was best suited to answering the research question (Roper & Shapira, 2000).

Although ethnography has its origins in a positivist tradition within cultural and social anthropology, it has evolved and adapted to be acknowledged as a qualitative methodology generating iterative-inductive research (Higginbottom, Pillay & Boadu, 2013; 0'Reilly, 2005). It has been used across a range of paediatric health care settings. Strong's (1997) study explored interactions between paediatricians and parents of children in an outpatients clinic. Whereas, Waters (2008) and Nightingale, Sinha & Swallow's (2014) studies centred upon children, parents and professionals' experiences of renal disease. Anspach's (1993) seminal work, Deciding Who Lives, investigated life and death decision-making within two NICUs. Seymour (2001) explored how WLSMT is managed in adult intensive care units. Although ethnographic studies have been conducted within the PICU setting, Austin, Kelecevic, Goble et al. (2009) and Mahon (2014), these have focussed upon the HCPs working within the PICU environs.

No consensual definition of ethnography exists, the focus being on the characteristics of ethnography (Fetterman, 2010). Ethnography involves producing a descriptive account of the everyday social life and culture, within a particular social system (Higginbottom et al. 2013; Vidich & Lyman, 2000). It is based on detailed, holistic observations of what people actually do over a period of time, with the objective of interpretation and understanding people's actions and behaviours as shaped by their experiences (Creswell, 2007; Roper & Shapira 2000). Savage (2006, 2000) asserts that ethnography is apposite as a qualitative health research methodology, having been effective in uncovering tacit skills, decision rules and subtleties within health care settings. It was an appropriate methodology for this study affording a unique opportunity to provide insight, within a single setting, into the decisional processes involved when choices about treatment/non-treatment have to be made from the perspective of families and clinicians (O’Reilly, 2012; Fetterman, 2010; Hammersley and Atkinson, 2). A distinctive feature of ethnography is the focus on the contextualisation and understanding of social systems (Aull-Davies, 2008). The depth of data generated enabled the researcher to engage with the complexity of daily lives providing insight into the experiences, beliefs and actions of parents and HCPs. Brewer (2000) suggests that ethnography is beneficial when information required is too complex and subtle to be elicited by surveys or other methodologies. The recording, analysis, interpretation and consequently understanding of actions, through the inclusion of research participants’ accounts, enable the exploration and development of different constructions of reality (O’Reillly, 2012; Seymour, 2007).

A recognised strength of an ethnographic approach is the ability to support the researcher to respond flexibly to emergent findings, enabling modifications to meet the challenges of fluctuating circumstances (Aull-Davies, 2008; Jones & Lyons, 2004; Stake, 1995). In accordance with high quality ethnographic practice (Addington-Hall et al 2005; Fetterman, 2010), the need to adapt responsively and sensitively to the vulnerability of children and their families was paramount. Given the often unplanned and chaotic nature of the PICU environment, acquiring knowledge about the real world was far from unproblematic and involved a constant interplay of theory, methods and experiences. All research, whilst using varying approaches, aims to search for knowledge and understanding. Nevertheless, formulation of meanings occurs as a result of how the data is viewed through these different lenses.

Debate abounds as to the effects the researcher imposes when undertaking an ethnographic approach. It would be naïve to assume that I, as a researcher, can be detached and unbiased. Angrosino (2005) posits that an objective reality cannot be achieved. Personal interpretations are continuously evolving and frequently inconsistent being contingent upon situations encountered. Therefore, as Hammersley and Atkinson (2007) propose, the emphasis throughout was on ensuring contextualised understanding by being reflexive during the planning, conduct and writing up of this study. Reflexivity is described as:

> *"A continuous process of critical scrutiny and interpretation, not only to research methods, the data, but also to the researcher, participants and context."* (Guillemin & Guillam 2004: 275)

The requirement for self-reflexivity cannot be overstated. Concentrating on how personal insights influenced the inductive process provides depth and credibility to the study and is demonstrated throughout this thesis. (Alvesson & Skoldberg 2000; Bonner and Tolhurst, 2002). It is not possible to unlearn previous knowledge, however it is feasible to be open, honest, critical and explicit about the rationale for decisions taken, to critically appraise prior assumptions and interactions between me, the researched and the research.

3.2.5 Case study design

A case study can be defined as the collection and presentation of detailed information about a particular participant or small group (Yin, 2009). On this occasion, the use of case study aligns to Stake's (1995) principally interpretivist standpoint, affording an intensive exploration and analysis of a complex phenomenon within a real world setting. This is consistent with the theoretical underpinning of this study, where little is known about how decisions about treatments in critically ill children are reached and the context surrounding them. Stake (1995, 2006) has organised case study research into three main types:

- Intrinsic: focuses specifically on the case, seeking clarity and deep understanding of a unique occurrence.
- Instrumental: whereby the case is not the prime focus, but contributes to developing an understanding of something else.
- Collective: whereby several instrumental cases are investigated either concurrently or successively.

Multiple case studies embedded within the wider case of the PICU enabled comprehensive observation of care and interventions given to selected children from shortly after admission to PICU to beyond death. This permitted in depth contextual understanding as befits the sensitive and emotive nature of a critical care setting (Seymour, 2007). The identification, interpretation and understanding of patterns emerging from combining findings across cases allowed both commonalities and differences to be identified, factors that may be lost in larger studies (Silverman, 2014;Yin, 2009; Flyvbjerg, 2004; Stake, 1995). The recurrence of patterns indicated to what degree phenomena are shared across cases and contexts. Thus, a rich picture was acquired providing explanation, within context, of events, processes, relationships and/or problems occurring when difficult decisions are being made within the PICU (Creswell, 2007).

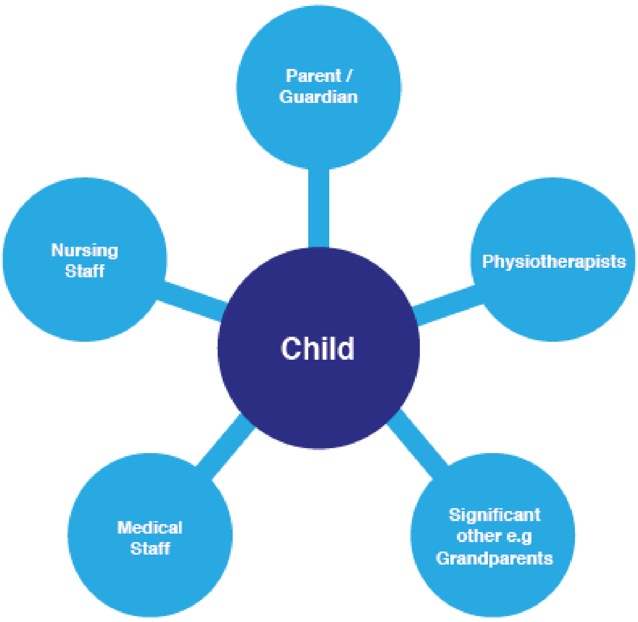
3.2.5.1 Constituting the case

Central to each case was a child admitted to the PICU with a life threatening critical illness. The child, whilst in the observation field, was not the main focus of the study. It is acknowledged that the child is dependent upon the decisions of others and it is the process of how those decisions and judgements were made that was being explored. Each case consisted of the interactions and perceptions of the parent(s), legal guardian(s) or main care giver, henceforth stated as parents, and HCPs involved in the care of the child (Figure 3).

Each ‘case’ enabled comprehensive observation of care and interventions given to selected children from shortly after admission to PICU to beyond death or transfer from PICU. Those with the highest probability of death for the PICU admission were purposively sampled (Bryman, 2008).

Identification of all facets of a case may not be practicable at the outset, the case evolving as the study progresses (Creswell 2017; Appleton &

Figure: Example of a case study



King, 2002). Given the difficulties in predicting in advance opportunities that may arise, the imperative throughout was to respond to situations and opportunities sensitively, working with participants, and particularly parents, at a level and frequency of engagement that they felt comfortable with. The emphasis on multiple methods of data collection, the 'toolkit' approach (Pope & Mays, 1993), afforded flexibility to enable modifications to meet the challenges of fluctuating circumstances within the real world setting (Stake, 1995; Jones & Lyons, 2004).

3.3 Selecting the field setting

The study was conducted in a single PICU, one of 26 NHS PICUs in England. It provides up to level 4 intensive care services[5] to critically ill children from birth to eighteen years of age, from across a wide geographical catchment area in central England. Located within a large urban teaching NHS Trust, the PICU provides regional and supra-regional services. However, cardiac and hepatic speciality services are not offered. Any children requiring critical care for these conditions is transferred to other centres. Children are admitted with a range of

---

[5] Defined by Paediatric Intensive Care Society standards (2010), Appendix p.5 as patients requiring 'intensive supervision at all times' and 'needs additional complex therapeutic procedures and nursing'.

medical and surgical conditions that require complex clinical care and specialist interventions including invasive monitoring, physiological system support and intensive therapeutic interventions. Children may be admitted direct from the operating theatre, via the emergency department, from wards within the children's hospital or having been transferred from another hospital within the locality. Occasionally referrals from further afield are accepted if no PICU bed is available in that region.

The PICU was selected because it had been involved in a retrospective analysis of deaths over a ten year period which identified that managed withdrawal accounted for a large percentage of deaths on the unit, (Sands et al, 2009). Furthermore, a conscious decision was made to embed the research with a collaborative ethos and included development of a consultative group composed of representatives from health care, education and service users who were involved in supporting the conceptualisation and development of the study. Parent support groups were also consulted and involved in development of the research proposal, the Child Bereavement Trust (now Child Bereavement UK) providing constructive feedback on methodological issues and ensuring the parent information sheet and study information leaflet were easily understood.

3.3.1 Access to and preparation of the field setting

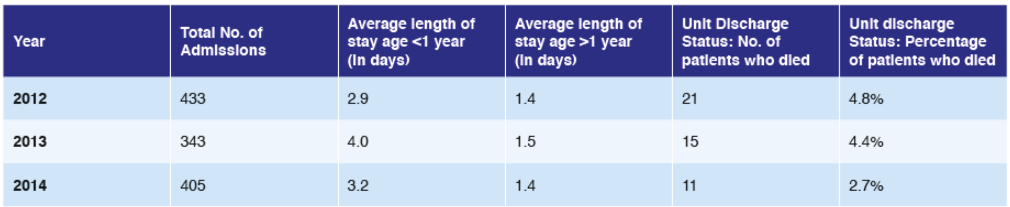
Negotiation of access for ethnographic research in healthcare settings is acknowledged as challenging, problematical and a necessary antecedent (Murphy and Dingwall 2007; Roper & Shapira 2000). A multifaceted approach to open access was required since, as Tofolli & Rudge (2006) identify, ethnographic research with its prolonged engagement is unsuited to NHS ethics procedures. However, access does not solely pertain to gaining research ethics committee (REC) approval and meeting governance requirements (National Research Ethics Service, 2011). My fragile status as a guest in the PICU field required considerable investment of time and effort (Murphy and Dingwall, 2007). I was always cognisant of maintaining appropriate conduct and behaviours towards my hosts, ensuring judiciousness and integrity in all interactions. Prior to gaining REC approval, discussion was undertaken with key stakeholders composed of representatives from health care, academia, and patient groups. This consultation was established to generate increased mutual understanding of standpoints, decisions undertaken and also as an opportunity to gain co-operation, trust and approbation of key gatekeepers (O’Reilly, 2012; Bryman, 2008). The remit was to provide expertise and guidance, particularly during conception and development. This enabled appropriate planning and design of the study, specifically pertaining to ethical considerations, recruitment and data collection techniques together with an agreement to support and participate in the study. Given the evolving nature of ethnographic research, the requirement for continuous modification and on-going negotiation of access (Fetterman, 2010) and consultation with key members was sustained throughout the study ensuring ethically responsible research.

3.3.2 Identification of research participants

Screening, selection and recruitment of cases occurred over an extended period of time January 2014 to December 2015, because of the unpredictable nature of patient admissions to the PICU. Life and death decisions are made infrequently (Bryman, 2008). It remains rare for a child to die in PICU, current national average UK mortality rate being 4% (Paediatric Intensive Care Audit Network, 2018). Specific data for the unit under study, during data collection period, are detailed in table 1.

The study aimed to gain participation from both parents and HCPs; parents having previously been under researched within this field. Prospective review of all children admitted to the PICU was undertaken.

Table 1: Statistics for PICU studied for 2012-2014 (PICANet 2015)

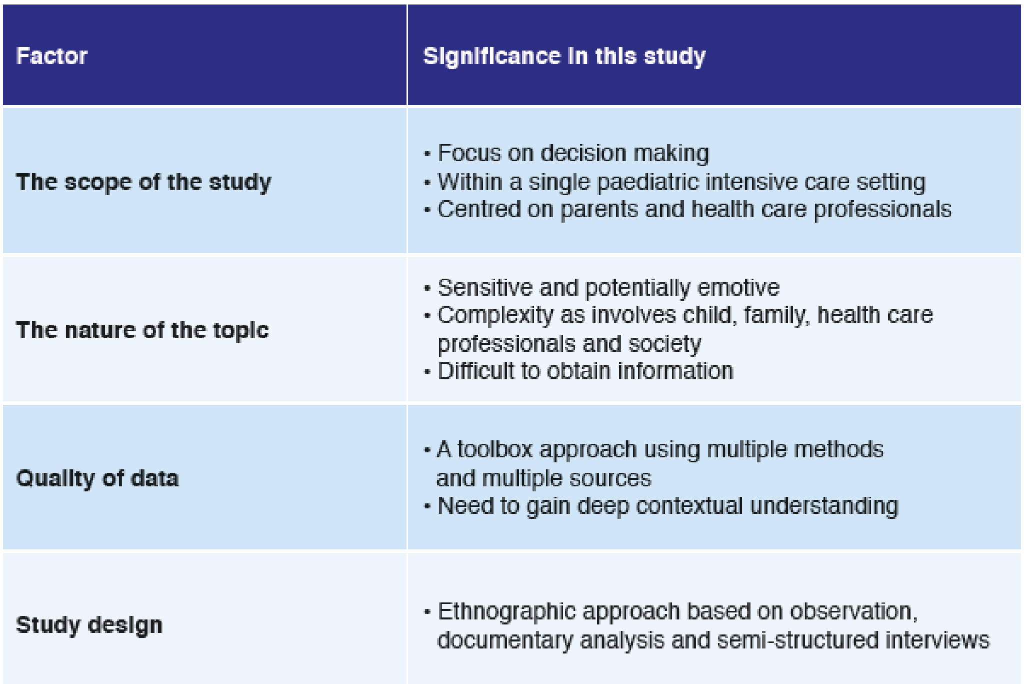


Year	Total No. of Admissions	Average length of stay age <1 year (in days)	Average length of stay age >1 year (in days)	Unit Discharge Status: No. of patients who died	Unit discharge Status: Percentage of patients who died
2012	433	2.9	1.4	21	4.8%
2013	343	4.0	1.5	15	4.4%
2014	405	3.2	1.4	11	2.7%

3.3.4 Sampling strategy

Qualitative research aims to gain a depth of understanding and therefore sampling techniques must reflect this (Creswell, 2007). Morse (2000:3) suggests that there are a number of factors that need to be considered when estimating sample size in qualitative research: the scope of the study, the nature of the topic, the quality of data, study design, and the use of shadowed data. Potential considerations pertinent to the study are detailed in Table 2:

Table 2: Considerations for sample size using Morse's factors (2000)



Factor	Significance in this study
The scope of the study	• Focus on decision making • Within a single paediatric intensive care setting • Centred on parents and health care professionals
The nature of the topic	• Sensitive and potentially emotive • Complexity as involves child, family, health care professionals and society • Difficult to obtain information
Quality of data	• A toolbox approach using multiple methods and multiple sources • Need to gain deep contextual understanding
Study design	• Ethnographic approach based on observation, documentary analysis and semi-structured interviews

In ethnographic research, sampling occurs at two levels: that of the observational unit, the setting, and that of individuals, events and incidents, which form the set of cases (Gobo, 2008). A purposive or reasoned sampling approach was adopted to select the PICU observation site, ensuring it was best suited to address the research questions. The PICU is typical of a unit specialising in caring for critically ill children within the UK which Gobo (2008) proposes is essential to protect against criticism of the generalizability of findings.

Having determined the setting, the focus turns to the individuals, events and incidents. Theoretical sampling was utilised to construct a sample on the basis of their relevance to the research question. Silverman (2000:105) indicates that there are three main characteristics of theoretical sampling:

- Individuals, events and incidents are chosen according to their significance to the research question
- ‘Deviant’ cases are selected
- And, the sample may change in size during the course of the research

Given the unpredictability of the PICU environment, this enabled sampling to be a process that was interactive, flexible, iterative and progressive.

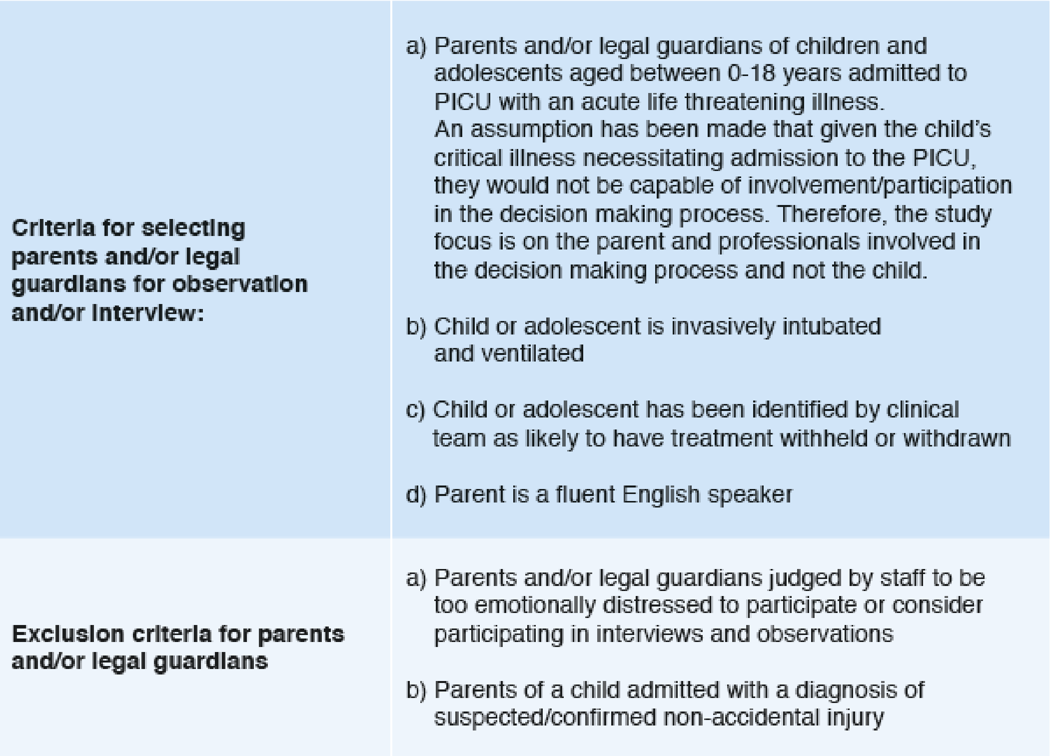
Over the duration of the study, a large volume and varying quality of data from multiple sources was generated. Estimating the number of case studies was problematic due to the randomness of admissions to PICU. Morse (2000) advises that it is the quality of the data elicited, as opposed to the quantity of participants, which enables the richness of data for analysis in qualitative enquiry. This conforms with the concept of saturation; the point at which no new information or themes are observed in the data (Gobo, 2008)

Qualitative research relevant to the setting by Carnevale et al (2006, 2011) has utilised between 6- 9 parent participants and Orfalli, Botti and Iyengor (2009) 19 parent participants. This study aimed to collect data through recruiting a maximum of 10 embedded cases. This acknowledged the difficulty in predicting cases and furthermore anticipated that some participants given the nature of the study may need to be withdrawn e.g. if the case became disputed or the child at the centre of a case is diagnosed with suspected/confirmed non-accidental injury.

3.3.5 Criteria for selecting patient cases

The process of recruitment was complex, see figures 5 & 6. In an attempt to minimise the potential for harm during the recruitment process an indirect and sensitive recruitment strategy was utilised. Details of the study were displayed throughout the clinical area using posters and information leaflets within the clinical and family areas within PICU.

Figure 3: Inclusion and exclusion criteria



Criteria for selecting parents and/or legal guardians for observation and/or interview:	a) Parents and/or legal guardians of children and adolescents aged between 0-18 years admitted to PICU with an acute life threatening illness. An assumption has been made that given the child's critical illness necessitating admission to the PICU, they would not be capable of involvement/participation in the decision making process. Therefore, the study focus is on the parent and professionals involved in the decision making process and not the child. b) Child or adolescent is invasively intubated and ventilated c) Child or adolescent has been identified by clinical team as likely to have treatment withheld or withdrawn d) Parent is a fluent English speaker
Exclusion criteria for parents and/or legal guardians	a) Parents and/or legal guardians judged by staff to be too emotionally distressed to participate or consider participating in interviews and observations b) Parents of a child admitted with a diagnosis of suspected/confirmed non-accidental injury

When approaching parents to seek whether they would take part only parents who:

1) had been deemed suitable for potential inclusion by senior medical or nursing staff;
2) had been approached by clinical staff about possible participation;

3) who had agreed to talk with me about the study and possible inclusion, were approached.

These steps allowed for checks to be put in place with the intention of improving capacity and gaining informed consent. It is acknowledged that participants in this setting are particularly vulnerable, being emotionally fragile and preoccupied with their child's needs. This approach allowed participants to decide for themselves if they felt ready to participate in the research (Dyregrov, 2004; Hynson, Aroni, Bauld & Sawyer, 2004). Olcese & Mack's (2012) experience with parents of children with cancer suggest self-selection is effective in identifying parents who can participate with minimal or no distress.

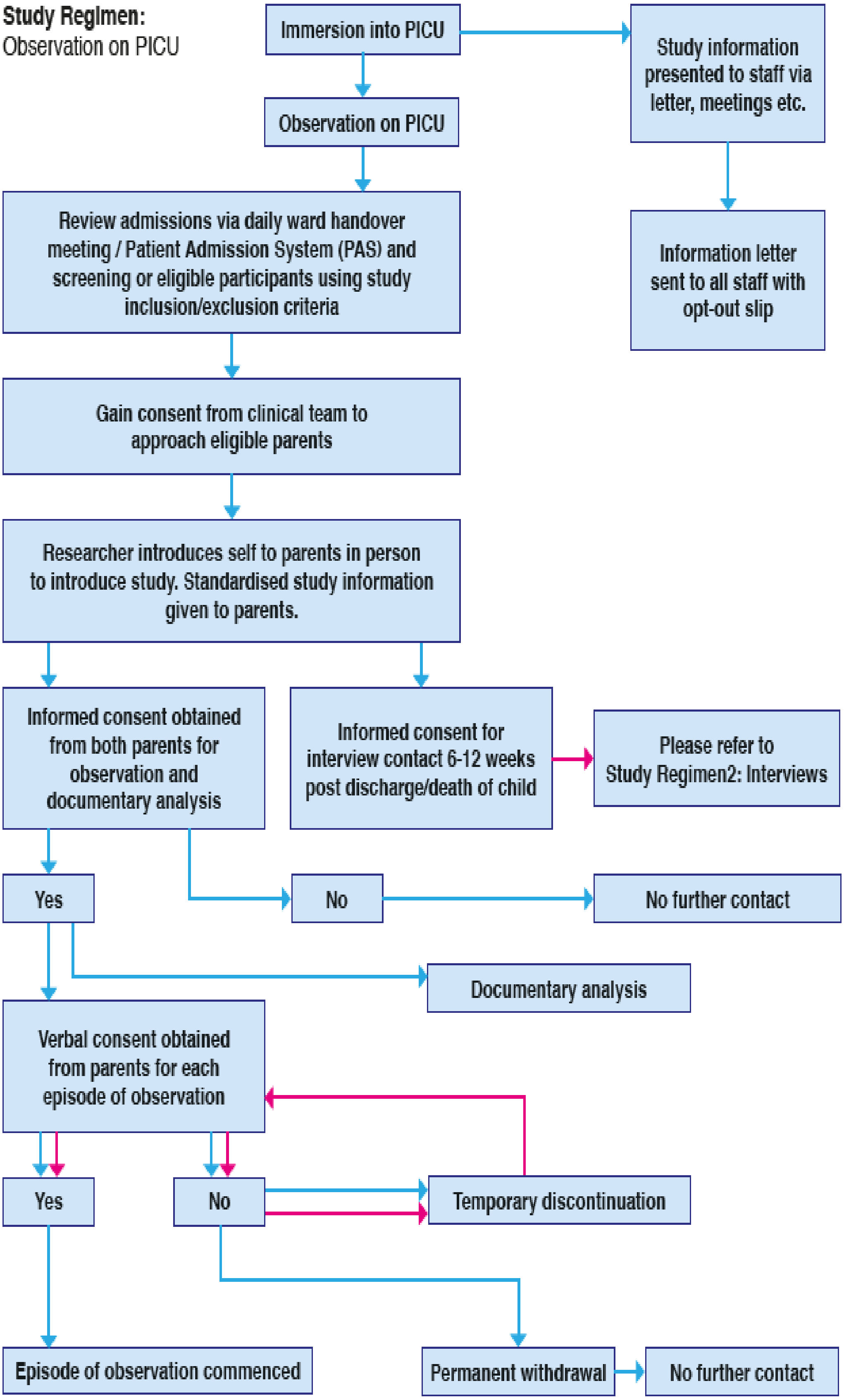


Figure 4: Study regimen observation on PICU

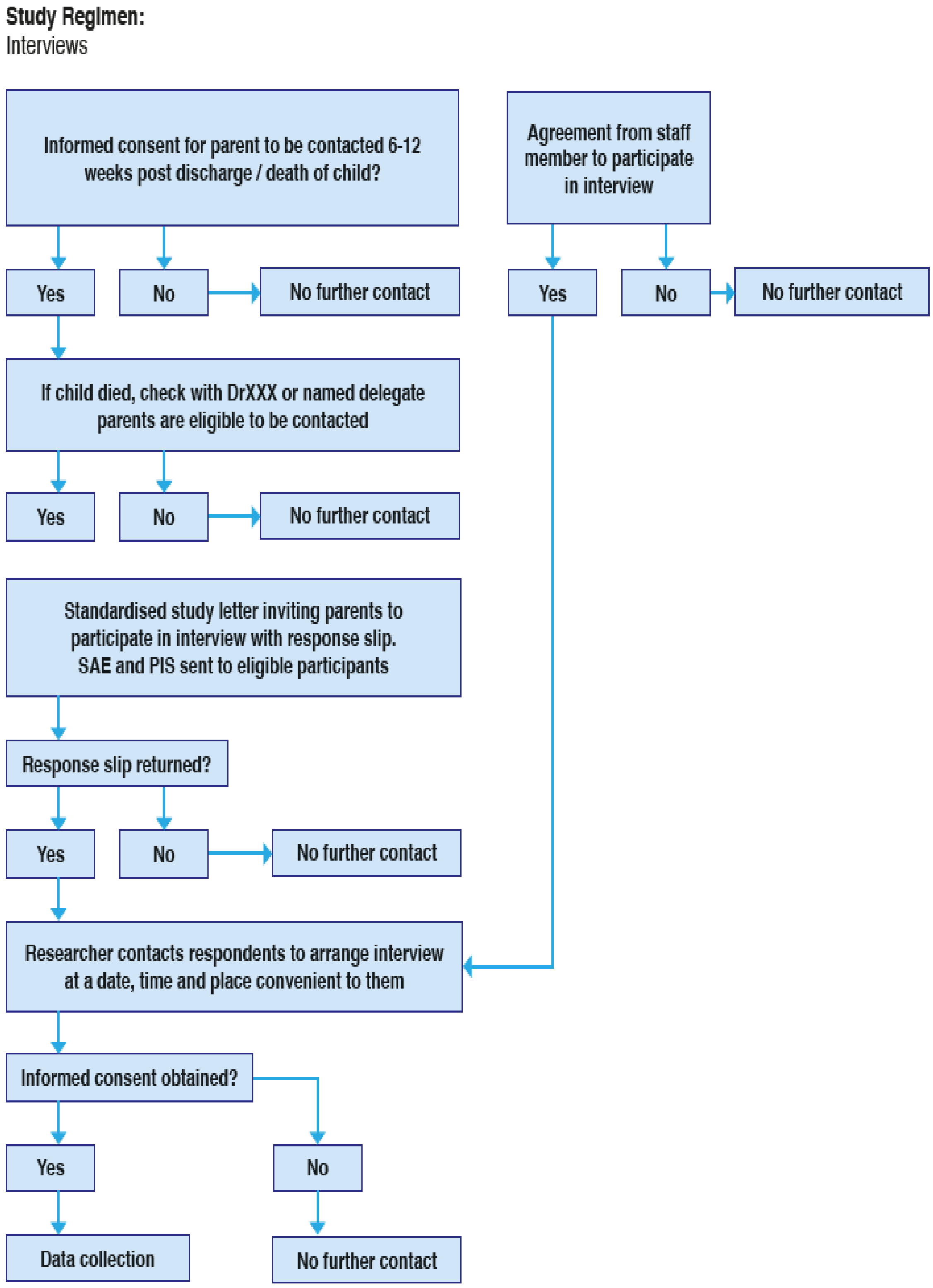
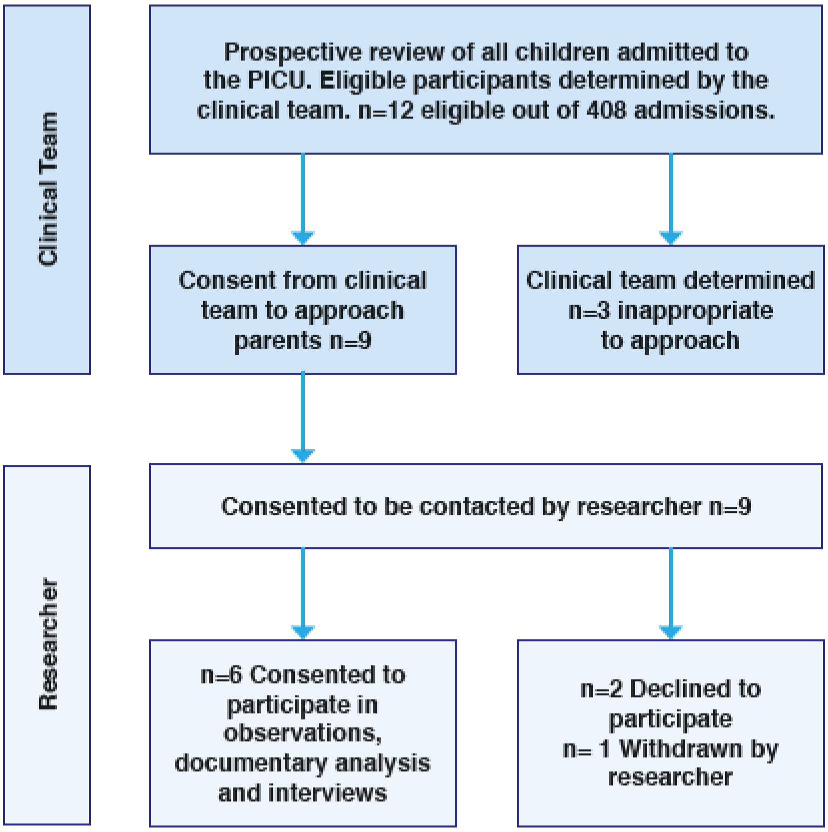


Figure 5: Study regimen interviews

During the period of the study 12 potential eligible children (out of a total of 408 admissions), who in the clinical teams' professional judgement were predicted as likely to have treatment withheld or withdrawn were identified. Reasons for not inviting parents to participate included: the PICU staff involved judged the parents to be too emotionally distressed to participate (n=2), both parents were not fluent in English (n=1), and that it was not a suitable time to ask the parents to participate (n=1). Nine sets of parents were invited to participate in the study, six agreed to take part. Two declined to participate, one directly and one indirectly by asking the nurse caring for their child to convey their decision. One set of parents for whom English was not their first language, despite verbally

Figure 6: Summary of case study selection

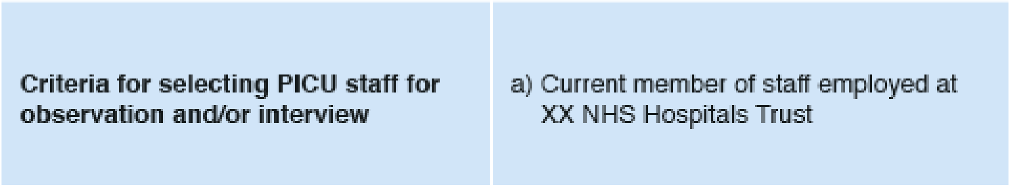


consenting to the study, were withdrawn when it became apparent that they did not fully understand the role of the researcher. Once informed written consent had been secured none of the parent participants subsequently withdrew during the study period.

3.3.6 Criteria for selecting PICU staff for observation and/or interview

Purposive sampling was also utilised to ensure that a range of medical, nursing and allied health professionals were recruited. Initial information about the study was provided to staff through the use of posters on the ward, meetings and informal discussions. A series of briefing meetings for staff, to explain the nature of the study, how they may be involved and to provide opportunity to answer any questions were held. Additionally, all members of the PICU team were individually informed by leaflet of the study purpose and the role of the researcher. It quickly became apparent that PICU team members, especially nursing staff, were interested in participant observation because of the potential for data generated to reflect what really happens, what people think and do. This was considered a rarity with other research studies being undertaken concurrently focussing specifically on measurable medical interventions.

Figure 7: Criteria for staff selection



Criteria for selecting PICU staff for observation and/or interview	a) Current member of staff employed at XX NHS Hospitals Trust

Following consultation with the local REC, to overcome concerns about coercion, the original intention to allow staff to opt-out of the study was amended, to an opt-in process for staff participants. This level of gatekeeping for staff participants appeared to reflect perceptions of increased sensitivity surrounding the undertaking of participant observation. Ironically, it was principally because participant observation methodology was being used, staff members and patient groups responded favourably to conducting the research when the study was being planned.

Sustained contact throughout the study allowed rapport to develop with staff, with recruitment occurring on a rolling basis. Junior medical and nursing staff carry out planned rotations for training through the unit on a six monthly basis. Informal presentations were undertaken as part of induction programmes, with staff encouraged to ask questions and make comments throughout. On the first occasion when medical staff rotated, although in principle the main gatekeeper was supportive, negotiating for a time to present required persistence and considerable flexibility. Yet, this proved to be an efficient way to recruit participants and allowed for full informed consent.

Staff were involved in the study throughout the period of observation, and more intensively for shorter periods as members of a case study. Some were involved in multiple cases. Parents were involved in the study for the duration of the child's admission to PICU and up to the final interview, which took place some weeks or months after their child's discharge from PICU and/or death.

3.4 Ethical approval

All research is liable to face ethical dilemmas, reinforcing the importance of planning for such during research design and development. Ethnographic approaches are fundamentally different, being unable to predict at the inception how the study will evolve (Aull-Davies 2012; Simpson 2011; Johnson and MacLeod Clarke 2003). Issues arising are explored reflexively within field work section 4.5.

The study was conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki (World Medical Association 2008), the principles of Good Clinical Practice (ICH GCP), and the Department of Health Research Governance Framework for Health and Social Care (2005). Approval for the study was sought from a National Health Service (NHS) Research Ethics Committee (REC) with full approval granted from East Midlands REC (Ref:12/EM/0407: Appendix

2). Access to the clinical setting was approved following a site specific assessment undertaken by the NHS Trust Research and Innovation Department where the study was located.

3.5 Chapter summary

This chapter has outlined the study aim and objectives and the philosophical assumptions. A detailed rationale and justification for the chosen ethnographic case study design including recruitment has been provided. Reflexive consideration of access to the research setting and the strategy for recruitment of participants has been detailed. The next chapter will provide detailed discussion, including specific ethical considerations of the ethnographic data collection approaches and data analysis process.

Chapter Four:

4. Field Work

In accordance with ethnographic principles, data collection entailed a combination of observation of the PICU and participants within the study setting, engaging in informal and semi-structured interviews to follow lines of enquiry and analysis of patient care records. Application of a multiple case study approach necessitated intensive immersion over a prolonged period of twenty-four months. The study focused on detailed engagement with cases, enabling comprehensive observation of care and interventions given to selected children from shortly after admission to PICU to discharge or beyond death. This permitted in-depth contextual understanding as befits the sensitive and emotive nature of a critical care setting (Seymour, 2007), allowing both commonalities and differences to be identified, factors that may be lost in larger studies (Silverman, 2014;Yin, 2009; Flyvbjerg, 2004; Stake, 1995).

Fieldwork was conducted on one to two days per week, with all seven days represented, and 35 minutes to eight hours per day throughout the 24-hour period to ensure a full picture could be obtained. Observational visits were intensive when a case study was recruited to ensure a comprehensive picture was realised. Staff were involved in the study throughout the period of observation, and more intensively for shorter periods as members of a case study. Parents were involved in the study for the duration of the child's admission to PICU and up to the final interview, which took place some weeks or months after their child's recovery and discharge from PICU /or death.

4.1 Participant observation

Participant observation is a central canon of ethnography and a popular research methodology within health settings since it has the potential to be an unobtrusive means of data collection (Rashid, Caine & Goez, 2015: Higginbottom et al 2013). Observation was non-continuous over the period of the study because of the unpredictable nature of admissions. Nevertheless, in order to remain acclimatised and acculturated to the PICU, continuing contact and less intensive observation periods were undertaken even when there were no participants who fulfilled the criteria for entry into the study. These general observations of the decision making process for children who were anticipated to survive provided additional enlightenment. Awareness of the study was promoted by the use of posters on boards at the ward entrance, in the main ward area and in the relatives' room. Whenever feasible I tried to be open with all parents of children admitted to PICU. I endeavoured to alert them to my presence as a researcher, though this was not always possible given the nature of the environment. During these periods, observations were undertaken on two to four occasions per week.

4.2.1 Structure of observations

Observation as a methodology initially appears relatively straightforward. Attend the study field, watch what is happening in respect of difficult decision-making and record these interpretations in field notes. Yet, conducting observations entails a variety of activities beyond acknowledging the importance of deliberating what to observe, when to observe, how to structure observations, was prerequisite to ensuring effective ethnographic enquiry. As detailed later, developing rapport, identification of key personnel, recording field notes, analysis and writing up are all fundamental. Particular emphasis was placed on detailing decision-making activities and the process of resolution of any differences.

Merriam (1998:97) acknowledges where to start looking is determined by the research question "*but where to focus or stop action cannot be determined ahead of time*". I was very conscious that decisions made at the commencement may impact on the overall study. Angrosino and de Perez (2000) detail three types of observation: descriptive observation in which one feels compelled to observe and record all details; focussed observation when the researcher is guided by participants' insights as to how to focus observations; and lastly selective observation where the focus is on specific happenings to describe differences in those happenings. Descriptive observation aligned to my early watches when as a naïve researcher I felt almost overwhelmed by a need to be ever-present on the PICU for fear of missing crucial data. It was not until much later on that I was able to be more discriminatory and comfortable in focussing observational episodes particularly when there was no continuing case study on-going.

4.2.2 Conversations

It was through the interactive nature of observations and conversations that knowledge was acquired and developed beyond description. Discretion was manifest in considering what constituted the public and private settings. Posters in public and main patient areas advertised the study. Verbal assent for my presence on the unit was always obtained on an iterative basis prior to each observation from the nurse-in-charge. Demonstrating judgement and integrity in notating ad-hoc conversations was crucial in ensuring continued immersion. A conscious decision was taken not to use any discussions occurring in the staff room, to avoid blurring of boundaries. This was the only area where staff members could relax and unwind when on duty. Informal and ad-hoc discussions were conducted with the staff and parent participants at a single or multiple time points during the study period. The number of conversations was dependent upon the significance of the person to the child, their involvement with them, as well as the length of hospitalization. Field notes were used to record meaningful characteristics of therapeutic interventions and the communication exchanges surrounding these.

4.2.3 Recording observational data

Prior to entering the observational arena it was necessary to consider how to record observations and the use of field notes (Hammersley and Atkins 2007; Wolfinger 2002). Field notes were undertaken in written format and included both descriptive and reflective information. Preliminary analysis occurred simultaneously to foster reflexivity, since reflexivity was essential for gaining understanding and ascribing meaning (Silverman 2000). Prior to commencing in the field, the importance of being inconspicuous was acknowledged, note taking throughout was required to be congruent to both circumstances and settings. Practically undertaking extensive field notes was undesirable, impractical and would have been disruptive (Lawton 2000, 2001). Consequently, it was not possible to write all field notes contemporaneously, resulting in selective description of salient issues in accordance with the research objectives during breaks from observations. Inevitably, perceptions of salience reflected tacit knowledge and beliefs, since choice was exercised in determining what was recorded (Wolfinger 2002). The importance of developing a rhythm to writing notes at the earliest opportunity following observations to aid memory recall was recognised (Silverman 2014). Code names were ascribed to all participants, so that identities were protected.

4.3 Presence in the field

4.3.1 Acculturation and acclimatisation:

Conducting research in a busy PICU was recognised from the outset as challenging. A strategy for an initial eight week period of acclimatisation and acculturation was scheduled. By primarily engaging in social interactions with the PICU team during this time, I wanted to establish a rapport with staff and initiate the foundations for development of trusting relationships (Hammersley & Atkinson, 1995; Seymour 2007). Given the sensitive, highly emotive nature of the study, development of trust and familiarity was necessary if honest, open and conversational discourse was to be engendered (Gerrish, 1997).

Becoming a ‘familiar face’ entailed repeated attendances at nursing and medical staff handovers, attending morning and evening ward rounds, ward meetings and doctors’ briefings. By making acquaintance with members of the PICU team, committing to clarifying the nature of the observation role, the intention was to minimise misunderstanding and avoid any erroneous notions about the study combined with facilitating staff recruitment.

This period of acculturation and acclimatisation also referred to as 'sensitizing' within social research (Padgett 2004; Charmaz 2003; Patton 2002), acted as a starting point for the study. Although the study focused on detailed engagement with cases, observation of the on-going operation of the PICU allowed me to gather an extensive knowledge and understanding of the unpredictable and erratic nature of PICU, of every-day activities and routines, how care is organised and delivered together with idiosyncrasies of practices. Observing patterns of professional and social communications and interactions both between parents and professionals and amongst professionals, permitted the generation of a nuanced understanding of the social relationships. Qualitative researchers have highlighted the importance and distinctiveness of these relationships (Gair, 2012; Holloway and Biley, 2011; Bonner & Tolhurst, 2002; Finlay, 1998). Collectively these insights further enabled me to communicate and establish rapport more effectively with participants, particularly clinicians and additionally guided where to focus attention when identifying potential case studies. Straightaway, being able to understand and interpret communications so that I could be cognisant and alert to what was happening in the research context was recognised as being paramount.

> *Handover would have been unintelligible without prior knowledge and experience of PICU. No accommodation was made for either self or medical student present. Assumption made that I would understand all diagnoses, treatments, etc. Will have to rapidly upskill and refresh knowledge base otherwise nuances will be missed.* [Extract from field notes, Day 1 Acculturation Period]

4.3.2 Prolonged immersion/staying in the field

Immersion into the PICU setting was recognised to need to be on-going throughout the study, given the difficulties in predicting when case studies may arise. Continuing contact and immersion in the field was costly in terms of time and commitment, not only by self, but especially on the part of the PICU team as hosts. Murphy and Dingwall (2007) acknowledge that the status of self as a guest in the setting is tenuous, being dependent on sustained engagement and conduct. This was especially important given the six monthly rotations of junior medical and nursing staff through the unit and the resultant changes in expertise and culture. The development of long-term trusting relationships positively influenced the quality of data obtained. HCPs may feasibly have manipulated their behaviours by seeking my opinion of actions during early encounters, focussing on aspects that they thought I may want to observe or hear.

> *The response of senior medical staff to the recruitment of the first case study has been supportive and welcoming. However, it was clearly evident during the ward round that x (consultant intensivist) anticipated that I should pass comment on actions. Proficiency in deflecting questions and withholding my thoughts and opinions is vital. Am also experiencing reservations that any questions posed by me have the potential to influence actions. Will my presence become less obtrusive over time?* [Extract field notes]

Prolonged engagement may feasibly have acted as a check against the so called Hawthorne effect whereby participants, in this instance the HCPS, modify their behaviours (McCabe & Holmes, 2013). Alternatively, as Mulhall (2003) proposes, given participants' other priorities in the PICU environment, researcher presence and characteristics may well be overlooked. Moreover, sustained immersion facilitated the collection of nuanced complexities and minutiae as opposed to superficial, self-conscious and reactive data.

4.3.3 Observer role /role of the researcher

Due to the in-depth nature of the study, Delamont (2004) cautions that relationships may be formed between the participant and investigator. This required me to be critically aware and to engage in a continuous struggle to both acknowledge and reflexively analyse any barriers and balance relations (Murphy and Dingwall, 2007). A number of characteristics, including my age, gender, professional status, and perceived power differences (Hewitt, 2007) will always influence any relationships involving participants and self.

Power relations between participants and self as a researcher were complex within this study. Status difference between medicine and nursing meant that I was on occasion perceived in a subordinate position by doctors, and a position of power by nursing staff being expected to know ‘what it is like’ (Cudmorree & Sondemeyer, 2007), together with an expectation that I may be able to act as an intermediary. As a female researcher in a caring environment, I was perceived as unthreatening by some families, particularly in lieu of brief self-disclosure of background and interest in this area. However, being female and a nurse limited access on one occasion. The family were positioned within an ethnic culture where the professional standing of medicine and being male enjoyed much higher status and was sufficient to deter parental involvement with the research project for fear of wider family opposition.

4.3.4 Insider or outsider

As Aull-Davies (2012) concedes, participant observation is oxymoronic, tension existing between observer and participant roles. In negotiating access, it was readily apparent that the roles of complete participant or complete observer were unethical and methodologically unsound (Bryman, 2008; Seymour, 2007). My professional background as a PIC nurse precluded me from adopting the role of a naïve enquirer. A dialectic relationship does however exist, since I was in the complex dual role of being both a researcher and clinician (Carter, 2006). Reflexive consideration of my role and relationship identified that I was placed between the ‘hybrid’ and ‘insider’ position within the study (Reed and Procter, 1995), since I had existing knowledge of some key clinicians from working directly in this speciality. McEvoy (2001) warns assumptions may be made about ‘insider’ knowledge, which may make it difficult to question matters considered self-evident or established practices. Goodwin et al (2003) similarly cautions that familiarity whilst generating thick description can simultaneously reveal and blind. Furthermore, others caution that I may be perceived in the duplicitous role of a ‘spy’ (Cudmore & Sondemeyer, 2007; Bonner & Tolhurst, 2002; Roper & Shapira, 2000). I openly disclosed my identity as a children’s intensive care nurse from the outset of the project.

Unsurprisingly, as I became integrated into the unit, my identity as a researcher became faded and amorphous. Relationships naturally formed, becoming a confidante or friend. On these occasions, tension existed as to how to proceed with information disclosed during these ad-hoc encounters (Atkinson 2009). Throughout, as Manias and Street (2001) describe, I continuously had to relocate myself, accepting and understanding the dynamic and developing research identity.

4.3.5 Researcher or nurse

Becoming an accepted and integral part of the team was paramount to the success of the study. Having determined from the outset that I would not take on the role of a nurse, this required me to be proactive in managing relationships. Initially the urge to gravitate towards a role I could identify with was great and corresponded with my desire to assimilate. During times when the unit was hectic, I undertook a role of a general helper, assisting in non-patient care e.g. tidying and restocking equipment and making drinks for staff who may otherwise have gone without refreshments. Undertaking these activities was fundamentally a means of assuaging my own guilt of being an observer of the goings-on. Such activities may also have made staff more accommodating and open. Throughout the duration of the study on occasions when the unit was particularly busy, some senior nursing staff who were aware of my critical care background propositioned that I should reverse roles and assist with nursing duties. On these occasions I felt guilty, caught between, as Brannick & Colgan (2007) describe, “loyalty tugs” and “behavioural claims”, belonging to neither the world of the researcher or the nursing profession. Subsequently, during clinical supervision I explored the fluidity and multifaceted nature of positionality. I then was able to recognise that I aligned to what Dwyer and Buckle (2009:61) describe as the ‘space between’ my role as an-observer-participant. By adopting a dialectical approach embracing and exploring the intricacies of situational identity within field notes and ensuing analysis I was able to engage without becoming a member.

4.4 Interviews

Follow up of the case involved a series of face-to-face semi-structured interviews, which were conducted with participants including parents and key members of the health care team. The use of semi-structured interviews was important to the study for three reasons. Firstly, it allowed participants an opportunity to clarify and put into context what had been seen and experienced, their ‘lived experience’ (Fetterman, 2010). Secondly, semi-structured interviews also served comparative and representative purposes, ensuring different perspectives were explored to gain a representation of social and cultural realities (Aull-Davies, 2008). Thirdly, they enabled detailed exploration of the values, beliefs and modes of reasoning used by participants when making decisions about treatments and facilitating exploration of theoretical issues identified within the established literature.

Interviews were designed to allow for a two-way conversational approach. Thus, feelings and experiences were able to be captured, expediting greater understanding of the process and fluidity of making difficult decisions as befits an under-researched topic (Murphy and Dingwall, 2003). What people choose to share is important in the qualitative interview enabling participants to have agency in construction of their viewpoint. Therefore, although schedules had been developed and informed by examination of the existing literature, not all areas outlined in the interview guides (appendices 8,9, & 13) were necessarily covered. Furthermore, questions were open ended to ensure that participants could determine the progression and content of interviews. As interviews sometimes progressed in unexpected directions such flexibility afforded greater opportunity to explore participants’ interpretations, pursing alternative angles and lines of enquiry that may otherwise have been neglected.

All interviews were digitally recorded, to facilitate interaction between the interviewee and myself. Immediately following the termination of interviews reflexive notes documenting thoughts, feelings, initial impressions and evaluations were recorded, contributing to overall data analysis. All interviews were transcribed verbatim, at the earliest convenience following the session, so that data could be analysed as they were collected.

4.5.1 Interviews with professionals

Interviews with staff members were conducted as soon as possible after observational periods, at their convenience, in a private room away from the clinical area. In total 26 interviews were conducted with HCPs during the study period, 12 with medical staff, 13 with nursing staff and 1 allied health professional (AHP). Interviews ranged in duration from 20 minutes to 1 hour with a mean duration of 42 minutes. Arranging interviews required considerable flexibility, the unpredictable nature of the critical care environment frequently resulting in interviews being postponed and rescheduled. Interviews were sometimes interrupted, when due to the exigencies of the field setting participants were ‘pulled back’. Consequently, despite in the main staff members readiness and commitment to participate, I was always conscious that time was pressured. Moreover, flow on occasions was dislocated, resulting in a failure to generate the breadth and depth of enquiry being sought.

Nursing and AHPs were very receptive and open within interviews. These provided a means of validating their experiences, and an opportunity to explore their role, which was frequently described as marginalized. For many it provided a safe environment for emotional release, being described as beneficial. The interview provided a rare opportunity to explore difficult and distressing events and comment on service related issues.

> *“I think when you revisit things like this it’s always better, because sometimes you just, you don’t get to talk about it again… the opportunity never really presents.”* [Nurse 9]

Senior doctors, across specialisms, were very supportive of interviews and forthright in discussion. Even so, significantly during one case study, Edward (Section 3.5.4. p 123), there was unwillingness by key protagonists to participate. On this occasion differences in values, beliefs and interpretations came close to breaking down professional relationships across the medical specialities, an atmosphere of distrust and professional suspicion was evident. Senior medical staff when invited to participate declined to be interviewed. One stated that they had little else to offer than had been discussed within a previous case study. A second advised that they did not perceive they were an appropriate person to be able to provide any knowledge and insight above what I had observed. The third, whilst initially verbally consenting to be interviewed, subsequently was unavailable, being unable to identify any available time, when requests to arrange an interview were made. Medical staff below the level of consultant genuinely believed and stated that they did not actively participate in decision-making, but were merely actors carrying out directions, mostly declining to be interviewed. Two junior doctors consented to interview, although one moderated their responses whilst recording was underway.

Although the junior doctor expressed willingness and consented to interview this was the most taxing interview undertaken. The interview itself felt adversarial in nature due to reluctance on the part of the doctor to fully discuss issues. Throughout the formal interview they sat with arms and legs crossed, leaning forward. On reflection, this great reluctance to commit to interview may have been a result of concern that somehow by doing so this could impact upon professional progression. Significantly, when the interview had finished and the recording device switched off, the doctor became much more verbose and visibly relaxed.

> *(name) commented that caring for Edward had been extremely stressful. It was divulged that they had suffered from sleepless nights and anxiety, because they were aware of power dynamics amongst senior staff and whether there may be any repercussion*

> *although it was not disclosed what these were.* [Extract from reflective notes]

It was explicit that these rich comments were off the record and therefore were not included in data for analysis. The dynamic in relationships meant that I primarily only engaged with junior medical staff on an informal conversational basis.

4.5.2 Interviews with parents

Retrospective interviews with parents took place between 6- 22 weeks after the discharge from PICU or death of their child respectively. Data generated remains relevant and enlightening of the study's aims affording parents' opportunity to share their experiences. The timing, setting and duration of the interview was largely determined by the parents, recognizing their agency and a need to adjust to their circumstances. This included willingness to talk, presence of others in the home/hospital setting and a genuine desire to avoid generating distress. Three sets of interviews took place in the family home, three within the hospital setting. On a practical level, negotiating interviews when the child remained within the hospital setting resulted in repeated attempts to schedule interviews.

Two sets of parents initially requested joint interviews, although one set, due to personal exigencies, were subsequently interviewed individually. This followed a maternal request, due to the sheer practical difficulties of negotiating a convenient time. For many parents the interview was the first opportunity to talk in depth about their child's illness, providing validation for their experiences. Most took the opportunity to talk expansively about difficult and distressing events, finding emotional release.

> "*it's actually been quite cathartic for me so thank you.*" [Eric]

This aligns with Stevens et al's (2010) research with vulnerable families caring for children with life-limiting conditions whose participants also described the interview process, despite the sensitive nature of the topic, as cathartic.

4.5.3 Documentary review

With permission, the medical records of case study participants were also reviewed, to retrieve data relevant to decision making about WLSMT alongside the use of observation, and interviews. Documentary analysis examined medical and nursing records at three levels: the level of discourse produced, the text; the level of the interaction i.e. the processes of production and interpretation that occur between individuals; and the level of the context, the social relationships between the author and intended audiences (Aull-Davies 2008). Furthermore, since the observational period was non-continuous, inevitably resulting in some gaps, by referring to the medical and nursing notes, in addition to liaising with key research participants, this enabled details to be apprised in accordance with ethnographic techniques (Fetterman, 2010).

Challenges in accessing documents required careful management due to them being ‘live’ documents open to constant examinations by professionals involved in the case. I was particularly aware of being unobtrusive when accessing medical and nursing documentation, being mindful that accessing these may influence HCPs. Entering the project, I had naïvely assumed that photocopying and anonymising documents prior to removal from the research site would be relatively trouble free and uncomplicated. I rapidly became cognisant to the practicalities of attempting to discreetly use an unreliable photocopier, situated within the busy main desk area on the PICU. A hand held scanner was purchased, transforming the collection of documents. Discreet upload of pertinent documents that contained reference to decision making processes was enabled. Nonetheless, the time required for uploading, anonymising and storage of in excess of 400 documents throughout the study was wildly underestimated.

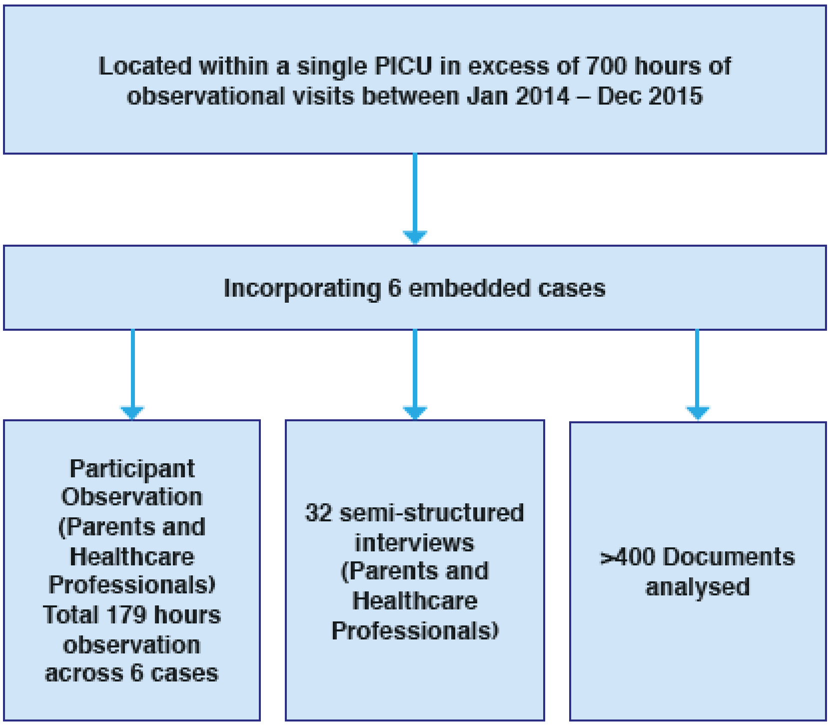
4.4 Data analysis

An immense body of literature providing guidelines for qualitative data analysis exists (Silverman, 2014; Boeije, 2010; Blaikie, 2007; Stake, 1995; Miles and Huberman, 1994), each offering different and nuanced approaches (Holloway and Todres, 2003). Whilst there is no one form of qualitative analysis, Hammersley and Atkinson (2007) propose that analysis of data collected by ethnographic methods is not conducted as a separate stage, but remains an inherent, on-going part of the research. Consequently, data collection, management and analysis occurred simultaneously, an iterative process allowing emerging issues and themes to be explored (Parahoo, 2006; Sharkey and Larsen 2005).

4.4.1 Data management and transcription

Data management involves the creation of manageable, catalogued and workable datasets. The fluid and emergent nature of qualitative research is ‘inherently messy’ (Sinkovics & Alfodi, 2012), producing vast quantities of data requiring management (Mays & Pope, 2000). Throughout the study, the main sources of data were from the observations, interviews, inspection and examination of documents, field notes and reflective notes as summarised in Figure 9.

Figure 8: Data collection process



Data was collected and governed in accordance with the core principles of the Data Protection Act 1998. All electronic audio data and scanned copies of anonymised documents were encrypted and uploaded onto a password-protected university server. Source data, including hand written field notes, were stored in a locked cabinet within a locked room. Access was limited to my PhD supervisors, any relevant regulatory authorities and myself.

Audio data collected in interviews was listened to and transcribed verbatim into an electronic format, Microsoft Word™. This process, whilst very time-consuming, enabled intimate knowledge of and engagement with the data (Bazeley, 2013). Once transcribed, and as part of quality processes, all identifiable information was removed and the transcript read whilst re-listening to the recording, to ensure accuracy. Ethnographic field notes and documentary evidence were also integrated into the dataset.

All data were originally intended to be imported into computer-assisted qualitative data analysis software (CAQDAS) NVivo10™, to facilitate the sorting, coding and categorising of the data. CAQDAS has been subject to criticism for over simplifying and fragmenting research (Bryman and Bell, 2004), and being too restrictive in application (Bazeley, 2013). Nonetheless, this process delivers, as far as possible, transparency and a detailed audit trail, consequently providing credibility and rigour when managing large volumes of textual data (Green and Thorogood, 2014; Sinkovics & Alfodi, 2012; Silverman, 2010). The researcher additionally retains responsibility and discretion, being required to utilise analytical skills to prepare, import, scrutinise and import data. This ensures that analysis extends beyond mere description of themes and provides understanding of the phenomena (Creswell, 2007; Thorne, 2000). The software also provided the researcher with links between the original passages and the codes, which permitted the quick retrieval of ideas and concepts during the (iterative) process of analysis (Bazeley and Jackson, 2013). The NVivo software additionally facilitated the creation of concept maps, as provided in Chapter 5 for each of the case studies. These informed the hierarchy and relationships among codes and themes presented in the subsequent results chapters. Throughout, the process of assembling the data corpus, a reflective journal, identifying insights, points of interest and early interpretations was kept and informed early data analysis (Bazeley, 2013).

4.4.2. Thematic analysis

This study aims to understand how difficult decision-making, within the context of best interests, occurs in the PICU, and how this is revealed across cases and contexts. Thematic analysis is one approach available to facilitate organisation, analysis and development of themes within a data set (Braun & Clarke, 2006). It is described as a flexible method, which allows exploration and detailed understanding of the perspectives of different research participants, enabling the identification of similarities and differences (Green and Thorogood, 2014; Braun & Clarke, 2006). Furthermore, King (2004) suggests that it is useful for large data sets, as in this study, providing a robust, systematic framework for inductive analysis. Findings emerge from the raw data via development of themes and codes (Blaikie 2007). Deductive approaches, through the imposition of a pre-determined framework, could distort findings and misrepresent the phenomena (Green and Thorogood, 2014; Holloway and Wheeler, 2010). While it is not feasible for data analysis to be purely inductive, given that prior knowledge and experience inevitably affects what emerges (Green and Thorogood, 2014), adoption of an inductive approach enabled development of the 'emic' perspective, (Parahoo, 2006, Steubert-Speziale and Carpenter 2011). Relationships between code categories and the establishment of significance of these were able to be realised from the dataset.

The process of analysis involved a combination of approaches as advocated by Miles and Huberman (1994), Braun and Clarke (2006) and Stake (1995) framework. Data were analysed using a two stage approach of multiple case analysis: within case analysis and cross case analysis (Yin, 2009).

The process of analysis can be problematical and lacking rigour if transparency in deciding how themes and concepts are sorted, coded and indexed is not upheld (Denzin & Lincoln, 2011; Ritchie, Spencer and

O'Connor 2003). A three-stage process for ethnographic analysis of the data: description, analysis and interpretation has been proposed by Wolcott (1994).

- Description - providing a straightforward, detailed description of the setting and events.
- Analysis – the search for themes and patterned regularities; comparison of the cases to each other and drawing connections.
- Interpretation – making inferences from the data including comparative interpretations.

Miles and Huberman (1994:10) similarly offer three phases of interactive and recursive activity: data reduction, data display, and drawing and verifying conclusions. Data reduction involves analytic choices, the process of coding, summarising and identifying categories and themes. Data display serves to seek meanings through the development and organisation of data into visual displays. The matrices or networks organise and expose relationships in terms of similarities and differences. This enables the incipient meanings and concepts including the subsequent drawing and verifying of conclusions to be derived from interpretation of the raw data. The cyclical process of data analysis consisting of "*sketching ideas, taking notes, summarising field notes, working with words, identifying codes, displaying data, reducing codes into themes, counting the frequency of codes and relating categories.*" (Miles and Huberman, 1994, cited in Creswell, 2007: 149).

Braun and Clarke (2006) propose an iterative and reflective approach for thematic analysis. This involves a moving back and forward between six phases of thematic analysis: familiarisation with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a report.

Stake (1995) proposes that within qualitative case study data analysis, because multiple data sources are utilised that the analytic framework should focus on triangulation to ensure that the multi-dimensional properties are explored fully. Stake proposes a four-step approach to data analysis and interpretation: categorical aggregation, direct interpretation, establishment of pattern and development of naturalistic generalisations.

4.4.3 Familiarisation with the data

This involved transcribing the interview data, repeatedly reading and re-reading through transcripts, documents and field notes, noting down initial thoughts and ideas. This enabled the emergence of first impressions and potential codes (Braun and Clark, 2006; Miles and Huberman,1994)

4..4.4 Generating initial codes

Data was entered on NVivo10™. Initial codes were generated through systematically identifying interesting features of the data by writing relevant codes more or less from participant's words or from memos (Braun & Clark, 2006; Miles and Huberman 1994). All codes were labelled and given a description which allowed for the development of code books which provided a brief and full definition of a code (Bazeley, 2013).

4.4.6. Searching for themes

Use was made of tree nodes and also the free nodes function within NVivo to sort and rank codes. In many instances it was feasable to identify how concepts related to each other, through building tree nodes and creating a hierachy of codes. However the need for flexibility, to be able to move codes between free and tree nodes, as well as to different tree nodes enabled opportunity for re-thinking, and re-sorting of the emerging themes. As Stake (1995) proposes, patterns were established through looking for similarities and divergence, and sorting into themes.

4.4.7 Reviewing themes

This included checking to see if the themes 'worked' in relation to the coded extracts. The process of making contrasts and comparisons, seeking to collate and assemble information to gain meaning (Bazeley, 2013) enabled generation of a thematic 'map' of analysis.

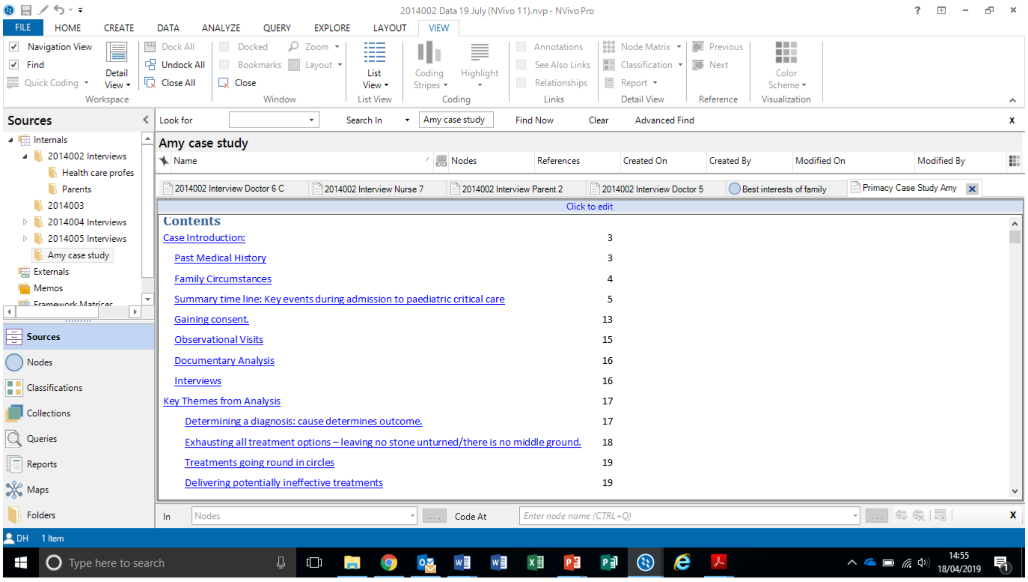
4.4.8 Defining and naming themes

As part of the on-going analysis, relationships across codes, and between two or more levels of codes i.e. categories, main themes and sub-themes (Bazeley and Jackson, 2013) were further refined to detail the specifics of each theme.

4.4.9 Within case analysis

For each case, once data collection was complete within case analysis entailed focusing on the multiple sources of data to formulate a comprehensive case study report (Baxter and Jack, 2008), Figure 10. Engagement included a contextual description of the case combined with bound insight of the phenomena. Stake (1995) advises that triangulation of data enables multi-dimensional exploration of the similarities and differences of the phenomena. These individual case studies ensured that the uniqueness of each case could be displayed within its own context (Stake, 2006).Connecting with the data set included

Figure 9: Screenshot NVivo case study report



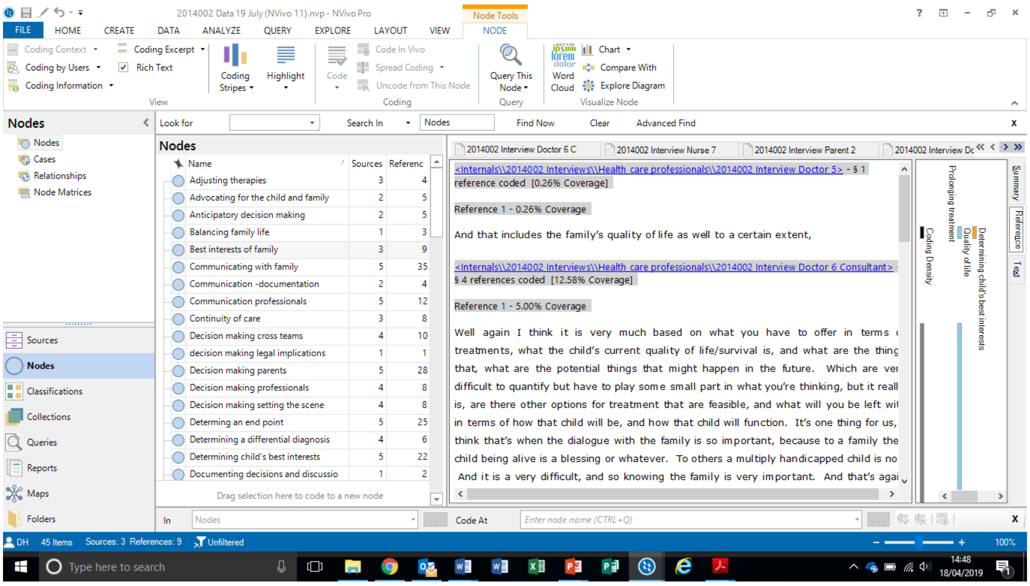
Contents

Case Introduction: 3
Past Medical History 3
Family Circumstances 4
Summary time line: Key events during admission to paediatric critical care 5
Gaining consent. 13
Observational Visits 15
Documentary Analysis 16
Interviews 16
Key Themes from Analysis 17
Determining a diagnosis: cause determines outcome. 17
Exhausting all treatment options – leaving no stone unturned/there is no middle ground. 18
Treatments going round in circles 19
Delivering potentially ineffective treatments 19

re- familiarising with multiple sources of data: reading and re-reading field notes and documents, listening to interviews whilst simultaneously reading transcripts. This was somewhat challenging in light of the sensitive and emotive nature of the topic, particularly when listening to parents in distress. Paradoxically, it was more emotionally taxing to listen to recordings than undertaking the interview, possibly, as Dickson Swift et al (2008) suggests, due to the freedom of being able to react.

Combing the different data sources enriched understanding, identification and analysis of concepts arising in each case (Figure 11). Accordingly, the themes generated were as Saldaña (2009:13) states *"an outcome of coding, categorisation and analytic reflection."* Emergent themes were refined, grouped and categorised thematically by the iterative, non-linear, cyclical process of progressive focussing (Hammersley & Atkinson, 1995). This approach provides the potential for exploration of emerging themes or issues across cases, accumulation of instances and identification of divergent cases.

Figure 10: Screenshot NVivo within case analysis



Nodes

Name	Sources	Referenc
Adjusting therapies	3	4
Advocating for the child and family	2	5
Anticipatory decision making	2	5
Balancing family life	1	3
Best interests of family	3	9
Communicating with family	5	35
Communication -documentation	2	4
Communication professionals	5	12
Continuity of care	3	8
Decision making cross teams	4	10
decision making legal implications	1	1
Decision making parents	5	28
Decision making professionals	4	8
Decision making setting the scene	4	8
Determing an end point	5	25
Determining a differential diagnosis	4	6
Determining child's best interests	5	22
Documenting decisions and discussio	1	2

<Internals\\2014002 Interviews\\Health care professionals\\2014002 Interview Doctor 5> - § 1 reference coded [0.26% Coverage]

Reference 1 - 0.26% Coverage

And that includes the family's quality of life as well to a certain extent,

<Internals\\2014002 Interviews\\Health care professionals\\2014002 Interview Doctor 6 Consultant> - § 4 references coded [12.58% Coverage]

Reference 1 - 5.00% Coverage

Well again I think it is very much based on what you have to offer in terms
treatments, what the child's current quality of life/survival is, and what are the thing
that, what are the potential things that might happen in the future. Which are ver
difficult to quantify but have to play some small part in what you're thinking, but it reall
is, are there other options for treatment that are feasible, and what will you be left wi
in terms of how that child will be, and how that child will function. It's one thing for us,
think that's when the dialogue with the family is so important, because to a family the
child being alive is a blessing or whatever. To others a multiply handicapped child is no
And it is a very difficult, and so knowing the family is very important. And that's agai

4.4.10 Across case analysis

Cross-case analysis refers to the process of searching for patterns, commonalities, anomalies and inter-relationships across the six case studies, expanding understanding. Stake (2006) suggests that the complexities of the study are enhanced because exploring how each case is unique bringing added understanding to the phenomenon.

Bazeley (2013) suggests that this includes three steps: identifying concepts, themes or issues that go across cases, grouping similar cases and thirdly synthesising interpretations through exploration of similarities and divergences to understand the study phenomena. Due to the extended duration of the study, cross case analysis occurred temporally as cases were completed and was also repeated across all cases when data collection finished. Through the iterative and inductive process of repeatedly reading case reports, re-examining findings, analysis was able to be refined and revised, allowing broader themes to be developed whilst retaining the context of each case. NVivo™ software enabled visual displays for cross case analysis to be generated, facilitating visualisation of relationships within the data. Throughout the process, memos recorded the rationale for decisions made about themes. This repetition of analysis enabled thorough interrogation of the data but, as Charmaz (2005) identifies, it is vital that the researcher remains open and that all data should be considered prior to confirmation or rejection of ideas.

4.5 Ethical issues in the field

4.5.1 Consent

Informed consent is fundamental to the research process and how consent is achieved can generate ethical concern (Johnson & Macleod Clarke, 2003; Gerrish, 2003; Jones, 2002).

As the study utilised ethnographic methods, consent was continuously renegotiated (process consent) as relationships evolved, especially during happenstance interactions (Fetterman, 2010; Roper & Shapiro, 2000). Consent is a process and not a one off event (Dewing, 2007; Butterworth, 2005), open to a myriad of factors that influence behaviours including culture, socio-economic and educational background. For parent participants there was recognition of their heightened vulnerability due to the level of stress a PICU admission brings. On-going assessment of decision-making capacity to prevent potential exploitation of parent participants was undertaken in conjunction with PICU staff. The need to continuously focus on the significance of peopling ethnographic investigations by adopting a reflexive approach whereby autonomy, dignity and privacy are respected is acknowledged and outlined in the study regimen flow diagrams (Figure 5 p71 & Figure 6 p72) (O’Reilly, 2012; Aull-Davies 2008). The imperative throughout was to work collaboratively with parents and the health care team at a level and in a way that they feel comfortable (Murphy & Dingwall, 2007).

4.5.2 Initial approach to parents

Participants, specifically parents, may be considered a “vulnerable group” due to the emotional turmoil of being a parent of a critically ill child. Studies exploring parental participation in research suggest parents of critically ill and dying children choose to participate in research to benefit future children and families who may find themselves in a similar situation (Lyons, 2012; Hoehn, Wernovsky, Rychik et al. 2005; Kassam-Adams & Newman, 2005). This altruistic perspective, of choosing to participate with beneficent intent, has also been a theme throughout the cases recruited to this study. Scott, Valery, Boyle and Bain (2002) acknowledge that parents expect to find aspects of participation painful, thus particular attention was given to monitoring and avoiding distress during data collection. Those parents that have experienced distress when participating in qualitative research studies still report that they found participation a positive experience (Olcese & Mack, 2012; Scott et al 2002). These findings are consistent with previous research exploring parental research participation into sensitive areas, including sudden and unexpected death of a child, and research with bereaved parents (Taneja, Brenner et al 2007; Hynson et al, 2004).

East et al (2010) suggest that participants are able to recognise their own agency when revealing information, contending that they find it empowering to be heard and represented. This concurs with Corbin & Morse (2003) who warn that participants should not be treated as passive recipients. Nevertheless, this had implications for the study, ensuring consent was continuously renegotiated as relationships evolve.

Additionally, within the PICU setting, participation in research is compounded with some children being eligible to be recruited to more than one study. It was not considered unusual, or a conflict, for children to be potentially co-enrolled to two or more studies. However, it does pose an ethical dilemma that parents within critical care may be overwhelmed by potential chances to participate. There is a requirement to work sensitively with families to ensure they are not overburdened. Considerable clinical judgement and negotiation with the lead consultant for the child's care was required when co-enrolling participants.

4.5.3 Timeframe for consent

It is never a simple task to find the right time to approach parents about participating in research, particularly when the nature of the research is so sensitive and the potential for generating distress high. The practice of obtaining informed consent from families was recognised as challenging prior to commencing the study and the process is detailed in Figures 5 & 6 (Figure 5 p71 & Figure 6 p72). Consent is a relational and sequential process (Murphy & Dingwall, 2007). Whilst conceding that there is no ideal time, being unable to predict what may or may not be useful to observe, or who it would be useful to interview, compounded the quandary. Ethical approval permitted observations to be conducted prior to gaining consent. When commencing observations, parental consent is tentative and limited, recognising that parents may well be experiencing extreme emotional distress. The need to be empathetic and sensitive to allow parents sufficient time to fully consider information and to reflect on what participation entailed was of paramount importance. Throughout, I deferred taking informed written consent until parents had time to confer fully amongst family members and with PICU staff. Usually, I arranged to return following an agreed interval, typically the following day. In the interim, verbal assent was considered sufficient to continue to proceed with ethnographic observations.

> *I clarified why consent had not been sought the previous day. Mum commented that she 'had been out of it yesterday' and wouldn't have been able to decide anything. This reaffirmed the decision to delay seeking consent……... The challenge, to obtain timely consent whilst ensuring parents are not pressurised and are*

> *afforded opportunity to be fully informed in their decision making…..*[Extract field notes]

Consultant intensivists were instrumental, when children were admitted to PICU, in acquainting parents with the study and advising that they may be approached.

> *The PICU consultant on call overnight alerted me as I entered the unit, ……He stated that he'd already mentioned to Mum about the research studies that were in progress on the unit and which they may be asked to consider participating in….* [Extract field notes]

These interactions with consultants and nursing staff influenced responses to requests for participation. By setting the scene, parents had an opportunity to ponder participation.

Entry into the study was voluntary. It was explained to parents that their child's treatment and care would not be affected by their decision. Parents were able to decline to participate as demonstrated within (Figures 4 & 5 and Appendices, 4, 6 & 7). Although legally only one parent is required to consent, if both parents held parental responsibility for the child, then consent to participate was sought from both parents. The prerogative of parents to exercise veto is exemplified in two cases. Whilst the parents in both cases gave informed consent, two fathers imposed limits to the extent of consent. One stated that although he had consented for himself and his child to be involved in the study, he did not wish to be interviewed following his child's discharge. He also did not want to be asked any difficult questions at the bedside, but was nonetheless happy for observations to proceed in his presence. The second father, ten days after I had first approached for informed consent, verbally consented to his daughter's enrolment. He advised, via his wife that he consented to me talking with her, to undertaking observations, and accessing medical and nursing notes. However, he did not wish to talk or meet with me. Following this expressed request not to be approached by me again, I sought clarity as to the validity of this second party verbal consent. Following discussion, between myself, academic supervisors and lead intensivist there was agreement that the consent was valid. Mutual trust was only achieved by being sensitive, flexible and being explicit about the limits of involvement with participants.

4.5.4 Staff consent to participate

To overcome anxieties about coercion, ethics approval was contingent on gaining individual consent of staff to undertake observations. Staff members' willingness to consent made me query why none were choosing not to participate. When I questioned a number of nursing and medical staff as to why they were happy to consent to the study a consistent theme emerged; the PICU is a semi-public environment and all aspects of care delivery and management was already subject to scrutiny by professionals and children's families alike. Consequently, another person observing was not considered intrusive or unusual. Nursing staff across all grades embraced being involved with the research. Some nurses commented that they felt that this research actively involved them as participants and would allow them to have a voice.

The imperative was, at all times, to work collaboratively with the health care team at a level and in a way that they feel comfortable. On-going consent for participation was continuously negotiated. The need to continuously focus on the significance of peopling ethnographic investigations, by adopting a reflexive approach whereby autonomy, dignity and privacy of all participants were respected was acknowledged (O'Reilly, 2012; Aull-Davies 2008).

4.5.5 Consent of others

As Gerrish (2003) acknowledges, there is no control over who enters the research field, PICU is a highly complex semi-public setting. It would be impractical, if not impossible to obtain fully informed written consent from all who enter the PICU observation area. With the agreement of key stakeholders during early planning stages, it was agreed that full informed verbal and written consent would be provided by health professionals employed within the PICU. Accidental participants, other

HCPs and others who happened to attend PICU provided (when possible) informed verbal consent. Practically, this entailed introducing myself and the study and the HCP giving their verbal consent for observation to continue in their presence. The ever-present challenge was explaining the study in a way that was meaningful given the brevity and nature of these encounters. In the majority of instances, there is a presumption that HCPs attending the unit possess power and have the capacity to make informed decisions (Halse & Honey, 2005). Throughout the study some accidental participants, both HCPs and others, declined to consent and no notes or observations of their interactions were taken.

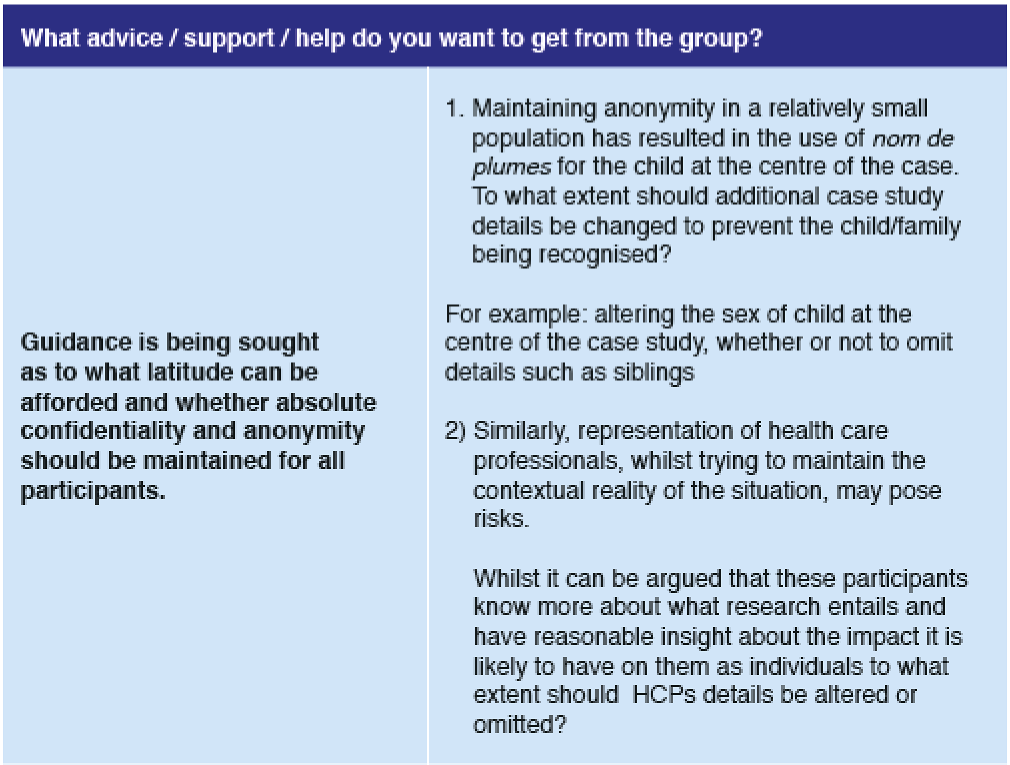
4.5.6 Confidentiality

Baez (2002) reports the ‘convention of confidentiality’ aspires for complete confidentiality as a means of preventing harm. Yet, maintaining confidentiality and anonymity, protecting the identities of participants, is acknowledged as particularly challenging in qualitative research (Kaiser, 2009). Tolich (2004) suggests deductive disclosure can occur within rich descriptions when individual participants or groups are able to be identified through characteristics and/or behaviours. Assurance of confidentiality was given during the securing of informed consent at the commencement of data collection (Appendices 11, 12 & 13). Yet, at this time how and what information will be used and disseminated is unknown and disregards the inductive nature of qualitative research (Aull-Davies, 2008; Johnson & Macleod Clarke 2003; Morse 2000). The singularity of the case studies generated meant that I was challenged by what Guilleman and Gillam (2004) describe as an ethically important moment. Whilst cleansing data of personal identifiers, I was aware that contextual identifiers may still remain, thus risking individual compromise (O’Reily, 2012; Gobo, 2008; Muprhy & Dingwall, 2007; Tolich, 2004).

Whilst ultimately the burden of responsibility for deciding what and how much to change lies with myself, there is considerable variance in what researchers do alter (Kaiser, 2009; Walford, 2005). Some make minimal adjustments in reporting their findings, whereas others generate entirely new personas, potentially altering meaning and validity of data (Kaiser, 2009). In consultation with supervisors and a medical member of the consultative group, it was acknowledged that HCPs, despite the use of pseudonyms may be able to recognise themselves and others both via descriptions providing contextualisation and through the use of quotes. Nevertheless, HCPs were all considered to be experienced in understanding and taking of informed consent. Therefore, it was felt that they have insight into the dissemination of findings and as Goodwin (2003:575) states “the community being researched is not passive.”

For study participants generally, there is a dearth of research exploring their perceptions about altering quotes and personal details. I took the decision to explore this issue with a Palliative Care PPI group, the specific queries detailed below in Figure 12.

Figure 11: PPI consultation schedule of questions



What advice / support / help do you want to get from the group?	
Guidance is being sought as to what latitude can be afforded and whether absolute confidentiality and anonymity should be maintained for all participants.	1. Maintaining anonymity in a relatively small population has resulted in the use of *nom de plumes* for the child at the centre of the case. To what extent should additional case study details be changed to prevent the child/family being recognised? For example: altering the sex of child at the centre of the case study, whether or not to omit details such as siblings 2) Similarly, representation of health care professionals, whilst trying to maintain the contextual reality of the situation, may pose risks. Whilst it can be argued that these participants know more about what research entails and have reasonable insight about the impact it is likely to have on them as individuals to what extent should HCPs details be altered or omitted?

Similar to Corden and Sainsbury (2006) study, polarised opinions existed amongst participants about having data amended. They concluded that details should not be altered, parents having provided informed consent.

Some PPI members suggested that they would not wish to be contacted having given consent for participation as to what data could or could not be included. Others aligned with Kaiser (2009) that a revised consent process that allows discussion of how data is managed could be introduced following final data collection. A decision was however made, not to go back to the individual families since this had not been made explicit as potentially occurring at the outset.

4.6 Chapter summary

This chapter has presented the methods of data collection and the process of data analysis undertaken in the field. Reflexivity has been demonstrated as to how ethical issues encountered were approached and managed. The next chapter will introduce the study field and six embedded case studies. It will also provide diagrammatic representation of detail of the key findings from each of the six case studies.

Chapter 5:

5. Setting the Scene

5.1 Introduction

The aim of this chapter is to 'set the scene'. The initial section presents the study field, a single PICU located in a Children's Hospital that provides regional services to a multi-cultural population in the UK. The second section introduces the case studies derived from the ethnographic fieldwork.

5.2 The study field

Typical of many critical care units, it is compartmentalised into a PIC zone and a separate High Dependency Unit (HDU) area. Given the focus of the study, children nursed in PHDU were not included in observations[6]. At commencement, the PICU was funded for six intensive care beds and four high dependency (HDU) beds. This increased to eight PIC and six HDU beds during the study. In excess of 400 children were treated annually (Table 1, page 66). During the eighteen month period of study a total of 4646 bed days were delivered and there were a total of 21 deaths.

5.2.1 The PICU team

The PICU intensivist coordinated and facilitated the care for seriously ill children, heading a multi-disciplinary team, which included other medical sub-specialists, nurses, clinical educators, physiotherapists, pharmacists, dieticians, occupational therapists, research nurses, social workers, clinical psychologists and others. Intensivists by virtue of their role must possess considerable knowledge and expertise across a spectrum of paediatric disciplines, their role having evolved as Epstein

---

[6] PHDU acts as a 'step down' from PICU and 'step up' from the wards providing specialist care for children requiring increased observation, monitoring and interventions than can be safely provided on a general paediatric ward, (Paediatric Intensive Care Society, 2010)

and Brill (2005) describe to being ‘generalist of paediatric sub-specialists.’ At the time of the study, the PICUs medical establishment was funded for six consultant posts, including a lead consultant who oversees the medical team. Five full-time consultants were engaged, the remaining post being locum filled. Throughout the study consultant vacancy rates varied, with considerable deployment of locums to ensure staffing standards were met (PICS 2010).

The children’s hospital provides RCPCH approved paediatric training for middle grade specialist trainees[7]. Six speciality trainees (ST) ST1-2 trainees and six grade ST3-6 trainees should be employed on PICU at any time to ensure minimum 1 ST1-2 and 1 ST3-6 cover on the unit at all times. Fill rates were however observed to fluctuate. Feasibly this reflects changing gender demographics within paediatric medicine and altered patterns of working (RCPCH 2012).

Nurses form the greatest proportion of the team, numbering 65 in total, ranging from Band 5 to Band 7. Those at Band 6 or above possess some managerial responsibility, being able to act as ‘nurse in charge of the unit’. This role encompasses co-ordinating the shift management of the unit, specifically the nurses, clinical support workers and to a degree the medical staff, whilst also responding to any issues arising. Band 7 nurses, whilst retaining a clinical role, have far greater managerial responsibilities. Clinical support workers assist in the general operation, undertaking tasks including housekeeping, administrative activities, manning reception, restocking and portering duties.

Staffing was acknowledged to be challenging and was observed to impact on all team members, increasing pressures. Recruitment at consultant level and increasingly band 5 nurses is a nationally recognised problem with vacancies existing at both levels (NHSE, 2019; The Faculty of Intensive Care Medicine, 2018). Senior nurses, in particular, were observed to provide additional support to inexperienced

---

[7] Following completion of Foundation level training, doctors undertake speciality training, split into two or three years core training followed by higher level speciality training at ST3 level (Modernising Medical Careers, 2010)

medical and nursing colleagues. Moreover, at times the use of locum medical staff resulted in a lack of consistency in care and this in turn affected staff morale and workforce retention.

5.2.2 Daily routine

For HCPs, nursing and medical handovers were the primary means of communication at the commencement of shifts together with the daily morning and evening ward rounds. Typical of many PICUs the morning inter-professional ward round (MIR) was the key decision-making forum. A heterogeneous group of clinical professionals including intensivists, PICU fellows, other medical specialists, nursing, physiotherapists, pharmacist and other allied health professionals meet to discuss the care plans for each child. The MIR was held either adjacent to the child's bedside in the main PICU area, or at the threshold of the child's room if the patient was being cared for in a cubicle. A junior physician would generally present the child's case having been assigned to undertake a physical examination and clinical review of the child during medical handover. Medical handover occurred prior to the MIR. The MIR provided opportunity for some teaching by the senior medical staff, but the key focus was discussion as to how best to progress care, including outlining and confirming the plan for the day. A structured approach to communication of information and standardised paperwork was utilised. However, despite pre-ward round preparation, information was frequently noted to be missing or incomplete. During the period of the study, the MIR was highly variable in duration, lasting between thirty minutes to in excess of two and a half hours with parents excluded from the unit during this time. Particular variants included the consultant intensivist coordinating the round, the patient census, the number of HCP participants and time constraints including meetings, timings of other tasks such as scans. Consequently, membership varied with nursing staff in particular observed to focus on patient care activities.

A second ward round was held daily in the late afternoon. This consisted predominantly of intensive care nursing and medical staff and was a much briefer event, used to communicate key information and events that had occurred during the day and prior to the formal nursing and medical team handovers to the night staff.

Notably, throughout observations parents were requested to leave the PICU for the duration of both ward rounds. For parents the bedside nurse, nurse-in-charge, allocated middle grade doctor and consultant intensivist on call acted as primary conduits for information on a day to day basis. Family conferences, generally preceded by multi-disciplinary team meetings were also used to convey important information. These conferences generally took place away from the bedside and were usually held in the family room on the PICU.

5.3 The case studies

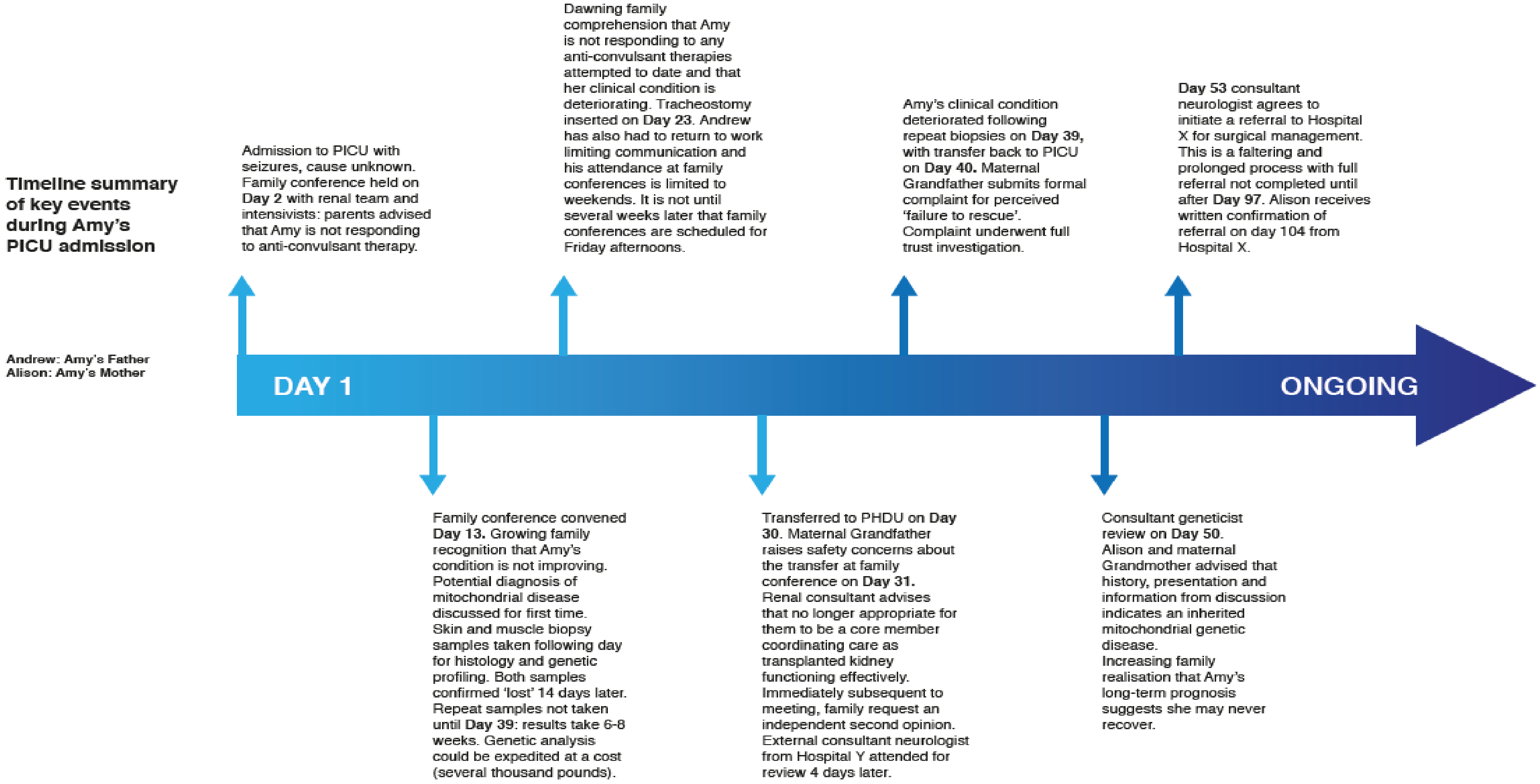
5.3.1 Amy

Amy, aged 15 years, was admitted to the PICU having developed refractory seizures following a living donor related renal transplant. Amy initially made a good post-operative recovery following the transplant but began having seizure activity on day 6 post-operatively. Amy is an exceptional case, having spent in excess of a 100 days being cared for in the PICU setting. At the study site, the median length of stay for children aged 11-15 years was 1.3 days with just over 9% of all admissions exceeding 7 days (PICAnet, 2015).

Prior to admission for the renal transplant Amy lived at home with both parents together with her younger female sibling, and her pet dog in a village location. Amy's child development had been normal up until 18 months of age when she first presented with muscle weakness. Two further episodes occurred at age 3 and 4 ½ years. Despite intensive investigation, no diagnosis was made and she recovered well. Even so, following these episodes, problems with fine motor skills, processing speed and memory deficits were noted necessitating additional learning support at school. In 2012 Amy was diagnosed with chronic renal failure, cause unknown. Initially, this was treated by peritoneal dialysis and subsequently haemodialysis. She attended thrice weekly haemodialysis sessions at the children's hospital prior to the transplant, travelling in excess of 100 miles to attend for dialysis. Despite the disruption renal replacement therapies incurred, Amy continued to attend main-stream education, remaining with her year group. Alison (Amy's mother) described her as a bubbly individual who had a strong core friendship group and active social life outside of school.

The decision to undergo a living related transplant, maternal grandfather being the donor, had been painstakingly considered by all concerned. Amy had been actively involved in decisions about her renal management prior to her transplant surgery. She was described as viewing the opportunity with a dichotomous mix of anxiety and positivity. For Amy's parents and grandparents, the nature of her PICU admission

Timeline 1: Summary of key events during Amy's admission



Timeline summary of key events during Amy's PICU admission

Andrew: Amy's Father
Alison: Amy's Mother

Admission to PICU with seizures, cause unknown. Family conference held on **Day 2** with renal team and intensivists: parents advised that Amy is not responding to anti-convulsant therapy.

Family conference convened **Day 13.** Growing family recognition that Amy's condition is not improving. Potential diagnosis of mitochondrial disease discussed for first time. Skin and muscle biopsy samples taken following day for histology and genetic profiling. Both samples confirmed 'lost' 14 days later. Repeat samples not taken until **Day 39**: results take 6-8 weeks. Genetic analysis could be expedited at a cost (several thousand pounds).

Dawning family comprehension that Amy is not responding to any anti-convulsant therapies attempted to date and that her clinical condition is deteriorating. Tracheostomy inserted on **Day 23**. Andrew has also had to return to work limiting communication and his attendance at family conferences is limited to weekends. It is not until several weeks later that family conferences are scheduled for Friday afternoons.

Transferred to PHDU on **Day 30**. Maternal Grandfather raises safety concerns about the transfer at family conference on **Day 31.** Renal consultant advises that no longer appropriate for them to be a core member coordinating care as transplanted kidney functioning effectively. Immediately subsequent to meeting, family request an independent second opinion. External consultant neurologist from Hospital Y attended for review 4 days later.

Amy's clinical condition deteriorated following repeat biopsies on **Day 39**, with transfer back to PICU on **Day 40.** Maternal Grandfather submits formal complaint for perceived 'failure to rescue'. Complaint underwent full trust investigation.

Consultant geneticist review on **Day 50**. Alison and maternal Grandmother advised that history, presentation and information from discussion indicates an inherited mitochondrial genetic disease. Increasing family realisation that Amy's long-term prognosis suggests she may never recover.

Day 53 consultant neurologist agrees to initiate a referral to Hospital X for surgical management. This is a faltering and prolonged process with full referral not completed until after **Day 97**. Alison receives written confirmation of referral on day 104 from Hospital X.

Timeline summary of key events during Amy's PICU admission *[continued]*

Andrew: Amy's Father
Alison: Amy's Mother

DAY 56

Consultant intensivist led meeting with Alison and maternal Grandmother, **Day 56.** Reiterated that Amy is not making any progress, proposes experimental cooling therapy. Cooling therapy abandoned within 24 hours as no improvement in Amy's condition and visible maternal distress. Alison stated, "she looks dead and feels dead."
Andrew has separate meeting with different consultant intensivist when resident over the weekend and asks what the worst-case scenario would be. Discussion focuses on consideration of Amy's best interests. Realisation by PICU team that parental sharing of information is limited. Recognition of the need for planned family conferences to be held on Friday evenings so both parents can participate.

Day 67: Histology results confirm mitochondrial disease. Family conference with mother and maternal grandmother two days later to discuss biopsy result including need for genetic screening of female family members. Amy's management plan, titration of anticonvulsants unchanged. Members of PICU team, particularly nursing staff and PICU fellows are vexed at reluctance to transition from active treatment to end of life care (EOL).

Day 74: MDT conference comprising all medical teams involved in Amy's care and nursing representation. Family have voiced concern to renal consultant that there are inconsistencies in care. Considerable frustration across teams: Intensivists are questioning the benefits and harms of prolonging treatment and proposing EOL care pathway; Neurologist wanting to pursue referral to Hospital X to exhaust all options – referral process still to be completed. Post MDT, family conference with neurologist, intensivists not present. Alison questions whether it is time to initiate a personal resuscitation plan.

Alison commenting to nursing staff over next couple of weeks that she is finding it increasingly difficult to be at her daughter's bedside. She finds witnessing her appearance and suffering distressing. Evident at handovers that nursing staff additionally find it challenging to care for Amy. Amy mainly allocated to senior and experienced nursing staff due to stress and trauma of caring for her. General perception that her care is medically inappropriate and futile.

Day 92: Genetic analysis result confirms rare mitochondrial disorder: only one reported case with same genotype in the world. Two days later MDT discussion prior to family conference: intensivists propose adoption of EOL care pathway. Neurologist rejects proposal to await outcome of second opinion During family conference Alison challenges medical staff as to why they are pursuing a plan "that clearly doesn't work" and questions how much longer would treatment continue.

Day 104: Hospital X advise that Amy would not be accepted as a referral. Following consultant intensivist intervention, Hospital X agree to meet with parents and intensivist to discuss Amy's case. Pre-bereavement nurse specialist, consultant intensivist and both parents attend a 2 hour appointment on Day 111 with consultant neurologist and consultant mitochondrial specialist at Hospital X. Parents return satisfied that all treatment that could have been undertaken, had been undertaken. Hospital X team comment to parents that if she has been receiving treatment there, palliative care would have commenced earlier due to pressure for PICU beds (allocation scarce resources).

Following day MDT discussion and agreement to progress to EOL care. Family conference. Alison stated that she did not wish to make a decision to progress to EOL care. Consultant intensivist stated that it was his decision and it was based upon Amy's best interests. Parents offered choice as to location of EOL care – PICU, hospice or home. Joint parental decision for hospice. Referral accepted, but delayed transfer for a week, due to bed availability.
PRP instituted on PICU. Nevertheless following acute deterioration in Amy's condition two days later, escalation of care contrary to PRP occurred at consultant intensivist behest. This was to ensure Amy was able to be transferred to the hospice: decision taken in family's best interests. Transfer expedited and completed following day: Amy died 14 hours after arriving at the hospice surrounded by her family.

DAY 105

following what should have been a life transforming, for the better, renal transplant was difficult to comprehend. Family adaptation was further unsettled and confused by knowledge that throughout Amy's admission the donated kidney functioned effectively.

Amy's illness trajectory was not straightforward, set against a backdrop of dawning realisation amongst HCPs and the family that Amy was not going to be the young person she had been prior to admission to PICU. The majority of the duration of Amy's admission to the PICU centred not only on the practicalities of attempting to control seizure activity, but establishing a cause for the seizures, since this was central in informing management.

Nothing can prepare a parent for an admission to an intensive care unit and dealing emotionally with the adjustments of having a child in such an abnormal environment is a long and difficult process. Amy's parents and family additionally had to deal with the considerable emotional impact of seeing their daughter fitting constantly. The PICU team were unable to stop seizure activity. Both parents commented on a number of occasions that they found it incredibly difficult to be present at the bedside.

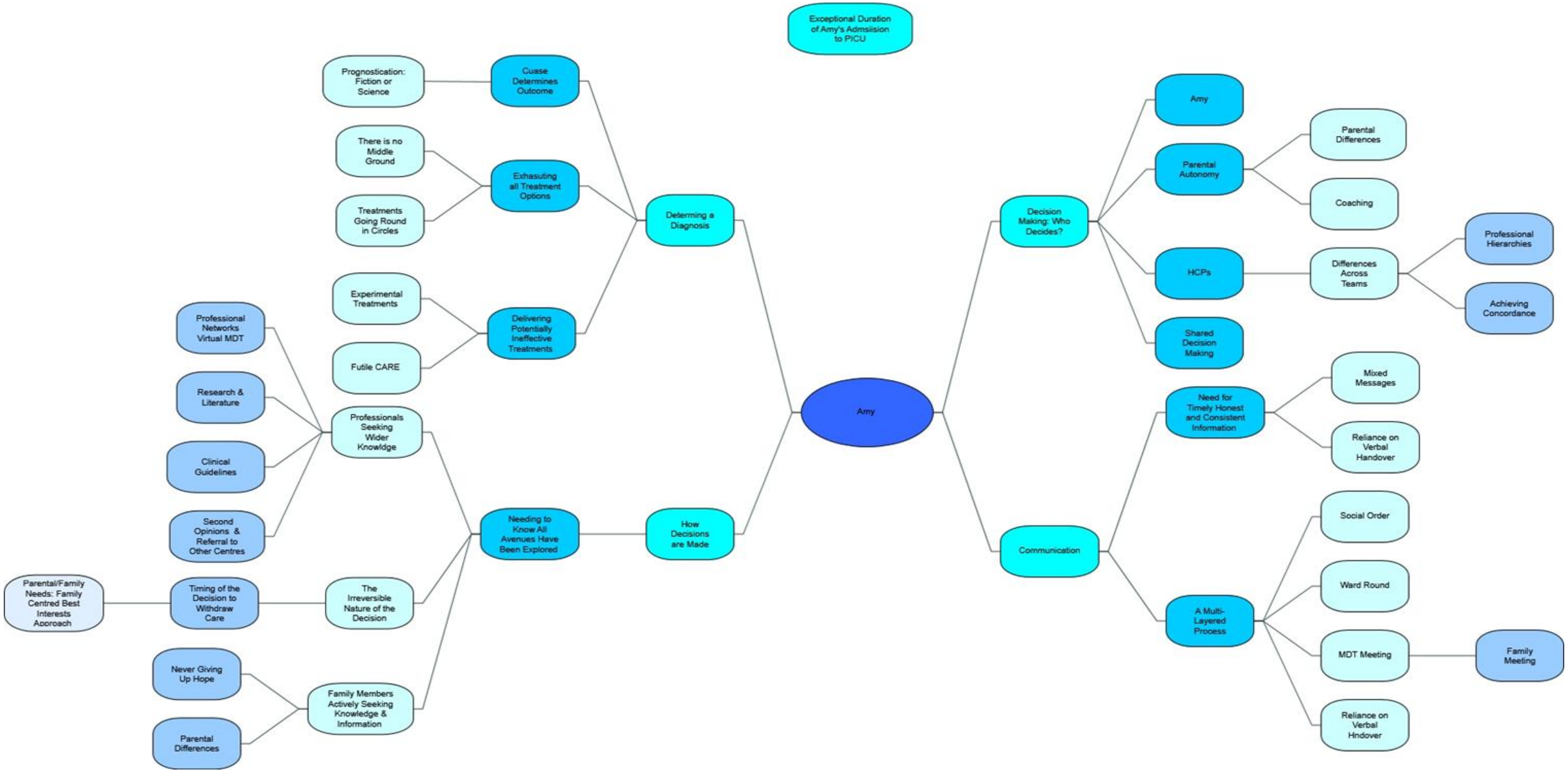
Both parents were resident when Amy was initially admitted to PICU, however Andrew (Amy's father) being self-employed rapidly had to return to work. Nevertheless, throughout the duration of her admission Amy's parents ensured that one of them was always resident. Alison took extended unpaid leave from her employer and was resident Sunday evening through till Friday evening weekly. Andrew would alternate with Alison, being resident on finishing work, from Friday evening to Sunday evening. The importance of attempting to maintain a degree of normality for Amy's sibling was paramount and splitting 'hospital duties' enabled both parents to have time with her, whilst also allowing her to remain in her usual schooling. There was recognition, particularly during the later stages of Amy's admission, that this arrangement potentially risked Andrew being excluded from decision-making and impacted upon the effectiveness of communication amongst parents and with HCPs.

Latterly, MDT family meetings were scheduled for Friday evenings to facilitate Andrew's attendance, but this often resulted in delays and missed opportunity to action outcomes. Both parents adjusted differently to their experience and it was apparent that for Amy's parents they found it hard to cope over the extended duration of her admission.

Ultimately, withdrawal of treatment for Amy and her family was a faltering process that occurred over a prolonged period of time. Amy was eventually transferred to a children's hospice, where shortly after arrival she acutely deteriorated. Amy died with all her family around her fourteen hours later.

Amy's case epitomises the impact of changing trends of deaths in PICUs, having spent a prolonged period of time in PICU prior to her demise. Such an extended admission illuminates the risk and benefits for the child, family and HCPs. Such lengthening also informs knowledge of the challenges of multi-disciplinary working within and across teams as well as the challenge of managing parental involvement and expectations.

Figure 12: Initial themes arising from analysis of Amy's case



5.3.2 Ben

Ben, aged 7 years, is a known patient to the PICU team. He is a long-term ventilated patient who is normally cared for in the home setting. Ben's health needs are such that he requires 24-hour supervision and care. Ben's parents are experts in knowing him and his ways of being and Beth (Ben's mother) is recognised as his primary carer. Both parents endeavour to ensure that Ben leads as full and as normal a life as possible. They acknowledge that this requires almost 'military' planning and is becoming increasingly challenging. The family live in a semi-rural community with minimal amenities, the local hospital is a 45 minute 'blue light' ambulance journey. Consequently, the family have developed considerable self-reliance and resilience in managing Ben's care.

Ben was diagnosed with a brainstem ganglioglioma[8] in 2012, with involvement of his brainstem, cerebellum and upper spinal cord. The ganglioglioma was deemed unsuitable for surgical removal due to location. Ben has undergone both chemotherapy and radiotherapy to try and reduce the tumour size. He is quadriplegic and reliant on mechanical ventilation. Ben is normally able to vocalise and communicate, albeit limitedly. He additionally has very expressive facial features, which he uses effectively to convey his needs and wants. Ben was receiving monthly chemotherapy, Avastin[9], prior to admission.

Ben presented to his local hospital the evening prior to admission to PICU with an acute onset of vomiting, abdominal distension, reduced bowel sounds, large aspirates via his gastrostomy tube and an increasing oxygen requirement. Ben was haemodynamically unstable and this was thought to be potentially sepsis related. The local DGH made a rapid referral to PICU requesting transfer for a surgical opinion and advice

---

[8] Ganglioglioma is a rare slow growing primary central nervous system tumour. In Ben's case the ganglioglioma determined by biopsy to be a benign tumour.

[9] Avastin is a monoclonal antibody, which works by targeting vascular endothelial growth factor, a protein that enables cells to develop blood vessels. By disrupting the supply of blood to the ganglioglioma and therefore oxygen and other nutrients, Avastin is thought to control and potentially reduce tumour size. Avastin is known to have a number of gastro-intestinal side effects, including diarrhoea, vomiting and sepsis.

Timeline 2: Summary of key events during Ben's admission

Timeline summary of key events during Ben's PICU admission

Bob: Ben's Father
Beth: Ben's Mother

Known patients admitted following PICU team retrieval. Acute deterioration in condition following arrival on PICU Multiple bedside discussions across all involved teams during first few hours with Beth participating to determine the limits of escalation. Bob present throughout, but expressed wish not to be involved in decisions. Family conference late afternoon day 1, led by intensivists, oncology consultant also participating. Escalation contrary to Personal Resuscitation Plan (PRP) agreed as potentially reversible event. Some explicit discussion as to limits of escalation should Ben's level of support continue to escalate.

Over ensuing three days, Ben remained haemodynamically unstable. Deterioration in conscious status observed, leading to neurosurgical team referral. Beth relatively unconcerned as Ben known to 'drop his GCS' when poorly: she returned home to care for siblings. Bob remained resident.

Urgent MRI scan **Day 4** following further clinical deterioration. During transfer back to PICU, Ben required emergency resuscitation and administration of cardiac medication and intravenous fluids. Consensus decision initiated by consultant intensivist that Ben would be for airway resuscitation, cardiac medication but not for chest compressions. Bob fully informed of events and decision. PICU registrar offered to telephone Beth to discuss, declined by Bob.

Day 5 MDT meeting to discuss how to progress Ben's care since no signs of improvement and evidence of brainstem instability. Decision to discuss situation with Bob to provide parents some time to start to consider options in advance of a planned family conference the following day. Recognition by MDT of the need to enable Beth to be able to participate fully in discussions and decision-making.

Family conference involving PICU team, oncologists and Bob. Team advised that treatment options are exhausted and that the time has come to consider whether it is fair for Ben to continue to receive intensive care. Bob advised that the proposal is to have a family conference involving Beth on her return. Bob again declined the option for one of the consultants or registrars to contact Beth.

Beth returned to PICU late afternoon Day 5 expressing anger that the situation had been discussed with Bob.

Overnight, dramatic improvement in Ben's condition. Beth remained angry and frustrated about decision to talk to Bob yesterday. Family conference deferred. Recognition voiced amongst professionals and also expressed by Beth, that future plans for escalation of treatment should be explored once Ben recovers from this admission.

Ben's clinical condition continued to improve over subsequent **72 hours.** Discharged from PICU to home, at parental request, despite nursing staff expressed reservations. Beth stated that she could provide the same level of care as a general paediatric ward area, but Ben would be happier. Following discussion with Beth PRP reinstated with no changes or amendments at that time.

management. Ben was admitted to PICU having following transfer by the PICU retrieval team from a local district general hospital (DGH).

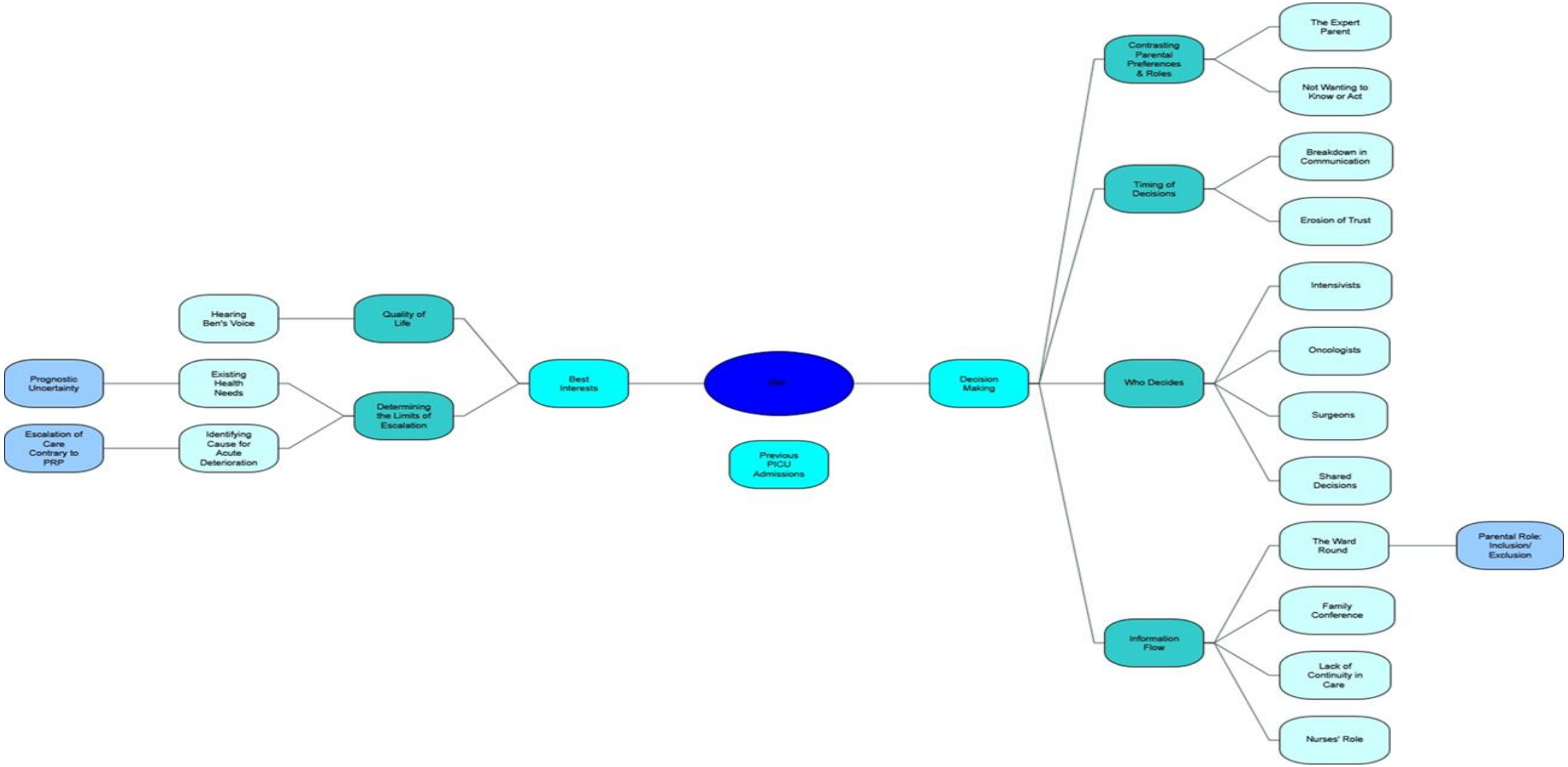
Ben's parents are acknowledged by all HCPs who know the family to demonstrate a mismatch in respect of participation in decision-making and care delivery. Ben's parents talk openly about their different approach to Ben's illness. These variations are complex and individual in nature. Beth is acknowledged to be the lynchpin of the family, being dedicated to providing for Ben's needs whilst also attempting to ensure his siblings are not disadvantaged or encumbered with care responsibilities. Accordingly, she had developed skills, knowledge and expertise to know and manage Ben's needs better than anyone else. Outwardly, she displayed a positive demeanour and approach to life, having as she reported, learned to appreciate what she had. Previous experiences of hospitalisation had, however tainted her relationships with HCPs. Her outward appearance belied emotions of frustration, powerlessness and mistrust when feeling vulnerable and out of control during crisis situations. She stated that she had generally learned to regulate her emotions, especially when interacting with doctors. Throughout Ben's admission she demonstrated confidence to be assertive in her interactions with HCPs, overtly acknowledging that doctors are not omniscient. She conveyed a sense of personal assurance and ability to act on her own when challenging choices made by HCPs.

Whereas Beth needed to understand and be fully involved, Bob demonstrated an approach of choosing not to be drawn into situations. Bob possessed an ability to disregard all around and focus solely on his son. Bob's expressed choice of devolving parental decision-making and interaction with HCPs to Beth generated challenges particularly when Beth ventured home to care for Ben's siblings and he remained resident on PICU. On these occasions, Bob exhibited behaviours that he was unable to assimilate or process information. Consequently, dynamics of interactions between HCPs and Ben's parents were complex. The fragility of relationships was underscored, together with latent potential of breakdown inherent.

Whilst Ben recovered sufficiently to be discharged home on day 11 both parents accept the uncertainty of the future, knowing that in the longer term their worst fears may be realised. The evolving and uncertain nature of Ben's illness vindicates their focus on the here and now, including the desire to spend as much 'quality' in the home setting as possible. Accordingly, Beth will only accede to Ben's hospitalisation if care cannot be provided in the home setting.

Ben's case reflects the complexity of caring for children with chronic critical illness during acute crises. He reflects the challenge of children who are living longer and who may previously have not survived repeated PICU admissions and the complexity of agreeing care interventions.

Figure 13: Initial themes arising from analysis of Ben's case



5.3.3. Carly

Carly, aged 5 years, was admitted to PICU having been transferred from another PICU, hospital Y, for a second opinion. A decision to accept a child for a second opinion is fraught with challenges for parents, medical and nursing staff alike. In the situation of limited highly specialised centres providing paediatric intensive care there is a need to create an opportunity whereby parents who are in disagreement do not feel isolated and are helped through the process. Yet such a situation creates professional and ethical dilemmas for the receiving PICU team.

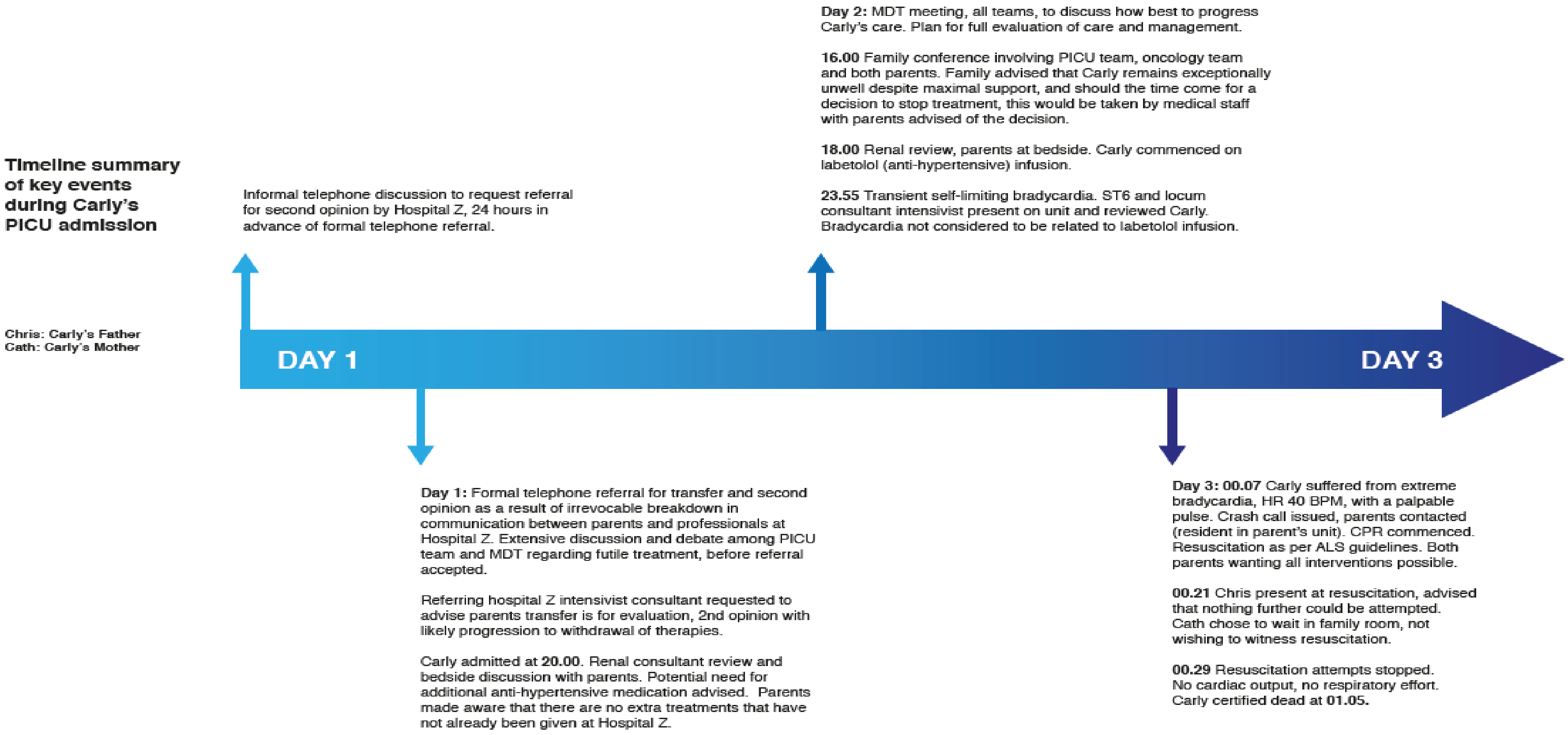
Carly was a patient known to the Oncology team based at the Children's Hospital, having been diagnosed some months earlier with leukaemia. Carly's initial presentation and diagnosis followed a very short, history of being non-specifically unwell, lethargy and chest infection. She underwent chemotherapy and treatment. However, she had a poor chemotherapy response and was transferred for a bone marrow transplant to Hospital Y.

Having initially made a good recovery post bone-marrow transplant she was diagnosed with Grade II Graft versus Host disease[10] (GVHD). Carly's response to GVHD treatment was up and down necessitating long stays in hospital Y, interspersed with brief periods of time at home. She had become increasingly unwell, as a result of her underlying illness, side effects of treatment and recurrent severe infections. Whilst at home she had a sudden deterioration, necessitating emergency admission to hospital Y with a gastro-intestinal bleed. In spite of acute management of the bleed her condition continued to deteriorate necessitating institution of intensive care therapies. She subsequently developed multi-organ failure, involving her lungs, cardiovascular system, kidneys, liver and gut.

---

[10] Graft versus host disease (GVHD) occurs as a side effect of bone marrow transplantation and generally occurs during the early post-transplantation period, usually within the first 100 days. The skin, gastro-intestinal tract and the liver are often the principal organs affected in GVHD, as in Carly's case. Steroid and immunosuppressant therapies were administered to try to suppress Carly's immune response and reduce inflammation.

Timeline 3: Summary of key events during Carly's admission



Timeline summary of key events during Carly's PICU admission

Chris: Carly's Father
Cath: Carly's Mother

Informal telephone discussion to request referral for second opinion by Hospital Z, 24 hours in advance of formal telephone referral.

Day 1: Formal telephone referral for transfer and second opinion as a result of irrevocable breakdown in communication between parents and professionals at Hospital Z. Extensive discussion and debate among PICU team and MDT regarding futile treatment, before referral accepted.

Referring hospital Z intensivist consultant requested to advise parents transfer is for evaluation, 2nd opinion with likely progression to withdrawal of therapies.

Carly admitted at **20.00**. Renal consultant review and bedside discussion with parents. Potential need for additional anti-hypertensive medication advised. Parents made aware that there are no extra treatments that have not already been given at Hospital Z.

Day 2: MDT meeting, all teams, to discuss how best to progress Carly's care. Plan for full evaluation of care and management.

16.00 Family conference involving PICU team, oncology team and both parents. Family advised that Carly remains exceptionally unwell despite maximal support, and should the time come for a decision to stop treatment, this would be taken by medical staff with parents advised of the decision.

18.00 Renal review, parents at bedside. Carly commenced on labetolol (anti-hypertensive) infusion.

23.55 Transient self-limiting bradycardia. ST6 and locum consultant intensivist present on unit and reviewed Carly. Bradycardia not considered to be related to labetolol infusion.

Day 3: 00.07 Carly suffered from extreme bradycardia, HR 40 BPM, with a palpable pulse. Crash call issued, parents contacted (resident in parent's unit). CPR commenced. Resuscitation as per ALS guidelines. Both parents wanting all interventions possible.

00.21 Chris present at resuscitation, advised that nothing further could be attempted. Cath chose to wait in family room, not wishing to witness resuscitation.

00.29 Resuscitation attempts stopped. No cardiac output, no respiratory effort. Carly certified dead at **01.05.**

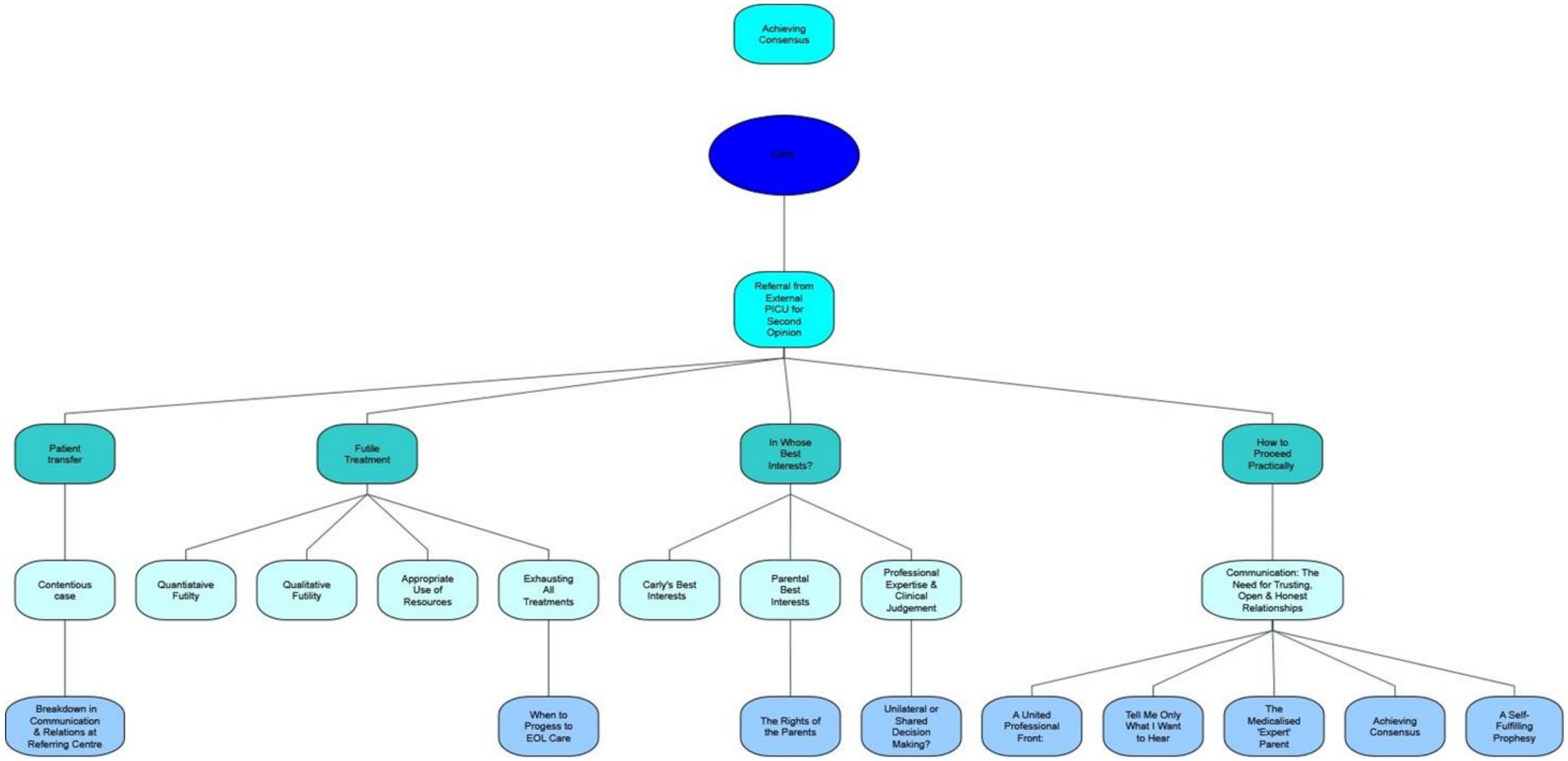
At the time of referral, Carly had already undergone 22 days of full intensive care. The multi organ failure, for which she had been referred, had not proved amenable to treatment. Similarly, her co-morbidity and poor physiological reserve made the prospect of significant and sustained recovery very minimal. Nevertheless, Carly's parents remained confident that she was slowly improving, refusing to accept her poor condition and lack of response to therapies. A breakdown in communications and relations between the PICU team at hospital Y had occurred when discussions had been initiated with the family as to what was in Carly's best interests, given her very poor condition and lack of response to therapies. Parents had subsequently requested a second opinion to be sought. The crisis of a collapse in parental trust in professionals, whereby the parents perceived that the health-care professionals' overall intentions for their daughter's care were so different from their own meant that any professional relationships at the receiving PICU were always going to be precarious. Relocation merely transferred the dispute. As occurs in any mediation, the parents were still pitted against professionals.

Even before Carly was transferred, the need to protect her interests and dignity whilst simultaneously balancing the various obligations and duties to do the best for the family as a whole, was apparent.

Carly epitomises the dilemma of knowing when to stop intensive care when the family resists or even opposes medical staff suggestions that it is time to stop treatment.

Carly acutely deteriorated less than 30 hours post-admission, requiring cardio-pulmonary resuscitation (CPR). Despite 24 minutes of CPR, Carly was noted to have no cardiac output and to have no respiratory effort. A decision was made to cease resuscitation attempts. Dad was present at bedside at the time of Carly's death.

Figure 14: Initial themes from analysis of Carly's case



5.3.4. Edward

Edward, a previously fit and well child aged 2 years, was referred and transferred from his local hospital to PICU, to receive life-saving neurosurgical intervention. Raised intracranial pressure had occurred as a consequence of a tumour obstructing the normal circulation and reabsorption of cerebral spinal fluid (CSF) within the ventricular system in the brain. Edward had presented two days earlier, to his local hospital with a one-month history of lethargy and intermittent vomiting. Prior to this admission Edward had experienced symptoms severe enough to be admitted to two different hospitals on two separate occasions. On both occasions following brief, less than 24-hour admission, he had been discharged home with a diagnosis of post viral syndrome.

On arrival at the Children's Hospital, Edward was immediately transferred to theatre. Following insertion of bilateral extra-ventricular drains (EVDs[11]), to relieve the symptoms of raised intracranial pressure. he was admitted to PICU post-operatively because of the higher level of support and monitoring that could be offered. Whilst recognising that there is no such thing as a 'routine' PICU admission, for some planned post-operative surgical admissions predictable pathways are anticipated. Edward was expected to have an unremarkable PICU admission. An acute deterioration in his condition during the first 24-hours of admission rendered it apparent that separation of life-saving and life prolonging treatment was crucial in determining the limits of interventions.

Relationships whether they are between parents and professionals, across medical teams or inter-professional are central to the PICU experience. Pivotal in Edward's case was the amalgam of the multiple professional teams involved: intensivists, neurosurgeons and oncologists. Edward's parents subsequently found themselves in

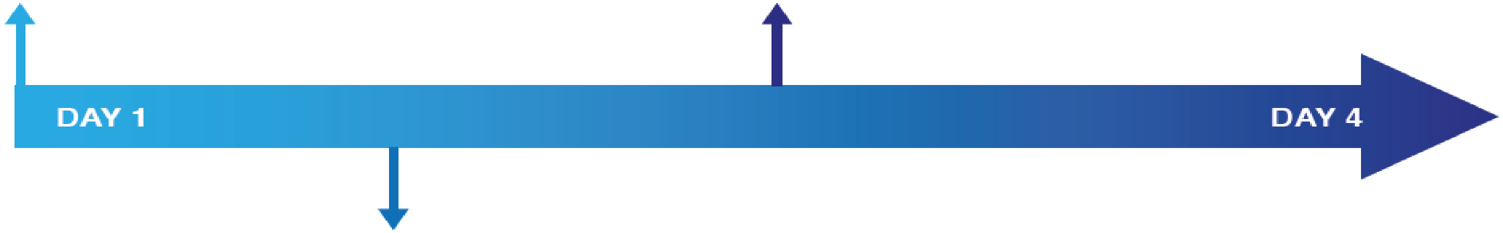
---

[11] External ventricular drain (EVD): A temporary system that allows drainage of cerebral spinal fluid (CSF) from the ventricles to an external closed system.

Timeline 4: Summary of key events during Edward's admission

Timeline summary of key events during Edward's PICU admission

Eric: Edward's Father
Emma: Edward's Mother



Day 1: Admitted overnight to PICU post operatively following emergency neurosurgery. Planned extubation at **09.15**. Acute deterioration in conscious level and seizure activity led to emergency re-intubation and mechanical ventilation at **11.45.** Parents present throughout and cognisant Edward's clinical condition had deteriorated.

Following emergency MRI scan at **17.15** parents have discussion with consultant neurosurgeon. No PICU team members present due to other emergency events on unit. Parents told brain tumour is too large and inaccessible for surgery. Advised not to treat.

Family conference led by oncology consultant 1, PICU ST5 (registrar) present approx. **18.30.** Three potential treatment options discussed:

1. Biopsy tumour and treat medically
2. Palliative and End of Life (EOL) care
3. Withdrawal of care

Consultant oncologist emphasised the need for time to assess Edward fully and to allow for second opinions. Parents encouraged to treat other consultant oncologists at Children's Hospital as second opinions, whilst also to use all resources open to them.

Day 2: Oncology and Neurosurgical Teams weekly changeover. Considerable variation of opinions within both teams as to on-going management resulting in parental confusion and upset. **08.30** Consultant oncologist 2 suggests to parents that this is a potentially treatable tumour, which should be biopsied before decisions made. Parents voice that they do not wish Edward to have active treatment.

11.50 Family conference with consultant intensivist and neurosurgical consultant 2. Discussed plan of management including biopsy. Parents again stated unwilling to put son through procedure as "too risky and limited benefit" and want to progress to EOL care pathway. Both consultants advise that the plan of care may change and will be dependent upon Edward's clinical condition post-extubation.

Addendum added to original MRI scan report suggesting a biopsy would be helpful to determine the course of action.

Day 3: Edward's case presented at weekly paediatric neuro-oncology review meeting. Members concur with proposal for biopsy, since without definitive diagnosis parents are unable to make informed choice.

11.00 Family conference. All teams and parents present. Challenging and at times confrontational meeting. Biopsy discussed. Emma stated that she felt they (parents) were losing control and questioned whether they (parents), should be allowed to determine best interests for their own child.

Early afternoon: Edward clinically improving, neurologically more awake, some awareness of surroundings and becoming visibly distressed. Nursing led request to re-convene MDT.

Family conference held at **14.45.** All teams and parents present. Discussion specifically stated to focus on acting in best interests of child. Parents expressed concern that felt bullied into decision to consent to biopsy and active treatment. Consensus agreement to progress to staged decision making with extubation, re-intubation if necessary and biopsy of tumour planned in **4 days.**

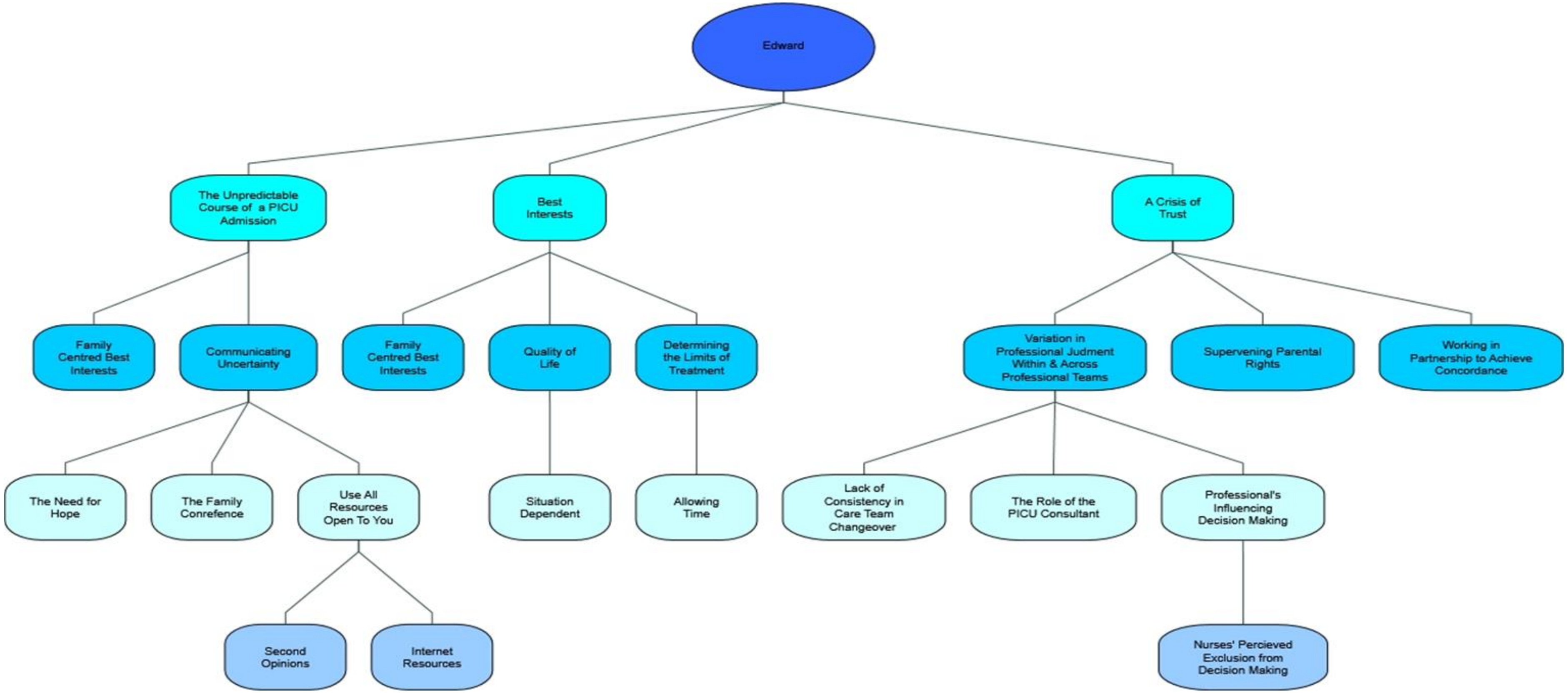
16.40 Successful extubation. Edward's clinical condition improved to allow discharge to oncology unit on **day 4.**

dichotomous and complex situation of navigating opposing professional beliefs and opinions. In Edward's case communication of uncertain outcomes, variations in professional judgement and prognostication created confusion and initial disagreement. The resulting loss of trusting relationships pitted both parents and professionals against each other.

Edward's case provides insight as to how parental educational and professional circumstances may render some parents better prepared than most to adapt and deal with the challenges of a PICU admission. Edward's father (Eric) is a medical practitioner and mother, Emma a lawyer. Edward's family were in a very privileged position, having access to resources and sources of information that for most families would not be readily accessible by virtue of Eric and additionally paternal uncle's medical background.

Edward was discharged to the paediatric oncology unit on day 4

Figure 15: Initial themes from analysis of Edward's case



5.3.5 Fiona

Fiona, aged 7 years, was admitted to PICU as a result of a sudden, unexpected collapse at home involving prolonged resuscitation attempts within the home, ambulance and local DGH emergency department. Fiona lived at home with her parents and older siblings in a rural village location. Despite having been diagnosed with Marfan's[12] syndrome in infancy she led a full and active life. On the day of admission she had been getting ready at home for school, when she collapsed having complained of suddenly feeling unwell, and having a racing heart rhythm. Fiona was known to suffer from abnormal heart rhythms, palpitations. She had previously received interventional treatment and was on medication, Losartin 20 mg and Flecanide 100mg twice daily, to minimise these episodes. She was receiving shared care with the regional cardiology team and consultant paediatrician with a special interest in cardiology at her local DGH.

It took a prolonged time, fifty minutes, for a return of spontaneous circulation (ROSC). Fiona's parents were both present throughout the resuscitation, with its initial focus on life saving interventions. Witnessing their daughter being resuscitated in the emergency department had already generated knowledge that Fiona was on the threshold between life and death. Parental education and professional backgrounds may have better prepared them to adapt and manage the challenges of what was feasible and that situations are ever evolving. Finlay's (Fiona's father) prior military background specifically may have afforded him a repertoire of strategies as to how to manage intensely stressful situations. It was evident throughout Fiona's admission that her parents worked as a team supporting each other to be able to respond and adapt to the demands of the situation they found themselves in.

---

[12] Marfan's syndrome is a genetic disorder of the connective tissues. More commonly, it is an inherited disorder but can also occur as a spontaneous mutation. The gene that produces Fibrillin-1 is defective and this results in an increase in a protein, transforming growth factor beta (TGFβ) Connective tissue being present throughout the body results in features of the disorder occurring anywhere, but more commonly heart, blood vessels, bones, joints and eyes.

Timeline 5: Summary of key events during Fiona's admission

Timeline summary of key events during Fiona PICU admission

Finlay: Fiona's Father
Fay: Fiona's Mother

Day 1: Admitted to PICU following PICU team retrieval. Parents having witnessed resuscitation attempts at DGH aware that she may not survive, but expressing hope. Clinical condition deteriorated, seizure activity observed.

Day 2: Seizure activity continued despite attempts to control. MRI scan reported, severe hypoxic brain injury. Family conference: Consultant intensivist led. Parents made aware this is a life changing, for the worse injury: unable to predict long-term prognosis at this time. Parents remain realistic but hopeful.

Day 3: PICU team notified that Flecanide level from sample taken at referring hospital Day 1 was at toxic level. Cardiac arrest may be a consequence of Flecanide toxicity. Information not shared with parents at this time.

Day 4: Fiona's clinical condition deteriorating. Family conference. Consultant intensivist and consultant neurologist jointly leading. Fay not present. Finlay advised that Fiona's injuries are potentially survivable, but life changing. Finlay states that the family will cope and manage even if Fiona is severely brain damaged.

Day 5: Increasing clinical signs of Fiona's deteriorating condition reflective of severe brain injury. Both parents, resident and participating in Fiona's care.

Day 6: 08.30 Continuing clinical instability and further deterioration overnight. Nursing staff highlighting urgent need to clarify Fiona's resuscitation status, concern that full resuscitation is inappropriate.

09.45 Family conference, jointly led, both parents present. Suggested by HCPs that time has come to consider what is in Fiona's best interests. Discussion re quality of life and what this means in light of family's religious beliefs. Acknowledgement of the need for time and all to be in agreement. Finlay questioned about experimental treatments and initiated discussion about process of withdrawal and whether Fiona would be eligible to be an organ donor. Fay queried the cause of the arrest. Dialogue about Flecanide toxicity. Resuscitation status clarified and confirmed limited interventions.

Day 7: Considerable discussion withib PICU team at medical handover whether continuation of care is in Fiona's best interests due to further neurological deterioration. MDT meeting convened to reach a united approach. Agreement for MRI to assess whether any changes. MRI not feasible for 3 days.

21.00 Abnormal heart rhythm observed and treated. Parents called back to unit. Shared decision for agreed management plan.

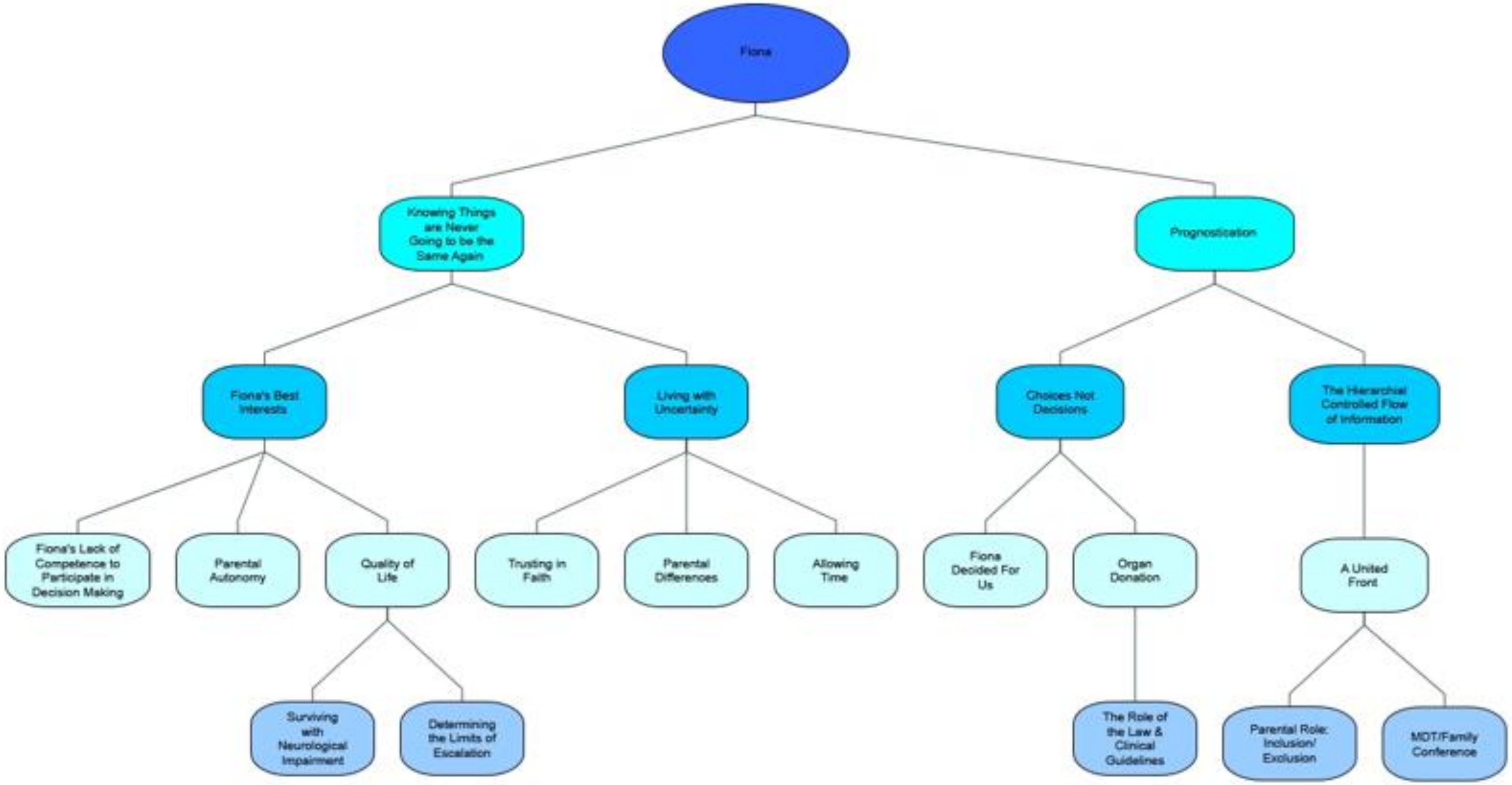
Day 8: 08.10 Sudden clinical deterioration. Both parents present and aware clinical condition indicative of terminal decline. Agreement across MDT and with parents that further treatment is futile. Prolonged discussions with coroner re planned management of withdrawal of care and parental request to donate Fiona's organs. Eventually confirmation received at **13.30** from coroner that restricted organ donation could proceed.

Organ donation protocol commenced, including escalation of therapies to preserve organs. Withdrawal of treatment did not occur until **06.37** on **Day 9**. Parents present and cuddling Fiona at time of withdrawal.
No respiratory effort on extubation.
Death confirmed **06.58.**

Analogous to previous cases, elements were present to render Fiona’s case contentious. The situation that Fiona’s family encountered was recognised within the first few days of admission to be one which may have been potentially avoided had earlier health care provision, coordination of care and communication been effective. Variations in professional judgement and prognostication were additionally evident amongst HCPs during Fiona’s admission to PICU. The whys and wherefores as to why then this case did not deteriorate into a contested and hostile situation warrant exploration.

Fiona died following a controlled withdrawal of life sustaining medical treatment. This enabled Fiona’s parents wish that their daughter would be eligible to donate her organs as a non-heart beating category 3: awaiting cardiac death donor (British Transplant Society Guidelines, 2016). This act has allowed Fiona’s parents, in their perception, to grieve more effectively and provided some meaning for the events they experienced.

Figure 16: Initial themes from analysis of Fiona's case



5.3.6 George

George, aged 8 months, was admitted to PICU via the emergency department (ED) at the Children's Hospital with a provisional diagnosis of meningococcal septicaemia and meningitis[13]. George, an only child, lived with Gaby (George's mother). George's father was separated from Gaby and had sporadic contact prior to the current illness. Maternal Grandmother, Grace who lived nearby provided on-going support to George and Gaby. Grace was a constant presence and prop for Gaby during the early days of George's hospitalisation.

George a previously fit and well infant, first presented as unwell less than 18 hours earlier. His Mum had three contacts with HCPs over the course of this time. On each occasion, she was assured that George was not seriously ill and provided with diagnoses of a viral illness. This was in spite of her increasing sense of foreboding and her perception that something was seriously wrong with her son.

On return to the ED late evening, having been brought in by emergency 999 ambulance, George was immediately assessed as being acutely unwell. He was observed to have two small petechial spots[14] on his abdomen. A decision was made to treat George for presumed meningococcal septicaemia. He was transferred to the resus room[15] and a request was made for the PICU team to attend. Contrasting with other cases, the diagnosis of meningococcal disease not only imposes a treatment pathway but also provides a knowledge base about usual patient trajectories.

George's rapid decline from being a healthy infant to being in a situation whereby death appeared imminent overwhelmed and incapacitated

---

[13] Meningococcal disease is caused by a bacteria, Neisseria Meningitidis and can cause meningitis or septicaemia or a combination of both these diseases. It is a life threatening disease and although most people infected do recover, they can be left with life changing disabilities.

[14] Small pinprick size rash that does not fade under pressure.

[15] An area in emergency department for patients requiring resuscitation.

Timeline 6: Summary of key events during George's admission

Timeline summary of key events during George's PICU admission

Gaby: George's Mother
Grace: George's Maternal Grandmother

Day 1: Admitted following PICU team attending prolonged resuscitation in Emergency Department. Gaby and Grace present, aware George extremely ill with likely meningococcal septicaemia and next 24 hours will determine outcome. Gaby numbed and detached, unable to respond to HCPs George profoundly haemodynamically unstable requiring considerable on-going fluid resuscitation.

Throughout the night George remained cardio-vascularly and haemodynamically grossly unstable despite maximal therapies: skin and tissue perfusion continuing to deteriorate.

05.00 Acute cardio-vascular deterioration, further resuscitation witnessed by Gaby and Grace. Following this event, family conference led by consultant intensivist, Gaby advised George is at high risk of not surviving illness. Maternal request for George to be christened.

Day 2: Review by paediatric and adult plastic and vascular teams due to continuing deterioration in limb and tissues. Use of experimental treatments discussed at bedside, plasma exchange commenced. Decision to additionally commence renal support therapies.

Bedside discussion with Gaby and Grace that George may not tolerate plasma exchange and dialysis: warned that he was likely to become more unstable when treatments commenced, but that without these he would be unlikely to survive.

Early evening family conference led by consultant intensivist. Parents and maternal grandparents present. Advised George's clinical condition precarious, he remains highly likely to die. If George survives it will be with life altering injuries to limbs and probably his kidneys. Likely limb loss will affect all four limbs, but full extent of damage will not become clear for 4-6 weeks. Confirmed that at this time George is for full resuscitation.

19.45 Consultant intensivist held telephone discussion with ECMO centre re-potential experimental therapy. Determined not in George's best interests.

Day 3: George's condition stabilised. Gaby advised to take 'hour by hour'. Limb and tissue loss uncertain, Grace commented 'people learn to live with disability' and that the family will cope.

Microbiology confirmation gram negative diplococcus, likely meningococcus.

17.45 Family conference, consultant intensivist led with paediatric plastic team. Gaby relieved that it appears George will survive, but admits she knows that George 'isn't out of the woods yet'. Focus of care now on titrating therapies to maximise salvaging as much tissue and limbs as possible for future functioning.

Day 4: Family conference, consultant intensivist led, parents and maternal grandparents present. Supportive therapies to continue. George likely to have protracted recovery and remains poorly. Prognostic uncertainty remains in respect of acute kidney injury, limb and tissue damage.

George remained on PICU for further 19 days prior to discharge to HDU.

Gaby. The case focusses upon the first 72 hours of George's admission. Difficult decisions about just how far to keep trying therapies was on-going during this time, with considerable doubt as to whether he would be able to survive the illness. It became apparent very early on that, should George survive, he was likely to suffer widespread tissue loss and amputation of all digits and feasibly limbs. Such devastating consequences were recognised to necessitate a prolonged hospital admission and intensive rehabilitation, but are acknowledged not to be central to this study.

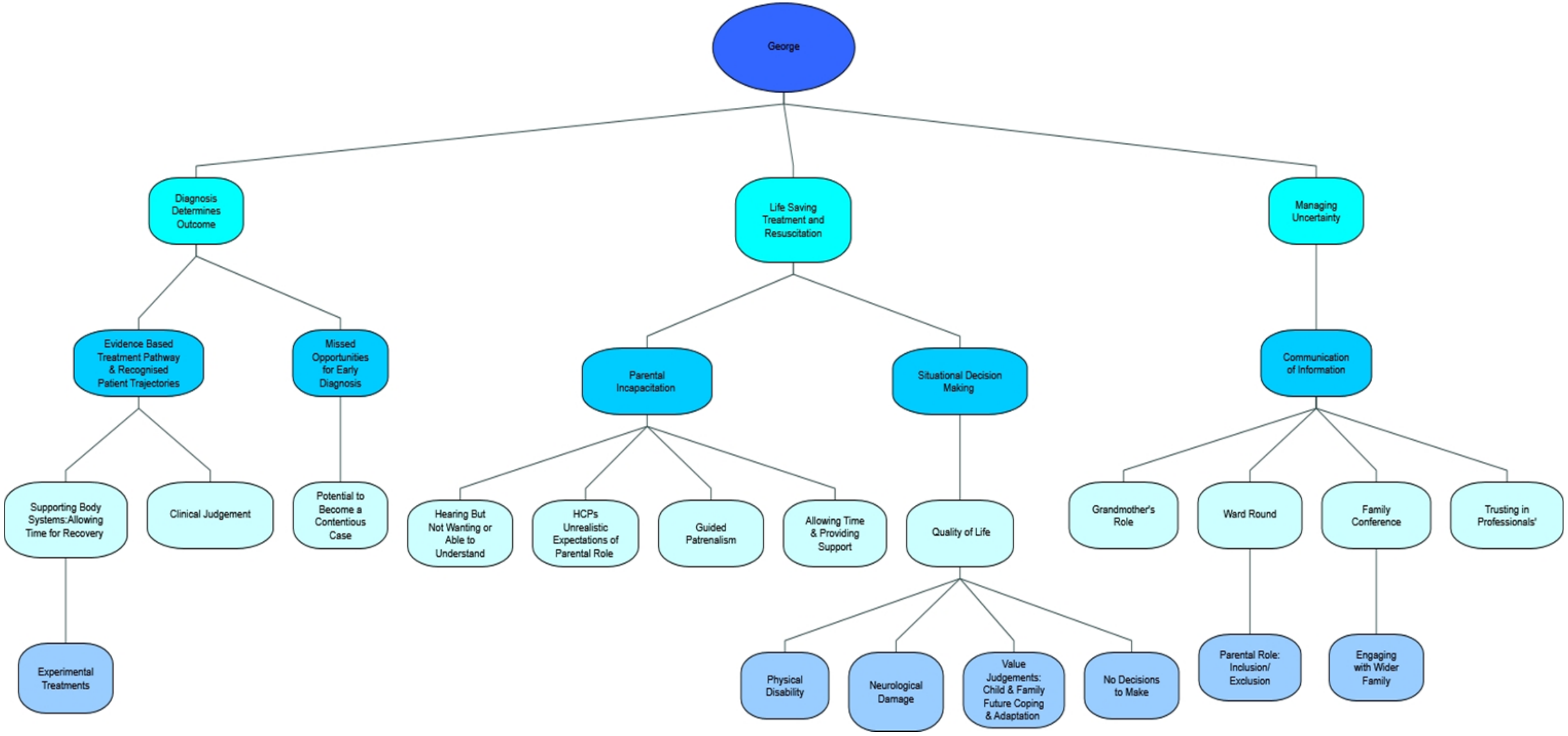
George's case provides understanding of how a diagnosis, through the use of clinical guidelines[16], can impel initiation and escalation of intensive care therapies. It challenges constructions of quality of life and provides insight into how parental coping and adaptation impacts participation in decision making.

George survived, but suffered life changing physical side effects. Correspondingly, Gaby's life similarly was also transformed, becoming a full-time carer. Gaby had to cease employment and move house. George remained on PICU for a total of 21 days, prior to step down transfer to the HDU and ward. He was subsequently discharged from hospital eight months following admission.

---

[16] NICE Bacterial Meningitis and Meningococcal Septicaemia Guideline CG102 (2010)

Figure 17: Initial themes from analysis of George's case



5.4 Chapter summary

This chapter has provided a contextual overview of the study site and introduced each of the six embedded case studies. Key events within each case is summarised to ‘set the scene’. Findings from within and across case analysis are explored in the next two chapters.

Chapter Six

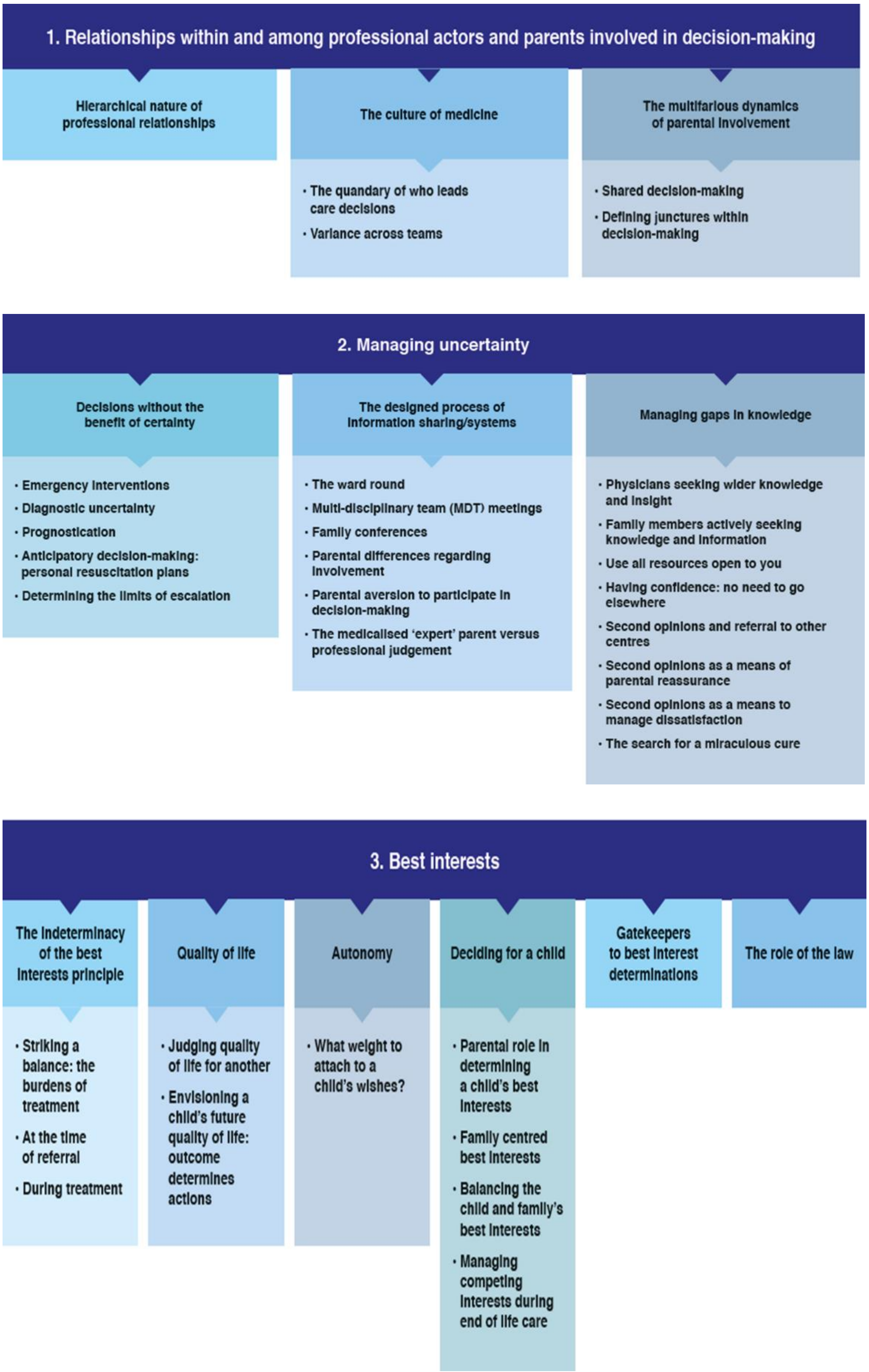
6. Findings: Decision Making

> *"We look for medicine to be an orderly field of knowledge and procedure. But it is not. It is an imperfect science, an enterprise of constantly changing knowledge, uncertain information, fallible individuals, and at the same time lives on the line."* Atul Gawande (2010:7).

6.1 Preface to the findings chapters

The major findings from this study are presented in the following two chapters. Based on the thematic analytic process (see Chapter 4 Section 4.4), principal themes, sub-themes and sub-sub-themes are presented from the within-case and cross-case analysis as outlined in Figure19. Chapter 6 explores how decision-making is constructed and experienced with particular focus on relationships, both within and among professionals and parents, and managing uncertainty within a PICU setting. Whilst the construct of best interests of the child was ever-present when making decisions, it was deemed to be crucial to present in a separate chapter. Chapter 7 therefore explores how difficult decisions were guided by the concept of best interests. These chapters, although discussing distinct themes are interconnected and do overlap. For example, communication is relevant to the development of relationships within the process of decision-making whilst also being integral to approaches that took place when attempting to determine a child's best interests.

Figure 18: Themes identified from within case and cross-case analysis



6.2 Introduction

Intensive care therapies are acknowledged to be an extreme intervention and there has to be a decision made as to what the team is prepared to do on behalf of each child and family. Whilst decisions may be seeking to carry out a child's best interests, the study reveals that diverse interpretations of best interests exist within the complex network of lay and professional stakeholders. This can make it incredibly challenging for family and HCPs alike to respond to and interpret end of life decisions. Helping parents and professionals to acknowledge that prolonging life by technological means may not be right for the child is a complex process and frequently difficult to achieve. Such decisions are contextual and how parents and professionals position themselves has been seen to vary across cases. Examples from the extended case studies are utilised to illuminate and provide a rich understanding of these distinctive nuanced experiences.

Decision-making is a fluid and dynamic process and within the PICU it was observed to be a highly complex undertaking, frequently occurring under intense time pressures. Findings reflect the complexity of making decisions being grounded in ever-evolving real world settings. A consideration of how decisions are made these cases, whilst exceptional, illuminates the processes that occur within the more routine admissions. This chapter explores the two major themes which were identified:

- relationships within and among professional actors and parents involved in decision-making,
- and managing uncertainty.

Before exploring these themes in greater depth a brief overview of the six case study family's parental attitudes towards decision-making is provided. (Figure 20). Overall, among these parents, there was a lack of desire to taking a lead role in decision-making.

Figure 19: Summary of parents' attitudes to involvement in decision-making

Amy	• Both parents ambivalent about participation, but explicit in wish to be kept up to date and informed • Parental need for hope led them to being proactive in seeking information and initiating request for second opinion, but explicit that they did not want to be decision makers • Exceptional duration of admission disrupted information sharing with parents cognisant of tension and conflict amongst HCP's
Ben	• Parental imbalance and difference to participation. Beth (Ben's mother) wanted to be actively involved. Bob (Ben's dad) didn't want to know or act, just to be involved • Demonstrated deference to professional opinion • Both parents struggled with the uncertainty Ben's chronic condition imposed and focused on practicalities of caring
Carly	• Parents confrontational and assertive, following breakdown in relationships at referring PICU • Wanted to take the lead role and direct decision making at a pseudo-professional level; perceived they had knowledge, experience and access to resources equivalent to medical team
Edward	• Parents recognised that they were reliant on professional competence of others • Perceived their role as requiring physicians to be accountable to them and provide them with justifications and rationale for treatment options
Fiona	• Parental difference to participation. Finlay (Fiona's father) active, logical - related to military background and able to navigate process. Fay (Fiona's mother) passive, expressed reliance on Dad as a conduit for information • Both expressed complete confidence and trust in expertise of staff • Both possessed strong Christian faith and trusted in God's will being enacted
George	• Gaby (George's mother) incapacitated adjusting to psychological and emotional burden of George's illness and admission • Adopted passive role, unable to process information shared and was wholly reliant on medical staff to make decisions

6.3 Relationships within and among professional actors and parents involved in decision-making.

All healthcare decisions involve selecting specific options over others and how parents and professionals position themselves was seen to vary across the cases. Achieving shared decisions between the parents and PICU team at a time of uncertainty is highly individualised and challenging as discussed within the literature review (Section 2.6.6, p43). For parents and the PICU team the nature of the relationship they navigated defined the context of the admission. From the process of within and cross-case analysis findings relating to the theme, relationships within and among professional actors and parents involved in decision-making, were aggregated to develop into three sub-themes and four sub-sub-themes as shown in Figure 21. Parents and professionals had different roles and responsibilities, arising from their relationship to the child, knowledge and expertise. This section will firstly explore professional relationships, the second part focusing on parental involvement.

Figure 20: Theme 1 Relationships within and among professional actors and parents involved in decision-making

1. Relationships within and among professional actors and parents involved in decision-making

Hierarchical nature of professional relationships

The culture of medicine

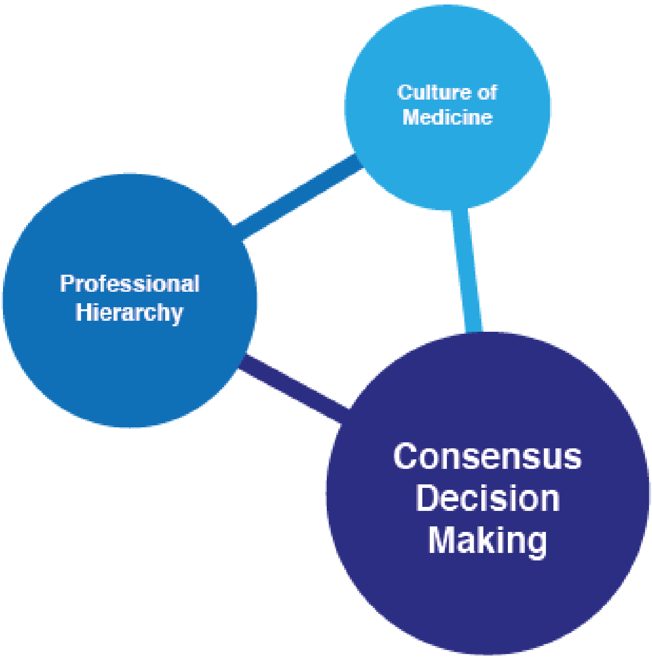
- The quandary of who leads care decisions
- Variance across teams

The multifarious dynamics of parental involvement

- Shared decision-making
- Defining junctures within decision-making

Care within PICU could not be provided by individuals and is dependent upon the collective practice of teams. How these teams work together in the acquisition, production and application of knowledge is critical to practice of decision-making. How professional relationships interconnect and play out was seen to impact decisions made as illustrated by Figure 22.

Figure 21: Professional relationships



6.3.1 Hierarchical nature of professional relationships

Team structures within the PICU were hierarchical, involving large numbers of staff and varying levels of expertise. Medical staff were seen to exert the greatest influence in the decision-making process due to their professional status and also legally sanctioned role.

> *"It's a medical, so it's a consultant. So it's our decision about what's the right medical treatment for someone."* [Doctor 4, Consultant].
>
> *"I think it is more a medical decision really, as to what happens with the treatment. We (nurses), obviously give our opinion."* [Nurse 1].

The traditional professional power of medicine dominated within the confines of PICU. Despite recognition that nurses' intimate and concentrated contact with child and parents provides them with unique insights and important knowledge, traditional relations persisted. Consequently, the nurses' voices in decision-making constantly had the potential to be discounted or lost.

> *"And I think the nurses are very important as well, they can vary and sometimes it's hard to hear their voice in the discussion."* [Doctor 4, Consultant].

During ad-hoc discussions and within interviews, nurses commented that they do not consider that their contributions are always valued when decisions are being made.

> *"..No matter what you said to them they just didn't want to listen, I felt like they just didn't want to listen, they didn't want to know."* [Nurse 9]

Nurses' perception was that their voice was sometimes overlooked, the power to influence decision-making being explicitly identified as the domain of the consultant.

Middle grade and junior PICU doctors adopted a predominantly unquestioning approach within intra-professional discussions. This possibly occurred out of deference to their senior colleagues' knowledge and experience, but perhaps was also because of the continued hierarchical nature of the medical profession.

> *"You learn very rapidly (said with a grimace) to work and do what each consultant wants…..can be very hard at times, particularly when you are tired…. It means you are always on edge, in case they change opinions."* [Memo: Ad-hoc conversation ST2].

Due to the nature of the workload on PICU when Edward's condition deteriorated on the first day of his admission, it was left to the middle grade doctor to represent the PICU voice within the MDT and family meeting, contrary to professional norms. When placed in such a situation, alongside senior consultants from other specialities, an obsequious and unchallenging stance was adopted. This may well be due to a lack of confidence in their own knowledge, experience and opinions, and/or recognition of the need to present a united front. Such deference could also be partially explained by the continued ordered nature of the medical profession and tradition of not challenging seniority.

> *"I think ideally this would have been consultant (PICU) led and it just happened that what else was going on in the unit prevented that."* [Doctor 7]

> *"I feel like to get that communication and to have that knowledge and the confidence, then it needs to come from a higher level. in the difficult decision-making process it needs to always be consultant led….. They have a vast experience in intensive care in these situations."* [Nurse 9].

Significantly, parents rapidly determined who controlled information. Both Fiona's parents identified that nursing staff, junior and middle grade medical staff were unable to provide them with the information they required to help them understand and prepare for treatment decisions.

> *"I think pretty soon it became, knowledge that the ones who gave opinions were (names consultant intensivist) and (names neurology consultant). They were the ones who gave any definite, future pictures."* [Finlay]

> *"No I am saying a junior, they could tell us there and then what was happening there and then to her body, not, this is where we are going."* [Fay]

Parental recognition of the distribution of power and control amongst physicians suggests that even at this time of emotional turmoil parents are able to identify who they need to engage with. This is particularly important because it is frequently supposed that parents learn to navigate their way through the PICU experience by seeking information and clarifying understanding of the situation from more junior staff at the bedside. Fiona’s parents’ decision to focus upon two key consultants as their communicators may have generated unrealistic expectations and could have manifested in communication breakdown. Yet, both had realistic expectations with their expressed priority being consistent and logical discussion.

> *“Yes in a false world you would love to deal with the same person day in day out but they have got to live beyond their work and you understand that. You know, life for a doctor is never going to be Monday to Friday…. So, you can understand that it is going to shift around.”* [Fay]

> *“I think I completely understand that (names consultant intensivist) is not going to work 24/7 for eight days, for the particular period of time that (names daughter) was in PICU….”* [Finlay]

Similarly, HCPs acknowledged the importance of teamwork and awareness that one person alone could not, and should not be responsible for the decision to withdraw care.

> *“We are usually doing this as a body, a consultant body, doing this together. We are not usually doing this as one single person in this style of cases.”* [Doctor 1, Consultant].

> *“I don’t think that one person could be responsible for it really. I think people need to be able to discuss it, so I don’t think you could make that decision on your own. You need to take other people’s experience and interpretation of the facts, and have the team come to that conclusion, and the family as well.”* [Nurse 2].

6.3.2 The culture of medicine

A fundamental aspect of care in the PICU setting is multi-disciplinary working and team working to ensure a coordinated approach. The care experience revolves around the interdisciplinary team. Yet the most common feature of multi-disciplinary team working was that professionals held differing viewpoints and assessments as to what actions were in a child’s best interests and quality of life. Compromise was seen to be achieved primarily through dialogue. Whilst the aim of dialogue may be to clarify choices and seek commonalities to genuinely understand difference, the difficulty is that consensus occurs within the context of tension related to the varying stances adopted and can be more apparent than real.

6.3.2.1. The quandary of who leads care decisions

Management of these problematical cases, whereby the child was admitted with a complicated illness with multiple pathophysiological alterations, can be argued to be best provided by specialist intensive care doctors as clinical experts. Their role was to provide strong leadership, act as a facilitator of communication and director, organising the many specialist teams involved. Yet, when multiple professional teams were involved there existed a lack of consensus as to who had overall clinical responsibility for decision-making within the PICU. When staff members, medical and nursing, were interviewed, all were asked who they perceived was responsible for coordinating care, a straightforward answer was unable to be given.

> *"Well the thing is there were different consultants for different things, because Dr…. was her renal consultant, the consultant of the week would have been her PICU consultant, and whichever neurologist was on duty would be her consultant, ……I think it should be the PICU consultant's decision, but with listening and respect to the visiting consultant…. Somebody needs to take the leading role. In [Amy's] case it seemed to be a very befuddled tripartite approach."* [Nurse 6]

This indeterminacy resulted from the number of medical teams involved in care. Some suggested that it was the PICU consultant on call, who co-ordinated and led care decisions, whereas others suggested it was always a shared approach.

> *"Well I feel like because they're on intensive care then our doctors need to be key.…So I think since the patient's on the unit, then I*

> *feel like it should be the doctors from intensive care, making sure that they liaise with the other specialities,……...”* [Nurse 10]

> *“I sort of lead the care of patients when I’m on call, but I feel it’s very much a team effort. So, I try and involve as many members of the multidisciplinary team and multi-professional team as possible. And I also confer with my colleagues, PICU consultant colleagues if there are particularly tricky issues.”* [Doctor 2, Consultant].

Significantly, across cases there was also comprehension that establishing a lead role was not clear cut and that transitioning between the various medical specialists remains problematic both in terms of timing and because of the requirement for expert knowledge.

> *“I think it has to be a bit of team effort, specialists involved….. I think it’s difficult to say who should be leading at what point, when you change over…It depends at what stage the patient’s at and what it’s about….. But ideally it would be one lead person.”* [Doctor 7]

> *“The intensive care team is primarily responsible, but then if there is a specialist,….., then I can't overrule that because of the finality of death. And for the potential arrogance of me saying that I know more about this than a specialist who’s trained in this and worked in this all their lives.”* [Doctor 3, Consultant].

A complex set of professional conventions including mutual respect, appreciation and deference to seniority appeared to cloud the issue. Telling, was the respect provided to colleagues in a different speciality, the inference that challenging professional judgement may be considered presumptuous. Underlying this may be a fear that exercising a challenge of another professional’s judgement could result in litigation. The need to reconcile judgements to foster solid and on-going relationships was witnessed to result in an intricate process of manoeuvring to engineer a desired outcome.

> *"I had to really carry the other team with me. It is often done very subtly, in the sense that you have to do so without impinging their area of expertise. But when it comes to the very sick children, I use the word chasm, but the chasm often has to be breached. The only way of doing that is to make sure that you bring the other team with you….making sure that the other team know that we, as the ICU consultants, are the primary decision makers.*" [Doctor 11, Consultant]

Attempting to navigate the complexities of these cases without expert speciality opinion would have been impossible but this ideal that ICU consultants are the lead decision maker was not constant. Rotation in cover, with different PICU consultants taking the lead on a daily basis, and use of locum PICU consultants resulted in a lack of coordination and consistency of care.

> *"it's a lack of continuity, it's a different doctor each time, …… and sometimes it's like hitting your head against a brick wall because they don't know him."* [Beth]

The dilemma of who leads overall care, inherent in all cases, was seen to influence development of effective communication and trusting relationships across not only inter and intra disciplinary teams but also with parents. This draws attention to the need for a single, lead doctor to coordinate and communicate with parents and HCPs not only to ensure the calibre of information but also to assess how it was processed and responded to. A pre-requisite for effective management is the need for early sensitive and consistent communication to assist parents in managing the complexity of information and the inevitable highs and lows. A difficulty within this setting was that relationships were transient and parents may not develop a long-standing relationship with either doctors or nursing staff.

Significantly, although communication events were documented extensively within the medical and nursing notes, there is a surprising reliance on verbal handover of information despite acknowledgement that this can be limited in accuracy and content.

> *"So if I know that there are potentially important or sensitive communication, not necessarily problems, then I'll try and get the information from my colleague who's been on before. Sometimes it's recorded in the notes, but not very consistently. I have to admit I tend to not look at the notes very much, unless I'm looking specifically for something. I tend to rely quite a lot on what I'm told in the handover by my colleagues."* [Doctor 2, Consultant]

> *"I think the more doctors that are involved the harder it is… Even things that are written in the notes aren't read."* [Doctor 4, Consultant].

This reliance on verbal communication across the multiplicity of professionals is a risky practice susceptible to breakdown in communication, knowledge being assumed.

6.3.2.2 Variance across teams

While involving others was essential to understanding how to act, manifest was the struggle between intensivists and specialist teams over perceived professional creed and practices. It was evident that there was a generalised perception within the wider medical team that those working within PICU tend to adopt a more pessimistic take on outcome.

> *He stated that "a very nihilistic viewpoint had been presented to the family and which parents have adopted."* [Extract observational notes]

The inference within this comment is that it was the intensive care team who steered Edward's parents when they initially decided to pursue a palliative care pathway. This stance generated animosity and a sense of distrust amongst the teams. From an observational perspective, the parental viewpoint appeared to derive from the emphasis placed within initial discussions, by wider non PICU team members, on Edward's judged poor prognosis and outcome. Although never explicitly referred to, the unspoken inference, from initial interactions with the Consultant Neurosurgeon and to a much lesser extent the Consultant Oncologist, was that subjecting Edward to treatment that was likely to be unsuccessful was not in his best interests. Decisions were always made according to the knowledge available at that time and, as previously alluded to Edward's condition did improve quite unexpectedly over the following 48 hours.

Significantly, there were open deliberations among the specialist consultants that the PICU team may be partisan in their perceptions of instituting and amending therapies due to a generalised pessimistic take on disability. This could result in an underlying level of tension and conflict before any situation specific discussions commenced.

> *"Sometimes I think there is conflict between what I may think, what neurologists may think and what PICU think too…….. That needs to be discussed."* [Doctor 9, Consultant].

> *"So I think very often the intensivists don't want a child to survive with disability. Neonatal intensivists probably even more so even than the paediatric intensivists. Whereas for paediatric neurologists and neuro-disability paediatricians, we are very used to having lots of patients who have disabilities. So we don't see that as such a terrible thing whereas, intensivists want the child to go home normal, and think it's a disaster if they've ended up brain damaged."* [Doctor 4, Consultant].

Divergence in opinions was also apparent between the neurology team and PICU team in Fiona's case. Variance in practice across the teams was seen to be discussed initially by bedside nursing staff caring for Fiona and later amongst the wider nursing team at handovers. Such discussion was not restricted to nursing staff, with the medical staff also openly acknowledging and voicing variance during medical handover.

> *The neurology consultant was commented to be optimistic in approach and unlikely to agree to active withdrawal during medical handover.* [Extract from observational notes]

Yet, there was clear understanding that neurology expertise was vital in any decision-making given Fiona's prognosis and the likelihood of neurological impairment should she survive. Remarks were made as to how to proceed allowing for the variance.

> *Commented during handover that decisions cannot be made in isolation, neurology expertise is required, but that their (neurology team) optimism will need managing.* [Extract from observational notes]

Significantly, on this occasion Fiona's parents were not aware of these variations within the medical teams on managing their daughter's care.

One intensivist perceived that medical staff external to PICU may be more reluctant to withdraw care and may attempt to prolong treatments.

> *"…one of the reasons why I was being very prescriptive was because I think that if it is left in a situation where there are various loopholes then the other team may use that loophole to continue with their own plans. And it sounds as if there is an element of confrontation and there isn't, I think it is just some people have great reluctance of withdrawing care, intensive care, because it is not their role. We do it because that is what we have to do."* [Doctor 11, Consultant]

This lack of harmony across and within medical teams and the struggle to achieve concordance has been a central theme throughout the study. Although there was open acknowledgement that prognostication varied and interpretation of future outcomes were at best guesses, dissonance across the medical teams existed as to how much time and debate should be permitted to formulate a clinical decision as to management was apparent.

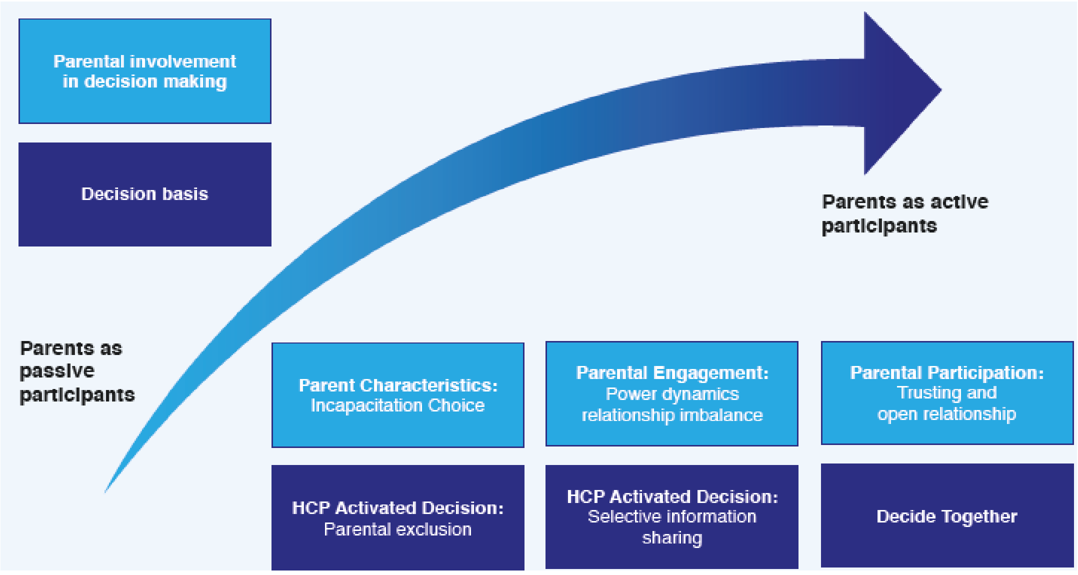
Whilst the need for consensus amongst the medical teams prior to engaging in discussions with parents was acknowledged, achieving agreement was seen to be a complicated and on occasions protracted process. One of the major reasons for this is that decisions involve the exercise of both professional and moral judgement. At a superficial level, it could appear that through frequent engagement in debate inter-professional collaboration and decision-making would increase synchrony of decision-making. However, this does not allow for the heterogeneity of individual consultant's values, beliefs and experiences within their own speciality.

6.3.3 The multifarious dynamics of parental involvement

Although most parents desired some level of involvement with the process of decision-making, their role and influence was very variable. A broad range of professional and parental manoeuvrings to accommodate their emotional needs and capacity to be engaged along with professional acquiescence was revealed throughout ethnographic observations and are represented in figure 21.

This section will explore how levels of engagement were seen to be at best an attempt in terms of HCPs providing information and guiding parents through the process, steering them as to what may be the best resolution for their child. It also exposes practices that exist within the PICU that can inhibit participation and the changing dynamic of parental emotional ability and capacity to participate.

Figure 22: Parental role in decision-making



6.3.3.1 Shared decision-making

The underlying ethos advocated within the study site and one championed by HCPs was of shared decision-making (SDM). SDM within the PICU occurred as a consequence of parents and HCPs coming together to try and fathom out what was the best thing to do for the child in unique and exquisitely difficult situations. SDM infers a meeting in the middle, all working as equal partners towards a common goal. The aim to construct a viable set of options that respect parents' values, beliefs and preferences whilst also being medically appropriate. However, no common definition of SDM exists, it is both a philosophy and a process. Whilst it requires partnership, how that is actioned is unclear and inexact, encompassing a broad continuum of involvement. The complexity of relationships was apparent. Parents were seen to exercise varying preferences as to the extent of their involvement and the location of responsibility.

> *"I think the parents can't, or it's very hard for them to make the decision, and so I think that we try and gauge what they want. But this is an attempt. But it's certainly not, there are no rules or formulas, it's very much going with feelings and emotions really."* [Doctor 2, Consultant].

Within the PICU individual parents varied greatly as to the information they wanted and how they wished to engage in decision-making. Recognition that parents may be ill-prepared to participate was apparent together with consideration that this may well be associated with how communication is organised and delivered together with the multiplicity of staff involved.

> *"We feel somehow that we have to make shared decisions about complex issues which often parents are not prepared for…. We are in a situation where we somehow feel that we have to let parents make the decision…... They haven't had time to think. All the various different people, one comparison after another after another…. I think that under those set of circumstances when*

> *parents are then expected to make decision about withdrawal it is not only, not right, but it is cruel to expect parents to do that. I think that this is where we as a clinician need to lead them, give direction and help make that decision.”* [Doctor 11, Consultant]

Whilst parental participation was largely supported, the singular dynamics of each relationship prevent the adoption of a generalised strategy. Provision of tailored parental support was seen to be essential to enable parents to work with HCPs to participate in a way that was meaningful for them.

6.3.3.2 Defining junctures within decision-making

Decisions made in relation to clinical management and support of care delivery were numerous, varied and were observed to be frequently quickly made in response to a child’s fluctuating clinical condition. Yet, very few decisions were seen to be made by a single individual. The majority were arrived at following consultation amongst HCPs, predominantly medical staff, and with varying degrees of parental participation. Such clinical decisions pertained to: whether to initiate treatments in light of child’s vital signs and other patient information; continuation of therapies in view of child’s clinical response; determining the limits of escalation of treatment; and whether to offer and/or withhold therapies. Significantly, it was observed that decision-making was not a linear process with a solitary decision resulting in an outcome. Rather, it was observed that a succession of multiple rapid decisions was required to complete a single task with each choice sequentially influencing and bringing about a series of consequences not only for the child but also for the organisation and delivery of care within the PICU. This section will initially reveal how the nature and availability of knowledge informs and influences production of a decision and progress to describe the intentional controlled flow of information to steer parental decision-making.

6.4 Managing Uncertainty

The theme of managing uncertainty describes the uncertainties in diagnosis, prognostication and treatments and the extent this impacted upon decision-making. Figure 24, refreshes the reader to the sub-themes and sub-sub-themes which were derived from the within case and cross-case analysis.

6.4.1 Decisions without the benefit of certainty

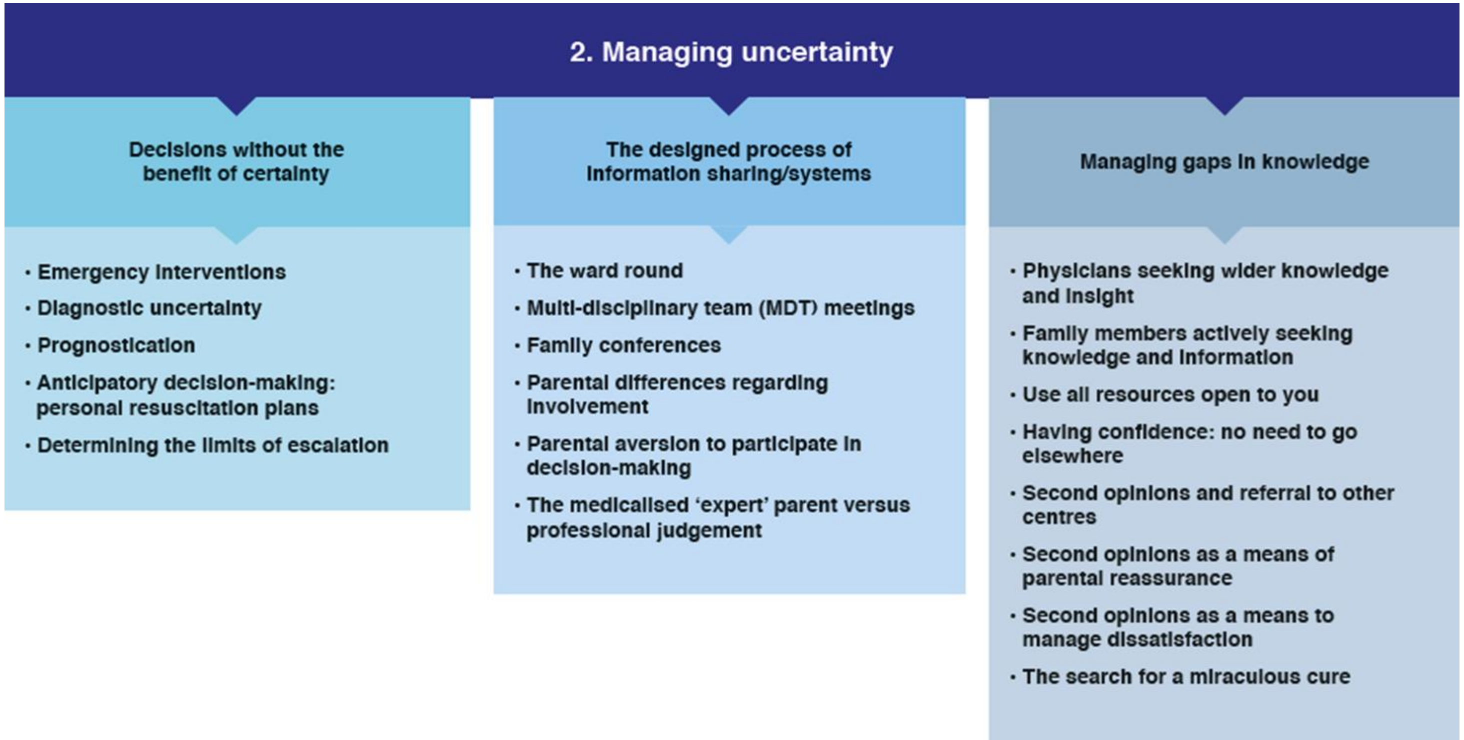
Whilst recognising there is no such thing as a ‘routine’ PICU admission, for some admissions predictable pathways are anticipated. For others the unexpected nature of the admission can leave professionals and parents struggling to adjust to the devastating change in circumstances. Ambiguity as to whether the child will survive, the possibility for future disability and unknown outcome impact upon parental behaviours and interactions.

6.4.1.1 Emergency interventions

Many situations in the PICU necessitate rapid decision-making in dynamic and fluid circumstances. Decisions occurred primarily at the bedside, immediate action necessary to attempt to stabilise the child’s deteriorating condition. HCPs were seen to rely on the application of intuitive decision-making, based on available clinical information, based on tacit knowledge, intuition and experience to arrive at a subjective determination. Strikingly it was observed that HCPs appeared ‘secure’ with being answerable for decisions made, despite the possibility that they may not have made the ‘best’ decision. That professional judgement may be flawed was seemingly an accepted feature of emergency management. Collegial support was in the main unreserved and unless there was a clear threat to patient safety then decisions made and acted upon were upheld.

> *“And the other thing about team working is that I think we have to work on the basis that once a decision has been made by an individual consultant that unless it is absolutely lethal, which is unlikely to be the case, then I think that we have to abide by that. Really.”* [Doctor 11, Consultant].

Figure 23: Theme 2 Managing uncertainty



2. Managing uncertainty

Decisions without the benefit of certainty

- Emergency interventions
- Diagnostic uncertainty
- Prognostication
- Anticipatory decision-making: personal resuscitation plans
- Determining the limits of escalation

The designed process of information sharing/systems

- The ward round
- Multi-disciplinary team (MDT) meetings
- Family conferences
- Parental differences regarding involvement
- Parental aversion to participate in decision-making
- The medicalised 'expert' parent versus professional judgement

Managing gaps in knowledge

- Physicians seeking wider knowledge and insight
- Family members actively seeking knowledge and information
- Use all resources open to you
- Having confidence: no need to go elsewhere
- Second opinions and referral to other centres
- Second opinions as a means of parental reassurance
- Second opinions as a means to manage dissatisfaction
- The search for a miraculous cure

Medical staff eschewed judging fellow colleagues, a natural reluctance to criticise colleagues due to the realisation that too may have made decisions that could be challenged under similar circumstances.

Achieving interdisciplinary consensus during bedside management resulted in parents witnessing debates about how care would proceed, including conflicting opinions about specific interventions and actions. Both Ben’s parents and George’s Mum recognised that their ability to participate was compromised and were cognisant of their need to trust HCPs.

> *“Like I say it’s a fine line and you think you’ve got to trust doctors.”* [Beth]

Reliance on recommendation from medical staff is perhaps to be expected since they are considered to be in possession of expert knowledge but may also relate to the sudden and unexpected nature of the majority of admissions.

6.4.1.2 Diagnostic uncertainty

Determining a differential diagnosis is of paramount importance when deciding treatment priorities, prevention of secondary complications and establishing prognosis. Diagnostic determination was seen to be a continuously complex, iterative and normally collaborative process involving information gathering and clinical reasoning. Within PICU diagnostic difficulty was frequently observed due to the variable, often atypical and unexpected array of presenting symptoms or illness. Whilst fundamental in informing management, the complexity of the clinical processes to confirm a diagnosis was seen on occasions to follow a protracted course. The challenge when inherent uncertainty in diagnosis occurs is to provide effective patient care whilst ambiguity exists as to the potential harms and benefits of treatments.

For Amy and her family establishing a definitive diagnosis was a faltering process that occurred over a prolonged period of time. The majority of the duration of Amy’s admission to the PICU centred not only on the practicalities of attempting to control her seizure activity but establishing a cause for the seizures since this was fundamental in informing management.

> *“So from an early stage if we’d found a cause of a life shortening or a fatal disease then that would have informed our management……… because it is the cause that mainly determines the outcome.”* [Doctor 4, Consultant].

Clinical recognition and determination of aetiology was observed to be challenging with concomitant alterations in management and resultant time delays.

> *“if you have that diagnosis suggested or highly likely, then you are going from the general understanding of what this condition’s natural course is…….. what the various options are, if there are any, and what actually these bring to the child and what is in the best interests.”* [Doctor 1, Consultant].

Continual diagnostic evaluation and changing prioritisation of differential diagnoses reflected the normal sequence of events with recognition across both medical and nursing teams that the means of determining a diagnosis was a process of exclusion.

> *“I think we were waiting so long for tests and things, and it was a prolonged admission….. we have had to wait for certain results to come back before decisions can be made,”* [Nurse1].

> *“I suppose because it was such a rare condition, they have to explore every other option first before you start going down the rare ones.”* [Nurse 4].

Despite this, there was frequently evident frustration at the length of time taken to establish a definitive diagnosis, which in Amy’s case was in excess of ten weeks. Diagnosis of mitochondrial disease can be protracted, yet significantly, one of the intensivists indicated that diagnosis may have proceeded more rapidly.

> *“ investigations should have been…. been expedited. It would have cost us another four thousand pounds to get the expedited mitochondrial work done…….one and a bit days of PICU,……… but, we’re not in the American game where you throw everything in the first go. But within a few days it was evident that the situation was very complex and, then I feel that sometimes you know we have to investigate very aggressively.”* [Doctor 11, Consultant]

Unspoken was the impact of the delay on everybody. This uncertainty in diagnosis was a result of diagnostic caution, conceivably resulting from a culture within the NHS of eschewing excessive expenditure. Yet in actuality this false economy caused avoidable suffering to all involved and especially to Amy.

Intrinsic within all the discussions about Edward’s on-going management and need to establish a definitive diagnosis was the concept of futile treatment. Yet, throughout the observations, it was illuminating that at no time was futility explicitly referred to. Perhaps this related to the fundamental difficulties and controversies surrounding futile treatment. Nevertheless, the lack of a definitive diagnosis meant that individual and polarised opinions about whether commencing further aggressive treatment or pursuing a palliative approach were evident. Without a biopsy and definitive diagnosis it was not possible to appropriately advise whether further treatment was a viable option. Perceptions about the effectiveness of treatments were based primarily on personal clinical experience and supposition. There was recognition, given the size and location of the tumour, that chemotherapy may have a low probability of success. Surgical excision was unanimously accepted as not feasible and radiotherapy was acknowledged to be not an option. Nonetheless, the dilemma remained as to whether it was possible to exclude a treatment where the chance of recovery exists. Unease was evident as to the perceived suffering and effect on quality of life that both Edward and his family may experience if chemotherapy was commenced. The difficulty demonstrated is that decisions, whilst informed by, and reached after, consideration of the available clinical evidence, involve a substantial interpretative component with gaps in knowledge plugged by value judgements.

Less frequently, there was a body of information available as to what actions should be undertaken. George presented to the emergency department the evening of his admission as acutely unwell with classic signs and symptoms of meningococcal disease. A protocol as to how to proceed practically in this uncommon situation existed. This suspected diagnosis of meningococcal disease not only imposed a treatment pathway but also provided a knowledge base about usual patient trajectories. PICU medical and nursing teams acknowledged that all intensive care therapies should be offered to George for the first 48 hours. The evidence base suggested that if a child could be supported through the first 24 to 48 hours then they would be highly likely to survive.

> "*he was in that first 24, 48 hours and I think really up until that point there's almost like, like we do everything………….. that first 48 hours is your critical point at which to kind of turn the corner.*" [Nurse 14]

Such unequivocal treatment pathways were rare. The more typical PICU course for these extremely complex cases was a sequence of events which reflected the uncertainty and complexity in clinical processes to establish a definitive diagnosis.

6.4.1.3 Prognostication

Pivotal to decision-making, including the on-going development of treatment plans, was the provision of information about prognosis. Communication of information, including explanation of uncertainty, by HCPs whilst determining a differential diagnosis was crucial. Such information had a significant impact for parents and HCPs upon treatment decisions, yet was acknowledged to be problematical due to the inexactness in predicting future outcomes. Appreciation of the importance of providing prognostic information was witnessed throughout the study, with HCPs and medical staff cognisant of the value of such bestowed by parents. Prognostication was predicted in terms of both immediate and longer-term survival as well as anticipated outcome of critical care interventions particularly in respect of a child's quality of life and future functional outcome.

Accurately predicting Fiona's outcome following an out of hospital cardiac arrest (OHCA) was openly recognised as challenging. Fiona suffered a primary injury at the time of her OHCA. This injury would be non-reversible and combined with a prolonged period of time, fifty minutes, without any return of spontaneous circulation (ROSC), made the likelihood of a good outcome for Fiona improbable. It was anticipated that if Fiona survived she would have sustained severe neurological impairment. Yet, since the potential for survival existed, the difficulty for the PICU team was to ensure that care was optimised to potentially minimise secondary injury, ensuring Fiona had the best possibility for recovery whilst not continuing to provide treatment in a seemingly futile situation.

> *"…it is very difficult in the first few hours after cardiac arrest to take decisions about their final outcome. That's why most guidelines suggest that you wait one to three days before you give the parents presumed outcome, final outcome….This was an out of hospital cardiac arrest, with a long no flow time and the initial rhythm was asystole. These three variables predict, not with a 100 per cent certainty, but most of the time, a poor outcome even if the person survives the episode of cardiac arrest."* [Consultant 8]

Nevertheless, there was recognition by the medical team that whilst there may be a very small chance of recovery her prognostic indicators were not auspicious. There appeared to be unanimous agreement with Fiona's initial management plan. This sanctioning of the maintenance and potential prolonging of Fiona's life was believed right and in her interests at this time. The potential did exist for Fiona, no matter how small, to make a recovery, therefore initiation and continuation of treatment was believed in her best interests.

> *"There was some signs, that the brain stem was not dead. We were almost sure that the ischaemic injury would be serious… but we had some signs, some respirations we see on the ventilator; cough during suctioning, and spontaneously opening of eyes, that the brain stem was not dead."* [Consultant 8]

Equally, throughout the resuscitation, with its initial focus on life saving interventions, Fiona's parents recognised that she was on the threshold between life and death. Both were able to recall that, whilst hoping and praying that she would survive, they knew if she did, then their lives would have changed immeasurably.

> "*And I the fact that she, it, took so long. I think we knew that, the fact that we couldn't resuscitate her, the ambulance people couldn't resuscitate her, and when we got her to A&E and they took an age. The knowledge that ……" [Fay]*
>
> *"Something was definitely" [Finlay]*
>
> *"Something. She would never be the same." [Fay]*
>
> *"I think it was more that life would never be the same because even if she made a complete full recovery, which was our hope at that time." [Finlay]*
>
> *"Yes it was." [Fay]*
>
> *"We knew things had changed." [Finlay]*

Throughout this traumatic unplanned trajectory, Fiona's parents were both able to recognise and understand her poor prognosis, whilst also maintaining hope. They knew that she was never going to be the same, that there was not going to be a good resolution. Yet retaining hopefulness aligned with their personal values and beliefs and was recognised by HCPs as part of their role as parents, to always hope for the best for your child. By not conveying an overly optimistic prognosis nor withholding information, trusting relations were sustained.

To not have instigated or maintained life-sustaining treatments for a period of clinical evaluation was considered by HCPs as erroneous and not best practice. Accepted practice would suggest waiting for a period of time post cardiac arrest to predict neurological outcome. Neurological injury accounts for the most common cause of death following OHCA . There was however recognition amongst both parents and healthcare professionals that, should Fiona survive, neurological impairment could occur on a spectrum from very subtle, such as short term memory loss to profound, for example, spastic cerebral palsy. Even when an MRI scan was undertaken documentary analysis highlighted the vagueness of the findings. Enlightening was the comment that it could be worse together with the acknowledgement of abnormality. Exemplified are the difficulties in attempting to calculate future burdens when the uncertainties of prediction are so indeterminate.

> *MRI scan shows moderate hypoxic brain damage. It could be worse, but it is not normal. At this point it is very hard to tell what the functional outcome will be.* [Extract from medical notes]

All through the study a pattern emerged of physicians delaying decisions about treatment limitation when prognostic uncertainty was evident. This led subsequently to aggressive intervention until death appeared certain, at which point any professional differences were resolved. Parental ability to understand and endure the complexity of prognostication is remarkable. The intricacy and indeterminacy of prognostication can result in parents fearing that information disclosed is incomplete, that they were misled which could consequently result in a break down in trusting relations and prompting parents to access other information sources.

Carly’s parents, by virtue of the length of time she had already experienced in intensive care settings, may conceivably have mistakenly believed that she could and would be saved. Although their daughter was at great risk of dying, being reliant on technology to keep her alive, her parents may have held unreasonable expectations. They had already witnessed her survive the rigours of chemotherapy, bone marrow transplantation and several previous PICU admissions. This optimism was contrary to HCPs' communications and attempts to discuss her prognosis in an open and honest manner. During the family meeting shortly after Carly's transfer to PICU, the consultant intensivist explained that, despite providing maximal support, Carly may not respond. Possibly in an attempt to word Carly's prognosis in a way that was meaningful to the family, the consultant intensivist likened the effects of prolonged intensive care therapies upon Carly as being;

> *"…equivalent to her running a marathon every day, and consequently if she doesn't start to improve the toll this will take will result in her eventually running out of reserve."* [extract observational notes].

Although her prognosis was not worded in terms of a percentage of survival, the uncertainty and limits of intervention were endeavoured to be conveyed by use of the phrase that at some point her body would run out of reserves to fight. Apparently, her parents were unable or chose not to interpret this nuanced prediction. Given their loss of trusting relationships with HCPs unsurprisingly Carly's parents were less ready to defer to professional judgement and experience. Parental desire to continue with aggressive and invasive life support therapies may be associated with the emotional, physical and psychological investment in the prolonged duration of Carly's treatment. Carly's parents understood that prognostication was an imperfect science and that the medical team could not state with 100% certainty that there would not be a miraculous recovery. They therefore rejected advice proffered and demanded further expert opinions. Allowing parents time to come to terms and move from a situation of anticipatory hope was associated with increased satisfaction with EOL care in some cases, including Amy. However, preventing or alleviating differences of opinion in Carly's care even with increased support and time may not have been an achievable or realistic goal.

Concern about the inherent uncertainty, recognition of multiple and varied interpretations of prognostic estimations, together with diverse levels of expertise in accurately communicating information could have led to a reluctance by physicians to share information. Continuing discussion was consistently witnessed about potential illness trajectories, clinical outcomes, including changes arising from interventions and results from diagnostic tests, in an endeavour to prepare parents emotionally and practically for decision-making. Yet, HCPs may possess unrealistic expectations of parents' capability to process and assimilate information. This may well be where some misunderstandings about future care can occur.

6.4.1.4 **Anticipatory decision-making: personal resuscitation plans**

The increasing prevalence of children with underlying chronic illness, such as Ben, who experience multiple PICU admissions, has resulted in increased use of anticipatory decision-making. Ben's parents have had time to be involved in shared decision-making outside of crises to explore and determine the limits of escalation of care. His personal resuscitation plan (PRP) was based on clinical information, parental judgement and HCPs' permission to make choices about interventions.

PRPs should be taken into account when making treatment decisions, but are not legally binding. Nonetheless, to assume parents can anticipate in advance what will be apposite ignores parental struggles to do the best for their child, while balancing hope with reality. It was evident prior to accepting Ben's referral from his local DGH, and also throughout his admission, that his situation was so profoundly complex that questions about the appropriateness of interventions were inevitable.

> *"I mean if Ben ….I'd take that into consideration of what else is going on around him and what we're doing. And then at least I've got that bit, where if I wanted to (change my mind) I could do, if that makes sense."* [Beth]

This raises issues for managing care, especially in crisis situations since a plan must be flexible to allow modification according to both the child's condition and also parental wishes. Parents were routinely observed by the researcher to be asked at the time of an emergency whether or not they were still in agreement with the documented plan. This may overcome parental concerns that declaration in advance of a crisis would effectively exclude them from decision-making at that time. Nonetheless, parental uncertainty about the best course of action in such an emotionally charged situation can generate considerable distress. Whether parents should take decisions about the appropriateness of actions, at the onset of a crisis is open to contention and reinforces the need for effective and ongoing communication. There is always a danger that an advance directive contracted some time ago may not be apposite in the current situation.

6.4.1.5 Determining the limits of escalation

In reality, as a child's condition deteriorates, or ceases to improve, the likelihood of a positive outcome diminishes. Yet the futility of a given treatment may not become evident until sometime after initiation, which can result in false parental hope that their child will survive.

There was recognition from the time of Amy's readmission to the PICU that both the duration of the seizures and the inability to control these through conventional medical means raised questions and divergent opinions about whether it was right to continue attempting treatments.

> *"I'm not a neurology specialist, but my understanding is that after fitting for a certain amount of time then the chances of recovery are minimal."* [Doctor 2, Consultant].
>
> *"And in my experience sometimes people can go through a long period of status epilepticus and make a reasonable recovery, either back to their normal state or not 100% their normal state,"* [Doctor 4, Consultant].

One of the difficulties of PICU is that the technology exists to keep children like Amy alive in extraordinary circumstances, such as intractable seizures. However, there is little information available to know whether this is the right thing to do. Different approaches were utilised by members of the PICU team when determining how best to proceed, with one consultant suggesting a probability approach akin to statistical analysis underpinned decision-making.

> *"So decisions are made on an equation based on the input data we've got…..some of the decisions we make, they are 51/49 decisions, which means 49% of the time they're wrong. But you must always chose the 51 decision,……you're going to choose the decision which is the lowest risk, even if there's only a 1% difference, or 2%.....If you know that you have made the 51 decision, you're not in charge of whether the outcome comes as 49 or 51, that's randomness, that's not anything I have control over, but I have control in making sure I pick the 51 side…..and if it ends up as a bad outcome, well I'll do the same thing tomorrow and the next day, and overall I'd be up."* [Doctor 3, Consultant]

Nevertheless, in situations where for the majority of the admission, as in Amy's case, there was no confirmed diagnosis, determining a probability of success was impossible and emphasises the difficulty of amassing the evidence to support such a judgement being made. Conversely another consultant suggested a statistical approach did not assist in decision-making.

> *"When looking to statistics for applying to a single patient it actually never works. So if you have a probability of 60% having something and 40% of having that one, then nobody actually tells you which side you are on."* [Doctor 1, Consultant]

Both parents and staff longed to see a positive outcome for Amy. However, views as to what was reasonable in terms of treatment vary over time in such profoundly complex situations.

> *"Well I think the big problem with Amy's illness was when do we switch from active full-on management, trying to stop the seizures, to the realisation that we cannot actually treat this problem. The fact this is a fatal illness. Everyone comes to that point at different times. I think there was difficulty with different individuals having*

> *vastly different speeds of acceptance that this was going to be the outcome."* [Doctor 3, Consultant].

Identification of transition points in care delivery was seen to be problematical all through the study. Effective management requires balancing of the child's well-being and finite resources, together with a need to accommodate parental and HCPs need for time and opportunity to recognise that everything that can be done has been done.

6.4.2 The designed process of information sharing/systems

Although parental preferences for involvement in the decision-making process were seen to be individual, their participation was complicated by the managed trajectory of sensitive discussions with HCPs. Three key junctures were identified within the study whereby influence was exerted to favour specific courses of action either through parental exclusion from the decision making process or by limiting options presented. These included ward rounds, MDT meetings and family meetings.

6.4.2.1 The ward round

At the time of the study, parents were generally not allowed to remain on the unit during ward rounds. The policy to exclude parents was cited by medical and nursing staff as primarily a measure to prevent breaches of confidentiality relating to other cases. It was acknowledged by some that parental presence may inhibit open and frank discussion between professionals. Considerable debate exists within the literature as to the benefits of parents being present. Both during ad-hoc conversation and within the interviews a number of parents expressed disappointment, anxiety and frustration about their exclusion from PICU for the duration of the ward round. These periods of absence were observe to occur for up-to 3 hours in a morning and generally 30-60 minutes in an evening. Partly parental concerns pertained to organisational issues, the lack of consistency in terms of timing and duration of ward rounds.

> *"I suppose it wasn't always at a particularly regular time. So you could go to the toilet, come back and the barriers would be in the way and, sometimes it could last quite a long time as well."* [Finlay]

Largely this linked to parental desire for information, to hear all that was being talked about their child and understanding the nature of the problem.

> *"We have to be out while they do ward round unless we stamp us feet and (names lead consultant) says yeah all right then."* [Beth]

For the parents the bedside nurse, nurse in charge and allocated middle grade doctor and consultant intensivist on call all act as primary conduits for information on a day to day basis.

> *"The doctors if you asked them outright they would tell you, but I know they like going through the nurses, and as I say depending on which nurse we had on was how informed we got….. It just depends on who is your doctor, which is your nurse for that day."* [Beth]

Beth (Ben's mother) perception when asked to leave during the ward round was that it inhibited information exchange and left her feeling frustrated. She considered it to add an unnecessary layer to communications, engendering tension in her relationship with staff. Whilst parents recognised the need for confidentiality they felt marginalised.

> *"… but if you were in the room (side room) then they would have us. I guess that is a medical in confidence thing for the other patients that are around."* [Finlay]

It was evident that the process of the ward round, whereby parents with children in the main PICU area are requested to leave acts as an obstruction to effective communication and partnership. Limiting opportunities to involve parents in understanding the complexity of decision-making, not exposing them to debates about the uncertainties within decisions may significantly affect the development of trusting relationships as well as parental understanding.

> *"It would have been nice to have been able to come back for ours, you know whilst they were there with (names daughter), rather than going away."* [Fay]

Fiona's parents felt better supported and more able to advocate for their daughter once she had been transferred into a side room. Admission to a side room enabled Fiona's parents to be present when her case was discussed. They perceived they gained increased insight into what may be planned for Fiona by being present. This was vital in allowing them to feel that they were always brought fully up to date. It also specifically allowed Finlay (Fiona's father) to ask questions and learn from the debates that on occasion took place amongst the medical staff. For some parents observing such deliberations may have resulted in confusion and a loss of confidence in professionals. For others, including Finlay, it may allow them to retain their sense of control and ability to stand up for their child.

6.4.2.2 Multi-disciplinary team (MDT) meetings

MDT meetings were central in ensuring consensus amongst the medical nursing and allied health professionals as to the agreed goals of care and how to conduct the family conference. Proactive management and effective preparation by HCPs for the family conference was considered vital to enhance parental understanding and participation in decision-making. Thus, through a strategy of guided paternalism, (as discussed in Chapter 2, section 2.5.3), HCPs agree in advance what choices about care would be offered to the family.

> *"I think it is easier to manage if there has been a pre-discussion about the patient….I am very comfortable with having this discussion with many of the PICU intensivists because they know the way that I am going to be speaking. ..so there is comfort with how we approach a situation, whatever the information we are going to impart is."* [Doctor 9, Consultant]

Any disagreements and differences amongst HCPs were recognised as required to be resolved in advance of family conferences. All staff were mindful that any disparity was disadvantageous, potentially damaging parental and professional relations, increasing mistrust and parental anxiety. Yet, discordance among staff was particularly evident in longer stay patients.

> *"It's very frustrating really. You obviously do not want the parents to see your frustration, because you are trying to be strong for them, maintaining a professional front, so it is very difficult. You ….really don't want them (parents) affected by it because they have to have every confidence that everyone is doing the right thing for their child."* [Nurse 5]

Finlay, in particular, possibly because of his military background, appreciated that sharing of information was a managed process. He acknowledged this allowed family members to understand the medical situation so that they could feel prepared to participate in discussions. Additionally he ascribed this structured flow as necessary to prevent potential misunderstandings, communication problems and ultimately a potential loss of trust.

> *"It was very much a controlled flow, a hierarchically controlled flow of information which I can understand because we are talking about life and death matters. I wouldn't want somebody uninformed opining about how it is going to be in a couple of days for them to be in trouble with somebody more senior, or for us to latch onto the wrong expectation."* [Finlay]

Nevertheless, his strong desire for information coupled with his need to protect his family resulted in some frustration that HCPs' communication behaviours meant initial discussions occurred without parental presence.

> *"I suppose, was it unhelpful. In the military it is different isn't it. You are a professional within a team and there's complete openness in terms of the information flow. I am sure that in that doctors' room that's closed that that's what it is like, where they are talking. I was just conscious they're talking about stuff, they are developing a better picture of what is going on with (names daughter) and at a*

> *point normally after rounds they'll deliver that to us. And it's not a complaint, because I can't imagine there being a better way of doing that, but I am just aware that somebody somewhere knew more stuff, before I did. I guess that is just a limitation of the way that the professionals work together but when you are so information hungry at the beginning I felt that information denied."* [Finlay]

HCPs do need to reflect on the impact that established behaviour patterns can have on the parents and families of critically ill children. The feeling of decisions occurring behind closed doors was as previously mentioned, exacerbated by the organisation of the ward round.

6.4.2.3 Family conferences

The family meeting engaged parents in dialogue, shared information and provided some opportunity to explore a pre-determined range of treatment options. Thus, the flow of information was seen to be controlled and managed by healthcare professionals. For parents, these were conceivably intimidating meetings, whereby every reaction and response was scrutinised. Alison (Amy's mother) was able to reflect that she had had to adapt and overcome inhibitions and express what she believed was right for her daughter to ensure that her opinion was heard.

> *"Well I've always been quite quiet, but I think in those circumstances you have to stand up for yourself and you have to speak and make sure that they're doing the right thing for Amy because she's the most important thing that they're having to deal with. Initially I was very quiet, as time went on, I sort of realised that I can't just back down, I have to speak up and that's what I did, yeah. And I sort of got the hang of writing every little thing down to ask about, but it took a while to get there, yeah."* [Alison]

There was recognition particularly from the nursing staff and social worker that parents do need to be prepared for such a potentially adversarial environment if they were to be encouraged to participate effectively.

> *"And I think it is also important as well that the families are informed beforehand that we are going to go in and we are going to talk about this, the plan, and if we can't do anything or we will try this."* [Social Worker 1]

> *"It felt like the parents knew that these meetings were taking place, that they should have been informed before going into such a meeting, what was going to be discussed, so they could prepare themselves for it."* [Nurse 9]

Ideally, the scheduling of MDT and family conferences would allow parents to be apportioned reciprocal opportunity to prepare for meetings. However, most meetings were unscheduled and the exigencies of clinical practice, specifically the availability of key consultants, meant that family conferences would occur immediately following the MDT meeting. Parental ability to participate fully was, effectively, limited by logistics. Organisation of routine weekly family meetings was only observed in Amy's case, this being reliant on the trigger of her prolonged admission to PICU and recognition that due to work commitments Andrew (Amy's father) was being excluded from discussions.

> *"With their circumstances (the parents) one was here in the week and one was here at the weekends so sometimes it was trying to deliver the information to them both at the same time, or in a reasonable time period so that they both had the same information….. So sometimes there was information that you want to tell, but you are waiting to get both of them together to be able to do that. But Mum and Dad seemed fine with that, Mum would want to wait for Dad to hear the information, rather than receiving it on her own most of the times."* [Nurse 5]

Yet this planning of meetings resulted in a degree of complicity occurring between Alison and nurses to manage the challenge of involvement. It was clear particularly towards the latter stages of Amy's admission, that Alison was prepared by some of the senior nursing staff to enable her participation.

> *"One or two of them, I used to sit down with them and go through all my questions and whether it was relevant to ask and they would help me out quite a bit."* [Alison]
>
> *Following the meeting Alison disclosed that she had 'been coached' as to what to ask. She stated that some of the senior nursing staff had phrased her thoughts into questions so that she would be able to express what she wanted to ask and say and that they had then helped her to write them down.* [Extract from observational notes]

It must however be questioned whether actions undertaken were done solely with beneficent intent, in the parents interests, or whether they were exercised in combination as an alternative means of presenting a nursing agenda.

6.4.2.4 Parental differences regarding involvement

Differences in parental response to decision-making are well documented in the literature and even acknowledged by some staff.

> *"Since I've been here there is definitely a difference between participation between Mums and Dads. …I think there's a very slight bias towards it being the dads that are the ones that don't really want to get involved."* [Nurse 8]
>
> *"I don't do decisions, Ben's Mum does those. You'll have to talk to her. …… I don't get involved with these chats, I don't want to think about it."* [Extract Observational notes].

One of the doctors additionally questioned whether gender differences may also be explained more by cultural and societal roles.

> *"I don't know whether that's because the mums are the ones that are doing a lot of the caring, and so seeing really what it is like to be that child on an hour by hour basis, or whether dads just find it more difficult, I don't know. But it's certainly not a unique situation."* [Doctor 5}

Conversely, Finlay was observed to adopt a logical approach focussing on each situation as it arose whereas Fay acknowledged that she found it difficult to cope emotionally with the adjustment Fiona's admission brought. She recognised that she relied upon her husband to act as a conduit for information, the implication being that she relied on him to lead when choices needed to be made.

> *"I find it all a bit hard to kind of remember how I felt during the time ….It all passed in a bit of a blur really. Thankfully you (Finlay) were there to take it all in."* [Fay]

Such individual parental coping and adaptation can place a considerable emotional burden on one individual. It was also imperative in such situations that a parent did not feel that they were getting second hand information from a partner or that they felt ill equipped to participate in decision-making.

Nothing can prepare a parent for an admission to an intensive care unit and dealing emotionally with the adjustments of having a child in such an abnormal environment was a long and difficult process. For Andrew this was compounded by both the exceptional duration of the admission, the necessity to resume everyday activities as a self-employed professional to maintain financial security for the family, and the distance of home from the PICU. By living at home during the working week, this enabled the younger sibling to try to continue with her day to day life in a supportive environment and able to maintain the normality of her daily routines, including attending her local school. Nevertheless, this added extra pressure, since this may well have deprived both parents of mutual support. They were only ever both present on the PICU for very brief periods of time on Friday and Sunday evenings when they would swap roles. It also meant information was not always communicated rapidly or effectively.

6.4.2.5 Parental aversion to participate in decision-making

Like any number of individuals who may find themselves in a similar situation, Gaby (George's mother) struggled with adjusting to the devastating change in family circumstances. The psychological and emotional burden of George's disease and admission to PICU upon his mum was conspicuous to all. Gaby described on a number of occasions during ad-hoc conversations being present, but not present, and tuning in to information only when she had to. This description of moving in and out of reality may well have been a coping strategy. Yet, again this highlights the need for recognition of the shock encountered by parents and family members when a child has been diagnosed with a life threatening Illness and admitted to PICU. Misunderstandings about future care may well arise as a consequence of HCPs unrealistic expectations of parental capacity to process and assimilate information.

> *"So he (Consultant) explained .... but you don't really take it in do you?"* [Gaby]

Gaby recognised that attempts were made to try and ensure that she was involved in events. Yet, she later acknowledged that having time to be ready to receive information was a luxury that cannot be guaranteed and that healthcare professionals may on occasions need to make decisions for parents.

Attempts were always made to engage both parents, whilst respecting differences in choice of participation in decision-making processes. Bob (Ben's father) approach of choosing not to be drawn into situations was consistent and acknowledged by staff members who had previous experience of working with Ben's family. Remarkably, this knowledge was not documented at all within either nursing or medical notes.

> *"I mean once you get to know them then you realise that the Dad isn't the right person for decision-making. He might want to be involved in it but not actually make decisions. It is a pity that you can't actually document it anywhere because it is not something that you can. It's not appropriate but yeah it would be helpful."* [Nurse 8]

Given the unit's philosophy of family centred and individualised care this reluctance to record parental decision-making preference was somewhat surprising.

Bob's reluctance to take direct responsibility by participating in decision-making, even though he may be in agreement with the decision, was something that the PICU team struggled with. Following an emergency situation when Beth had gone home, a breakdown in communication occurred. The PICU consultant and oncology consultant endeavoured to engage Bob in discussions about the goals of future care. Bob adopted what could be construed as a 'blunting approach' whereby he distracted himself from the information being shared. The goal of the interaction was to recap what had happened and to introduce the idea that the time had been reached when it was necessary to start to consider whether to persevere with intensive care since Ben's condition had shown no sign of improvement. A preparatory family meeting was held with Bob to try to explain the emergency events and to propose that a formal family meeting should be held the next day. This would allow Beth to have the opportunity to arrange childcare and to be present. The purpose of the following day's meeting would be to explore whether further escalation of and persevering with intensive care treatments was in Ben's best interests and to agree a plan for future care. The information was perhaps not structured or communicated in a way that Bob could understand or engage with since his response was to become upset and exit the meeting.

> *"But after Dr (locum intensivist consultant) had spoken with (Names Consultant Oncologist) they decided that it was an appropriate time to talk to the parents. At which point they spoke to Dad. And Dad said I am not good at this sort of thing, I can't really take in what you are saying. And they (Names Consultant Oncologist) and (names locum intensivist consultant) said what we would really like you to do is get Mum to come in tomorrow and we will sit and discuss what we're doing."* [Nurse 8]

> *“.. so the discussion was more of introducing the thought that we might have to have that conversation, rather than having the conversation itself. It was to say that I think we need to sit and have this conversation, it would be good if we could have mum here, and can we arrange this.”* [Doctor 5].

Bob’s response was such that it questions whether his known reluctance to make such a decision should be accepted and acknowledged and whether his desire not to be forced to do so should have been respected.

It remains unclear what, if any, information was ever communicated to Beth by Bob about the above situations. When the middle grade PICU doctor involved offered to telephone Beth to discuss both situations at separate times, Bob declined these offers. As suspected at the time and later confirmed during interview with Beth, she had very little awareness of these discussions including the rationale as to why the scan had been necessary. It may well have been that Bob was unable to assimilate or process the information and therefore unable to share with Beth.

> *“Yeah, all I know is that nobody actually told me why he was going for the MRI. … and they probably told Dad, but Dad don’t take it in. Every doctor there should know what Dad’s like. But then again it depends whose doctor you’ve got dealing with it...”* [Beth]

Timing of decisions is a balancing of actions. Beth’s perception was that there should have been time for the medical staff to wait for her to return. This may reflect the unequal knowledge professionals and parents possess. It also underlines the difficulty in trusting one parent to convey information to the other parent. Parents’ cognitive, emotional and behavioural responses to individual decision-making situations were unknown. Nevertheless, the observed aim of the PICU team was to help them to tolerate and cope with uncertainty. Imbalance and differences in preferences between parents should be anticipated and managed.

6.4.2.6 The medicalised ‘expert’ parent versus professional judgement.

Parents’ participation was recognised by HCPs as emotionally burdensome and in practice, not always desired. Chris (Carly’s father) declared that his knowledge and views about Carly's clinical condition, prognosis and EOL care were developed from avid reading of medical literature and internet contacts with other parents and experts (other than Carly's Doctors). Some parents, particularly those with children with life threatening illnesses, seemed rapidly to acquire skills to access and appraise medical literature via the internet. It was apparent both during discussion and observations that Chris had spent considerable time and effort accessing resources. His demeanour during the family meeting suggested that he felt both a need, and was comfortable with, trying to take a leading role in medical decision-making at a pseudo-professional level. Additionally, Cath (Carly's mother) disclosed that they had made contact with families of children who had experienced a similar condition and illness pathway. She intimated that this had further equipped them as parents with strategies for improving their ability and confidence to manage medical decision-making. Both parents were assertive and confident enough to tell those present during the family meeting that they knew everything about Carly's condition, Chris went so far as to suggest that in some respects he knew more than the doctors. He was openly confrontational in manner, challenging the professional competence and judgement of consultants and advocating for change despite having a partial or limited understanding. It was striking that Chris, who had no medical training, was prepared to challenge and reject a professional opinion that did not align with his viewpoint. For both of Carly's parents, their experience of having a child with both a chronic illness and being critically ill was an all-consuming experience.

6.4.3 Managing gaps in knowledge

The primary function of information for HCPs was as a tool to support informed and confident choices to enable the delivery of high quality and where possible evidenced based care. The difficulty in these challenging cases was that the information needed was not always readily available in a timely manner.

6.4.3.1 Physicians seeking wider knowledge and insight

Physicians sought to bring the best available knowledge and insights to inform care delivery. All PICU consultant medical staff used a number of different strategies to inform their decision-making. These included means beyond the traditional reading around the subject using reputable and time honoured journals and texts.

> *"When we are struggling to get things right, we are always are looking for options, to have somebody else's experience and opinion. And also digging out of the literature, or any web sources including talking to people which have more experience in that…"* [Doctor 1, Consultant].

> *"I have a group of colleagues,…..international colleagues and once a week we sit and discuss on Skype complex patients around. General conversations, so there are no specifics, ….. it's a good way of having a virtual MDT. I think it is a good format. It is something that benefits patients here, but also benefits me because I get better educated at the end of the day……This informal grouping is very important because it just allows you to contact people and expertise that is not always available locally. It is tapping resources, which are hugely gifted and experienced. You often find that you have no answers which is fine. But at least you have done your very best."* [Doctor 11, Consultant]

This was acknowledged to be an accepted part of practice, particularly when struggling to manage care. Notably this quest for information did not appear to be coordinated in any way. In Amy's case, the pursuit of knowledge appeared to arise out of personal frustrations and tensions between the consultant intensivists and the neurologists over the ongoing management of Amy's seizures.

> *"I emailed out to PICU, sort of in a chat room thing, with parents' consent. I just summarised her case and asked if anybody else had anything else to say. That showed nothing helpful. It was sort*

> *of a PICU asking for help, as opposed to going to neurologists."* [Doctor 3 Consultant].

> *"And then with continuing failure of treatment I was able……, with the mum's permission,… at an annual meeting to talk to two or three colleagues there. One said with this particular drug they'd had someone who hadn't responded to anything else that responded,..."* [Doctor 4, Consultant].

This quest for additional knowledge was openly discussed with parents, with consent sought to discuss cases within professional networks. Alison disclosed during an ad-hoc discussion that she found solace in knowing that opinions were being sought from other experts, because this meant that everything that could possibly be done was being done. Equally, for parents, such behaviours could engender a lack of confidence in the abilities of the PICU team. Moreover, external opinion was acknowledged as potentially generating further confusion for medical staff as to the possible options for treatment.

> *"They (neurologists) sought external help, but then once again, if you ask 20 people, if you each have 20 combinations then you're just multiplying the permutations.…"* [Doctor3, Consultant].

6.4.3.2 Family members actively seeking knowledge and information

Families within the PICU setting did not solely rely on HCPs as their source of information. The practice of encouraging parents to seek as much information as possible and from a wide variety of sources was a norm that was evident throughout the period of ethnographic observation. Exploring and using all possible resources to inform care management options was explicitly advocated by HCPs as being of vital importance to assist parents in decision-making.

> *The oncology consultant emphasised the importance of having all information available to fully assess the situation. He also suggested that the family access all resources available to them……..(he) suggested that the family should ask other people for advice.* [Extract from observational notes]

A genuine desire and will to endorse parental access to information was witnessed. Knowledge and expertise were seen as valuable tools to promote parental participation in decision-making.

The internet proved to be the most accessible source of alternative medical information for the majority of families. Alison disclosed early on in the study that she frequently searched both her daughter's symptoms and treatments on the internet. Searching for additional and corroborating sources of information was particularly apparent when testing for mitochondrial disease was undertaken with Amy. Alison candidly discussed her internet findings with bedside nursing staff. This was especially so when she found out Amy's mitochondrial diagnosis would likely be a very poor outcome. The internet's influence was also evident with wider family members, particularly grandparents, in relation to their knowledge and understanding of situations. Amy's maternal grandmother questioned, within a family meeting, whether the use of alternative treatments such as cannabis would be beneficial. It was also clear that family members had been trying to identify centres of neurological excellence where another expert opinion may be able to shed light on their daughter's case. Such use of the internet did not commonly appear to adversely affect relationships between family members and HCPs. There was unanimity amongst physicians who regarded internet use and searching for alternative sources of information an accepted norm. Parents and wider family members articulated that knowledge acquired empowered them to question and challenge professional opinion.

This strategy, signposting and encouraging parents to access information reflects the evolving nature of relationships and response to increasing access and globalisation of information within contemporary society. Potentially such an approach is fraught with risk if parental expectations are not managed. The importance of aligning parental and clinician viewpoints about the goal of care is of paramount importance to avoid potential conflict. An emergent role for HCPs, witnessed during the course of the study, was that of an interpreter of parentally sourced information, assisting parents to fathom and appraise material.

6.4.3.3 Use all resources open to you

More unusually, and reflecting the family's unique circumstances, Edward's family were in a very privileged position. They had access to resources and sources of information that for most families would not be readily accessible, by virtue of Eric and additionally Edward's paternal uncle's medical background. During ad-hoc conversation, both parents commented that they recognised that they had limited capacity to interpret information and recognised that Eric's brother had some expertise in this field which could be used to both interpret and question findings. Such access did not appear to be perceived by medical staff as challenging or intimidating. Several commented that they would do the same in a similar situation. Access was immediately forthcoming and with the benefit of digital health records, scan images and test results were e-mailed directly to the uncle.

> *The oncologist then asked about brother in law's experience (as a consultant) and suggested that the family use him as a resource and seek opinions from his networks.* [Extract observational notes]
>
> *"He (Uncle) actually had spoken to the paediatrician in (names hospital) as well just to start to get an understanding of what was going on. So, I asked for him (Uncle) to be involved and everyone was open and willing to include him in what was going on……….. he spoke to Prof (names neurosurgeon 1) on the phone and they had a fairly frank discussion."* [Eric]

Both Eric and Uncle recognised that, although they were knowledgeable and were able to have in-depth discussions, their expertise was limited and that they were reliant on the professional competence of others. This meant that the supporting, yet slightly more dispassionate, role that the Uncle had initially adopted rapidly transitioned to being one whereby he would use his expertise to seek and screen alternative viewpoints, and search worldwide for innovations in treating brain tumours.

> *“And within a relatively short space of time I think my brother got in to that space as well because he is in a totally different area. This meant when we were in a kind of state of shock he was able to take information in. He was still obviously very emotionally effected as well because it is his nephew, but he was able to be slightly more objective.”* [Eric]

With considerable astuteness, Eric recognised that as a parent, albeit with insider knowledge, he did not have the time, opportunity or clinical detachment to become an expert in his son’s condition. Choosing to do so would, in his perception, have been destructive and generate increased stress and anxiety for the family as a whole. Unlike other parents he did not consider himself, nor appear to wish to be considered as being, on the same level as paediatric specialists caring for his son. This does not mean that he did not wish to be fully involved in the decision-making process, rather that he perceived his role as requiring the physicians to be accountable to him and provide him with justification and rationale for their treatment decisions. This he asserted enabled him to act in the best interest of his child by acting as his champion.

> *“And so every time I actually went looking for information because you are only taking off a tiny bite of all the available resource and you are not there being objective or being thorough either. I was actually finding that I was creating more unnecessary areas for worry than by doing nothing…… it was for me to harvest the information that others were bringing,… to ask them difficult questions, ask them to justify why something was better than something else and to ask them to explain their reasons why. And not to give up until I was satisfied that, that was the best that it could possibly be. That was something that, we learnt quite quickly. Being able to ask questions is really what my key role was.… And then trying to figure out the best way forward. I wasn’t the designer of the plan but just to, sort of hold people accountable.”* [Eric]

Eric, whilst not wishing to be the decision maker, recognised that he lacked expertise, but did wish to be involved in a problem solving capacity so that elements of professional judgement could be understood. By identifying available alternative treatments, and engaging in discussion about the anticipated risks and benefits of each, the medical staff allowed a layering of information. This does not, however, always indicate which option should be selected. There remains an element of judgement. Shrewdly, Eric realised that rather than his involvement being perceived as confrontational, by generating a well-informed probing approach, he was able to cultivate a level of tolerance amongst HCPs not previously observed by the researcher.

> *"We're not trying to second guess but we do want to understand what is going on. I think they seem to acknowledge and respond well to that….. I am not at any point trying to tell them how to do their jobs. They have got expertise way beyond my lay expertise in the area. But they have been completely accommodating that I am going to ask questions and that they have to have qualified and proper answers for them. And they have."* [Eric]

Such deference to parental questioning of treatment plans may partly be a consequence of both Eric and Uncle's professional background and the collegiality of medicine. Nevertheless, Eric's adoption of a positive stance and focus on analysis of specific issues prompted HCPs to undertake a more rigorous scrutiny of evidence than in other cases. Whereas, in Carly's case, parental involvements were seen to be aggressive and quarrelsome, Eric's veracious approach minimised the negative and emotive undercurrents contained within a questioning tactic. By avoiding critique of individual persons or teams and focusing on the pursuit of knowledge to improve the care for patients, Eric's style made it easier to act as a team, by appealing to medical professionals' quest for the advancement of knowledge.

6.4.3.4 Having confidence: no need to go elsewhere

In contrast to the other cases under review was Fiona's parents' trust and complete confidence in the HCPs who communicated with them. During the period of observation, Finlay disclosed to the PICU consultant that neither parent was accessing the internet to research their daughter's prognosis or to seek alternative opinions or experimental treatments. Unusually, there did not appear to be a desire or need by either parent to establish a body of knowledge or seek expertise beyond that of the current medical teams. There appeared to be genuine respect for the contributions of experts.

> *"Our concentration was purely on (Fiona) and we had, I had confidence in them. I really did have confidence in the staff that they needed, that they would tell us what we needed to know."* [Fay]

It was evident that Fiona's parents did reflect on and mull over things. They demonstrated a capacity to consider the situation they found themselves in and were able to recognise where they could access the information they required. Finlay in particular acknowledged that whilst he may have sufficient knowledge to understand the situation he was insufficiently knowledgeable to fully assess and evaluate what was right for Fiona. Plausibly, both parents' interpretation of the antecedent situation, including witnessing their daughter being resuscitated in the emergency department, had already generated knowledge of what was feasible. They may have considered that they had sufficient information since it appeared to align with their anticipated perception of what would likely happen. It is also likely that parental belief and apparent total trust in God's will may have led them to believe that the outcome would be preordained.

> *"I think Fiona's family were a lot more accepting than (name's another child) family."* [Nurse 12]

Gaby also admitted a complete lack of desire to actively search for information from other sources during the first period of admission to

PICU. Following her experiences with both the GP and emergency services earlier in the course of George's illness when he had been initially discharged home, it would have been unsurprising if her attitudes towards medical authority and reliance on professional judgments had been impinged. Feasibly, the communicative and technical competence of those engaging with the family during the initial encounters may have reassured the family. Nevertheless, it is notable, subsequent to George' initial admission to PICU, that Gaby chose to access additionally sources of information.

> *"Later down the line I looked at, actually read into meningitis and the different types but at the time I just went on what they told me. …It must have been a month after that I thought about looking into it (meningitis).*" [Gaby]

This may be something that became more important as George's condition progressed to a more chronic illness where management would be much more dependent upon Gaby's future role and knowledge. It highlights the temporal nature of parents responses which can change following experiences encountered, the duration and also the frequency of admissions.

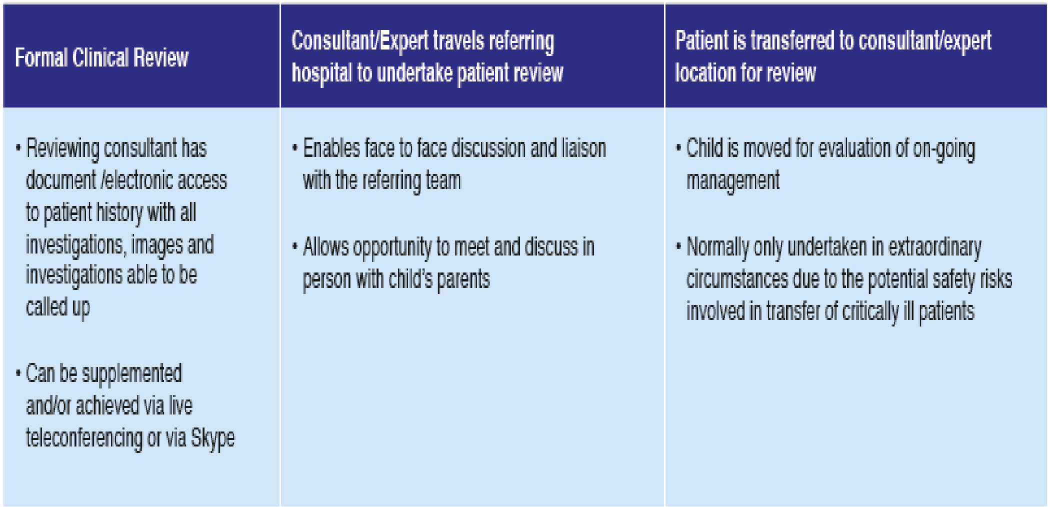
6.4.3.5 Second opinions and referral to other centres

The practice of doctors contacting other doctors was significant throughout the study site and occurred as described above via professional networks and also through the more traditional and formal means of referral for second opinions, Figure 25. Such consultations, initiated by the medical team, seek additional expertise, aiding differential diagnosis, providing therapeutic management advice and as an endorsement of treatment undertaken and/or proposed. Consultations may be accessed from either within the same children's unit or a comparable external centre. Relationships between professionals is generally one of mutual respect and trust. Tellingly, parents were encouraged to think of all internal referrals for diagnostic assistance and further management advice within the children’s hospital as second opinions.

> *”......talk to (names oncology consultant 2) and seek his opinion, treat it as a second opinion… and he (names oncology consultant 1) said don’t just stop at a second opinion get a third opinion….. And in the end that was the right advice because that’s what happened.*” [Emma]
>
> *(Oncology consultant) encouraged them to explore different opinions, that they would be supported, but that they have to do the right thing for Edward.* [Extract from observational notes]

Utilising different speciality consultants within the same hospital setting as second opinions may demonstrate insight by an experienced consultant that there are likely to be divergent opinions within specialist teams. These could then be used as a positive strategy to provide parents with a readily accessible means for gaining contrasting information and promoting discussion. Such use does imply to parents that there is scope for negotiation, should differing opinions occur.

Figure 24: Approaches to seeking a second opinion



Formal Clinical Review	Consultant/Expert travels referring hospital to undertake patient review	Patient is transferred to consultant/expert location for review
• Reviewing consultant has document /electronic access to patient history with all investigations, images and investigations able to be called up • Can be supplemented and/or achieved via live teleconferencing or via Skype	• Enables face to face discussion and liaison with the referring team • Allows opportunity to meet and discuss in person with child’s parents	• Child is moved for evaluation of on-going management • Normally only undertaken in extraordinary circumstances due to the potential safety risks involved in transfer of critically ill patients

Referral for external second opinion were observed to occur within half of these exceptional cases. Requests were seen to arise when treatment options appeared to be declining and there was increasing parental recognition of a likelihood for poor outcome, or when there was parental disquiet about aspects of care. Uncommonly, referral also occurred when a breakdown, actual or potential, in communications and relations arose e.g. Carly's case.

6.4.3.6 Second opinions as a means of parental reassurance

Medical staff appeared to accept second opinions initiated by parents as a reasonable request, acceding that there was a need for the parents to be comfortable with decisions and if that entailed seeking external opinion then that was acceptable. Requests did not appear to prejudice care, being recognised as resulting from a parental desire to assuage their need to do all that is possible and potentially as a strategy to reduce future parental self-censure. Anecdotal comments by HCPs suggested these to be occurring more commonly. Such requests may infer unhappiness with advice given, but also highlighted the fragility of relationships between the family and HCPs. Second opinions were seen to be used by parents as a means to corroborate and validate opinions given, especially at times when parents were expressing feelings of vulnerability and powerlessness. Notably an element of choice was given to the family when selecting a second opinion, with a list of potential referral centres and experts identified for Amy's parents to choose from. However, by virtue of the PICU team selecting experts, this may be part of a management strategy with potential for only like-minded colleagues, who will very likely endorse their views to be selected. Professional etiquette may presuppose that unless the second professional opinion was in total disagreement with proposed patient management that the primary viewpoint would be endorsed. An external consultant travelled to review Amy. This implied that potentially there would be some scope for negotiation should the second opinion put forward an alternative viewpoint: although in Amy's case this was never put to the test. Still, this does generate questions as to what may occur should the second opinion differ: whether Amy's ongoing care would be untenable at the current PICU? Would transfer to the second Doctor's centre become necessary if alternate therapies were proposed? This arrangement only really allowed for a snapshot review, yet clinical judgement is acknowledged to vary over time. Careful consideration and counselling for potential outcomes arising from such review is warranted with parents in advance of instigation. The potential exists to damage trusting relationships with HCPs. Conversely, for the PICU team, such consultations can be genuinely useful and helpful in proposing new ideas.

Timing may also be problematical for parents, with any delays in referral open to misunderstanding. For Amy's parents there was disappointment that Hospital X did not wish to review their daughter in person and just wanted information sent electronically for a MDT discussion. Prevailing opinion and practice throughout the PICU networks would similarly advocate that a patient already receiving intensive care should only be transferred in exceptional circumstances. The transfer of patients for second opinions goes against the rhetoric of the patient safety culture, since it means removing a critically ill child from a place of safety, against that child's best interests.

> *"I just thought that they might be able to do something for her. And you think if someone actually came and saw what was happening, then that might make a difference. But I was told that that wasn't the case, that they saw all the MRI scans, all the details, they make the decision like that. And that it wasn't safe for Amy to travel that far anyway."* [Alison].

Alison especially found this virtual review difficult to comprehend and felt it made her daughter seem less of a person and perceived that it made it easier for Hospital X to decide not to treat.

Particularly remarkable were the extraordinary lengths the PICU team went to in providing additional support for Amy's parents when the request for referral was declined. A unique situation occurred with Amy's parents, an intensivist consultant and a pre-bereavement nurse specialist travelling to Hospital X for a meeting with specialist consultants. Such accommodation allowed parents to finally make the decision that it was in their daughter's best interests to stop active treatment.

> "*That (meeting at Hospital X) actually put my mind at rest completely…... I asked whether if Amy was their patient they would do anything different. And the reply I got was that they probably wouldn't have kept her for that long. So that put my mind at rest that, you know, everything was done as it should be.*
>
> ***I: That must have been difficult to hear though.***
>
> *Everything was difficult to hear. But they more or less said that we were doing the right thing by letting her go in the end. And I needed to hear that from someone, because it was someone who dealt with metabolic disorders and a neurologist as well, to know that they thought the same. Which was my thinking anyway, but I, just needed to hear it from them. Just to know that everything has been done, there was nothing anyone could do."* [Alison].

For Amy's parents and family, having an extended length of admission did allow them to have the knowledge that everything possible had been done for Amy and resulted in satisfaction with her care whilst on PICU. Yet equally the comment made by Hospital X team could also have been interpreted by parents that their child had experienced what may be perceived as unnecessary pain and suffering by persevering with treatment for so long, potentially giving rise to recrimination and dispute.

6.4.3.7 Second opinions as a means to manage dissatisfaction

A request for a second opinion in Carly's case highlights the profoundly complex problems faced by HCPs when medical treatment is unsuccessful and a breakdown in communication and relations has occurred. Carly's case was contentious, an impasse having been reached at hospital Y, with parents leading the request for referral and transfer to another specialist PICU. Concurrence with this request appeared to be an attempt by the referring PICU to try and circumvent the likely need for seeking the support of the courts in drawing to a conclusion Carly's care and the proposed withdrawal of treatment.

Referral and transfer remains a relatively rare occurrence due to associated patient safety concerns and risk of harm. For Carly, her clinical condition was such that no one could predict whether she would be able to cope with transfer between the two units and there was a very real possibility that she may die during transit.

Given the controversial nature of the referral it was noteworthy that opinion of the PICU team at the study site was canvassed in advance by the referring consultant exploring the feasibility of acceptance of Carly. This may reflect recognition at this time that Carly's case had the potential to transcend everyday medical decision-making and descend into a more public and legally contested case. Although this situation had yet to cross the threshold of a legal dispute, it had gone well beyond a difference of opinion and it was apparent that the differences in viewpoints had become untenable. This made it incredibly challenging for Carly's parents and HCPs alike to respond and resolve end of life decisions.

There was recognition amongst all the team that Carly's parents were unable to relate to medical staff at the referring hospital due to their clash of belief and values systems. By offering independent expert review of Carly's situation the team may have aspired to reaffirm parental trust in care management. This may be why the oncologists in particular considered that an opportunity to try and involve Carly's parents in effective and meaningful communication was essential.

In such an acute situation where there is some uncertainty or 'greyness' surrounding the benefits of offering treatment, then the default position is to provide further intensive care until assessment is complete. The intention is to help parents and HCPs to acknowledge that prolonging life by technological means may not be right. It may also affiliate with HCPs' appreciation of parental need to ensure that all avenues have been explored, as also occurred with Amy. Nevertheless, given that the continuation of treatment would still involve considerable suffering with minimal likelihood of improvement in Carly's clinical status, such optimisation could be seen to conflict with acting in her best interests. A more controversial debate, broached by the nurse in charge and endorsed by some medical staff, centred on the justification that provision would be potentially harmful to other patients. During initial discussions, prior to acceptance of her referral, there was acknowledgement that should Carly's admission result in a prolonged admission, then this may result in situation of being unable to provide or denying treatment to other patients. The cost of treating a child in PICU is significant. Consideration of cost-effectiveness, an important albeit an awkward issue, warranted deliberation, but was not observed by the researcher to have been discussed on this occasion. The difficulty in these situations is that there is no clear or consistent local or national guidance to apply. Whilst the transfer could be argued to offer little benefit to Carly, ethically justifying a decision not to accept her referral on the grounds of finance and limited availability consideration of resource constraints appeared to be too sensitive a topic to probe at this time. This situation vividly illuminates the substantial challenges parents can face when irretrievable conflict arises.

6.4.3.8 The search for a miraculous cure

In desperate situations, despite acknowledgement that a child may be suffering, some medical staff were seen to adopt a position that the evidence did not support, reflected in the use of high risk and experimental therapies. These interventions go beyond mainstream treatments. Amassing the evidence to support the use of a disputed or unproven intervention was problematic with deployment idiosyncratic. How they were incorporated may link to both parental and professional desire for a miraculous recovery, including a reluctance to concede defeat to illness. Usage may also reflect professional curiosity and desire to explore and advance therapeutic boundaries. Given the experimental nature of some of these interventions and the risks of adverse effects, considerable dilemma existed as to when and if treatments should be attempted.

Differing thresholds for pursuing experimental and high-risk therapies were witnessed throughout observations and exposed professional and parental disparities in interpreting benefit. Consensus agreement for implementation was not always secured, customary practice observed to be undermined. This difficulty of determining whether a treatment is efficacious and in the best interests of the child was epitomised by a decision to commence an experimental treatment of induced hypothermia with Amy. Induced hypothermia, whereby Amy's core body temperature was artificially reduced to stop seizure activity, was recognised to be a therapy with a low probability of success. This decision typified the quandary of whether it is possible to determine if any treatment with a possibility of success can or should be excluded on the grounds of futility.

> *"essentially we were unable to stop the seizures, despite all known therapies and some therapies which were completely off piste and just trying anything which we could………….. From the reading that I had done, people have cooled for seizures in the past. It is a very effective treatment, because the whole body slows down and so that's what you're trying to do to the brain. It didn't work,…"*
> [Doctor 3, Consultant]

There was divergence amongst the PICU team at the introduction of cooling therapies. Significantly, given the experimental nature of the therapy and the risk of adverse effects, dissent was evident with several of the nursing and medical staff making comments to the researcher that just because something works in theory this didn't mean that it was right to undertake in practice. Disquiet was also expressed about the perceived suffering for both Amy and her family.

Employment of experimental therapies could further engender unrealistic parental hope about their child's survival. Alison was exceptionally honest in disclosing during ad-hoc conversation that she chose not to face the reality that giving up hope would result in. Her strategy for coping, to focus on the here and now, may explain her acquiescence in attempting this experimental therapy.

> *“he'd said, we're going round in circles now, he said we don't know what else to do. But he'd been doing research on this cooling method and he said about the complications, that it can have severe consequences on her heart…. So (he said) we've got nothing to lose by doing it, can we do it? I had to say yeah… we had to try it because we couldn't not.”* [Alison]

It was particularly apparent that throughout the time Amy was artificially cooled that Alison was more visibly distressed and found it more difficult to be present at the bedside. She expressed to nursing staff that she found it difficult to sit with her daughter for any length of time, to touch her or participate in intimate care, as she usually did, saying repeatedly that to her Amy looked and felt dead. This underlines the tension of HCPs wanting to explore all avenues whilst acting benevolently towards the family.

It was evident that the team went to exceptional lengths to explore all possible options to try to ensure George’s survival and reduce morbidity. Perhaps this related to a professional will to act benevolently to George and his family given the circumstances of him requiring critical care. There was overt recognition of the sudden unexpected and devastating impact of meningococcal disease in a previously fit and healthy child. Conspicuously documented in George’s medical notes is a brief record detailing consideration as to whether Extra Corporeal Membranous Oxygenation (ECMO) may be viable as a rescue therapy. ECMO is not a conventional therapy offered for the treatment of meningococcal disease. Significantly, consideration of this intervention was not shared with his mother. Feasibly, this was to mitigate against development of a false hope and possibly in recognition of her incapacitated state. Underlined was the dilemma of balancing comprehensive disclosure of information but at a time and pace that a parent can comprehend. The strategy not to disclose was undertaken to prevent information overload, but could vindicate some parents’ perception that information is intentionally withheld and lead to a lack of trust.

> *d/w ECMO team @ ………. Unlikely to be of benefit. Will discuss and call back.* [Extract from medical notes]

It was perhaps an indication of the gravity of George’s circumstances and reflected the desire of the medical team to explore all potential options that ECMO was considered. This was despite recognition amongst those present that it would be exceedingly unlikely, given his cardiovascular instability and coagulopathy, that George would have survived being transferred to the ECMO unit, let alone tolerated being commenced on such invasive treatment. Consideration may reflect that the team were united in their recognition that the only potential options available were high risk and considered more experimental. Unsurprisingly, the receiving ECMO unit declined to accept the referral. They commented to the PICU consultant that the risks versus the potential benefits made the prospect of recovery extremely unlikely and could precipitate death. Feasibly, the PICU team may have anticipated this response, and this explains why there was no evident dissension about making the referral amongst the wider PICU team.

There was also knowledge that should George survive he would be likely to sustain considerable tissue damage. Therefore, attention simultaneously focussed on alternative therapies to try and minimise tissue destruction and injury. It was openly discussed and acknowledged across medical teams during handover and also at the bedside that these were desperate measures with no real evidence to suggest they would be effective, but equally nothing to lose.

> *PICU consultant commented during handover that if we do nothing we will lose the limbs and if we do something we may still lose the limbs. This (GTN patch) is a last ditch measure. The registrar similarly commented that there is no real literature to suggest it will work.* [Extract from observational notes]

Improved technology and advances in treatments have undoubtedly resulted in improved survival. From a practical perspective use of an experimental therapy highlights the difficulty of gathering evidence to support the introduction of an intervention and the value judgements made by staff in determining whether an intervention is perceived as beneficial or not. It also highlights the considerable emotional burden placed on parents, who may acknowledge the desperateness of the situation and improbability of success, whilst still hoping for the best. Potential additionally exists for experimental therapies to be offered as a means for HCPs and/or parents to avoid making difficult decisions and delay inevitable progression to EOL care. Whereas this was anticipated and has been aligned with hope from a parental perspective, it was evident that hope was not specifically a non-professional issue. Whether gaps in professional knowledge created space for an emotional response amongst HCP is unclear. The need to assuage professional curiosity may also relate to a desire to push the bounds of science. Nevertheless, when professional judgement and evidence was equivocal, tension was evident and it appeared that HCPs were unable on occasion to detach professional judgement from their emotional responses, as the desire to ensure the child’s survival prevailed.

6.5 Chapter summary

This chapter has provided insights into the complexity of decisions with the multiplicity of themes evident. It highlights the impracticality of trying to impose structure, in a rigid way, as to how decisions are going to be constructed. This study has demonstrated is that the uniqueness and peculiarity of these complex cases renders such a formulaic approach unworkable. The inimitability of the human condition exhibited the parallel approaches adopted by parents and professionals including the battle between logic and faith, temporalisation and the difficulty of committing to a decision with the finality of death ever present. Professional courtesy functions as a mechanism for containing or concealing arrogance. Strategies of professional courteousness versus professional arrogance have been shown to be used as control mechanisms amongst involved

HCPs and parents. These occurred alongside a genuine search for consensus and whilst simultaneously functioning as a team. Though HCPs may well have been cognisant of the uncertainties in diagnosis, prognosis and treatments, the extent this impacts upon professional and parental relationships when constructing care decisions has emerged. Professionals were seen to strive to involve parents in clinical decisions but this may well be unrealistic, perhaps misguided and highlights that the parent's ability to exercise choice and make decisions about their child's care is shrouded in ambiguity. Yet, implicit within shared decision making in the contexts of family centred care is an expectation that parents will be able to choose for their child and that parents will decide what is in the best interests of the child, even when their child is in a critical care setting. Recognition that parents may be ill-prepared and may not wish to participate was apparent, together with consideration that this may well be associated with how communication is organised and delivered.

Chapter Seven

7. Findings: Best Interests

> *"In any moment of decision, the best thing you can do is the right thing, the next best thing is the wrong thing, and the worst thing you can do is nothing."* Attributed to Theodore Roosevelt

7.1 Introduction

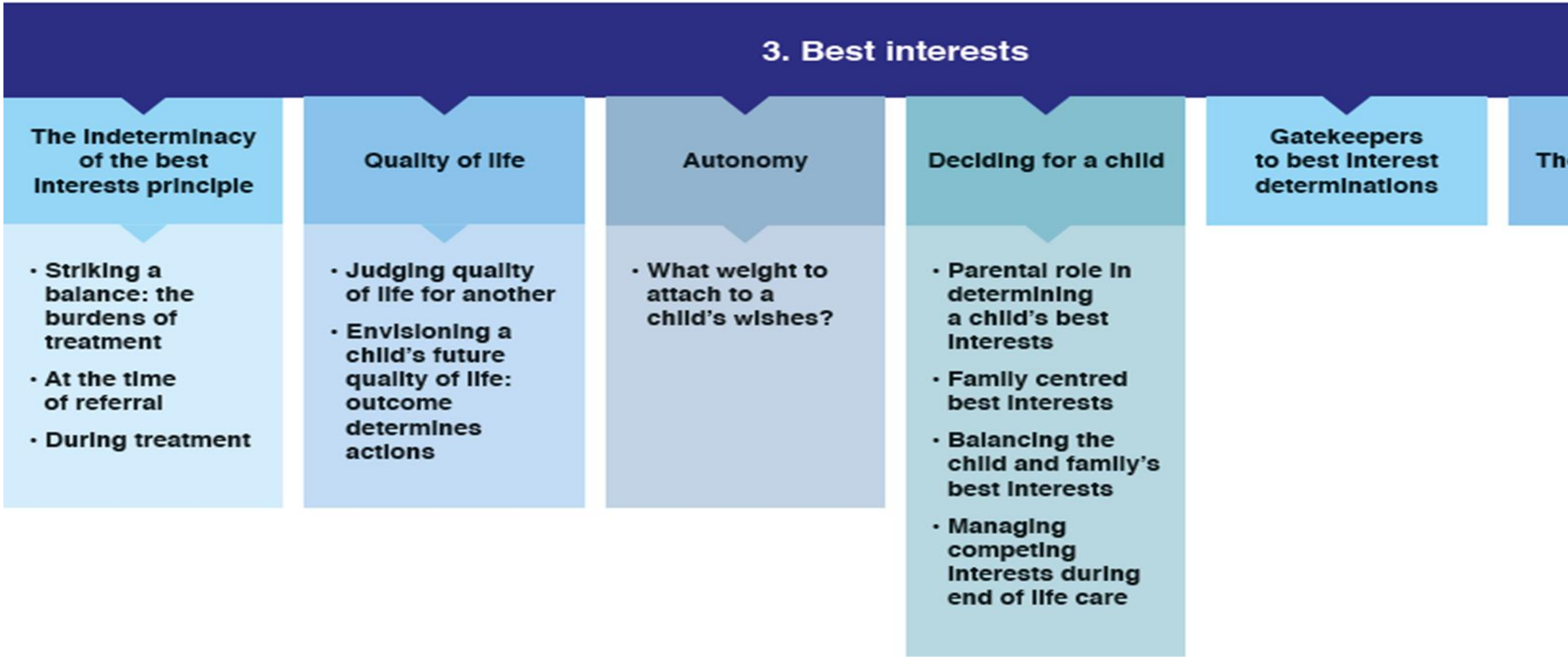
The aim of this chapter is to explore how difficult decisions within a PICU setting were guided by the concept of best interests. This requires re-articulation of earlier expressed notions within the literature review (Chapter 2) concerning best interests and the paramountcy of the child. How such a legal and ethical principle operates and is applied within the critical care setting warrants close scrutiny, because it shapes outcomes for children and their families. As outlined in Chapter 6 the construct of best interests of the child was ever-present when making decisions. A graphic of this major theme, including sub-themes and sub-sub-themes is detailed below, figure 26, and these will provide the structure for this chapter.

The chapter begins with an exposition of how best interests emerge and are advanced in light of nuanced interpretations pertaining to welfare. It considers the contentious concept of quality of life, how it is perceived by parents and HCPs, and how individual values and beliefs are used to justify decisions made. The chapter then considers who is best placed to decide for a child, highlighting the mediated positions pertaining to the autonomy of children, their parents and HCPs. Finally, the chapter will also consider how appeal to the concept of best interests is used in these desperate situations to mitigate against legal involvement.

7.2 Best interests

Intensive care including sophisticated medical intervention can blur boundaries between living and dying. This may make it challenging for

Figure 25: Theme 3 Best interests



family and HCPs alike to respond to, and interpret, end of life decisions, which reflect best interests.

> “*Every entire day on PICU is putting the child through a trauma, physical trauma, and only really ethical to do that if they’re going to get some outcome at the end and not just die. So that’s the main consideration.”* [Doctor 4, Consultant]

Though the function of PICUs is orientated towards preserving life, not all children can be saved, despite maximal intervention. Observational data from this study support findings identified within the literature review (Section 2.1, pages 8-9) that most deaths happening in PICUs occur following a decision to WLSMT.

7.2.1 The indeterminacy of the best interests principle

Helping parents to acknowledge that prolonging life by technological means may not be right for their child is a complex process and difficult to achieve and featured in all the case studies. Consideration in the PICU centres on whether treatment remains in the best interests of the child. ‘Best interests’ functions as a legal and bioethical decision making principle to help determine limitations of treatment decisions. HCPs have both individual and collective responsibilities to always act in the best interests of the child. The premise is that best interests are entities, which can be identified and managed. Yet judgments of best interests have long been criticised for their indeterminacy, and the best interest standard is considered elusive, fluid and problematical. As Carnevale (2013) identifies, it is a substantively undefined concept that can result in conflict. Best interests are purported to enable the determination of ostensibly the best outcome, but this study makes apparent that such outcomes in reality are determined through subjective judgement, interpretation and contextualisation by involved decision-makers. Differences in construction and interpretation have profound and lasting consequences for children, their families and HCPs.

Determining the meaning of best interests when deciding treatment options, particularly those including a need to communicate uncertainty, was in this study inherently situation and time-specific. It relied on all parties advancing their position, thereby allowing those involved to establish the ‘truth’ and make the best decision. The implicit understanding was that decision-makers would objectively balance the benefits and burdens for the child whilst holding in abeyance personal values and beliefs. Thus, in any given situation it should be clear as to what ought to happen if best interests are to be achieved. The fundamental difficulty, however, was that there was no objective way to determine the balance, thus rendering every end result problematic to some degree.

7.2.1.1 Striking a balance: the burdens of treatment

Whilst acknowledging there was no objective means for determining how to calculate which course of action should be followed in problematical cases, the consequence was that any decision was discretionary. If different individuals review the same body of evidence, opposing but equally reasoned and sound deductions may be reached. The indeterminacy of best interests, there being no neutral perspective, and use of discretion is especially illustrated within the process of referral and admission to PICU and when making considerations regarding prolonging or initiating treatment.

7.2.1.2 At the time of referral

Medical staff, in conjunction with the nurse in charge of the unit, were observed to consider two issues when accepting any potential patient: First, the purpose of the admission and then secondly, whether there was a prospect of benefit. Primarily this was considered within the context of the individual child. This required the family and HCPs making the referral and the PICU team to jointly discuss and determine treatment preferences based on the application of the principles of best interests, informed consent, professional judgement and parental wishes. Decision-making was relatively straightforward when it was agreed that treatment could result in a good outcome (including maintenance of quality of life), but where there was uncertainty the situation became more difficult.

In Ben's case, the consultant paediatrician at the referring district general hospital initiated discussion with Beth about whether escalation of treatment including transfer to PICU was appropriate. In order for Ben's parents and HCPs to agree a clear plan of care, there needed to be discussion as to whether treatment was worthwhile. The agreed position was that Ben's primary illness was incurable. He had a serious, progressive illness whereby decline over time was considered inevitable. Ben had done well since initial diagnosis and following treatments, his symptoms had been managed and he had been discharged home. However, he had experienced intermittent episodes of acute deterioration. Subsequent recovery, though, was not to Ben's previous level of functioning prior to each episode.

Beth acknowledged during both ad-hoc discussions and interview that referral to PICU was always discretionary. The local DGH team made professional judgments in combination with the family as to why and when to seek additional assistance. For Beth the strong presumption was that he would be transferred to the PICU where there was access to expertise to enable a judgement about whether to give additional treatments. It was also evident that on receipt of the referral, the accepting PICU consultant initiated discussions with the specialist oncology and surgical teams who would also be involved in Ben's care, as to the potential underlying diagnosis and the appropriateness of escalating care.

> *"So despite the fact that he's got a plan (PRP) in place, …the oncologist felt that if we can get him over this …we may actually be able to give him a little bit longer with his quality of life. So we know he's palliative, but get him well and while it's not going to change his prognosis, it may actually prolong his lifespan."* [Nurse 7].

Fiona's case was similar to Ben's, as there appeared to be unanimous agreement with the initial management plan to admit Fiona to PICU and err on the side of caution. Since some potential did exist for Fiona, no matter how small, to make a good recovery, initiation and continuation of treatment was judged to be in her best interests. In most cases observed, agreement about the best course of action was reached with parents and professionals concurring.

Contrastingly, when Carly was referred to PICU there was lack of consensus amongst HCPs as to whether prolonging Carly’s life was in her best interests and whether additional measures would successfully resolve her health problems. Determination required consideration as to whether any net benefit could be gained by Carly transferring PICUs. Nursing staff and middle grade medical staff who expressed opinion during ad-hoc conversations on PICU at the time of referral, deemed that Carly had reached a point whereby the advantages of transferring her for a second opinion would be outweighed by prolonging treatment. These staff situationally judged that continued administration of non-beneficial and painful therapies was contrary to Carly’s best interests. They perceived, with concern, that she had already endured a prolonged admission at another PICU with no real benefits from treatment. Some even suggested Carly was now in an intolerable situation and should be allowed to die. Strikingly, throughout discussions, although the concept of futile treatment was alluded to, it was never explicitly mentioned. Rather, the nursing and middle grade medical staff spoke in terms that the prospect of Carly making a recovery was so remote that the pain, distress, suffering and indignity of treatment was medically inappropriate. The difficulty with these subjective opinions is that they are based in individual value judgements and possibly limited knowledge and experience. Nevertheless, some would contend that even with the burdens of treatment the fact that Carly was still alive, despite her prolonged admission to PICU, rendered hers a life worth living and one that should be preserved at all costs.

The receiving PICU consultant could justifiably have made a decision not to admit Carly. Provision of further treatment, including transfer, could be argued as contrary to Carly’s best interests and to cause her harm. The PICU consultant, however, chose to discuss and perhaps distribute the decision with members of the PICU team, the oncology team and renal team to ensure that all options available to Carly and her family had been explored. The PICU consultant acknowledged that he may need to be guided as to what options were available, specifically in terms of renal management. This pivotal role, recognising the importance of establishing a body of expertise, respecting the contribution of other professionals irrespective of the difficulties in achieving a consensus, was presumably based on protecting Carly's best interests.

As observed in many instances, disagreement about the management plan was evident. On this occasion, debates revolved around sanctity and quality of life. Although there was not total agreement that the transfer would be beneficial, there was correspondingly no disagreement with the renal consultant's opinion that some current therapies could be better optimised. Disagreement centred on the perception that continuation of treatment involved suffering with minimal likelihood of improvement in clinical status. Such optimisation could be seen to conflict with acting in Carly's best interests, with prioritisation given to parental preferences for continuation of treatment. The imperative to do all that is feasible irrespective of the prospect of a successful outcome may, as some members of the medical profession anecdotally reported, also still relate to them viewing death as a failure.

Determining whether transfer to PICU was in a child's best interests also occurred prior to formal referral. During ethnographic observations, HCPs at referring hospitals called upon PICU consultants during telephone conference calls to endorse judgements they were making about whether to escalate care. Such actions frequently placed the PICU consultants in a difficult position, underlining the challenge of making decisions based on limited information, without opportunity to formally review or discuss with all parties.

> *The referring doctor specifically asked the PICU consultant whether he agreed with the decision not to escalate treatment. PICU consultant commented that it would not be appropriate to*

> *prolong suffering. He then asked again whether the PICU consultant agreed with a decision not to ventilate. PICU consultant commented that it was difficult to make a judgement when the only information to undertake a review was what was written (on the referral form) at the time of the first contact, and the current conversation.* [Extract from observational notes of a telephone referral of a child who was not one of the embedded cases].

This case involved a 'looked after' child. This was acknowledged to be impacting upon the ability of the referring hospital team to be confident in making a definitive decision as to whether to escalate care. Indeed, there may have been an implicit fear of the local authority challenging any decision. Regardless, the deleterious effect of delaying a decision as to whether this child's care was being escalated to include PIC, resulted in an unacceptable period with 'minimal' intervention. Sadly, for this child, by the time a decision was made to escalate his care, his clinical condition was hopeless. The child suffered a cardiac arrest and died during the course of the telephone conversation. A difficulty with considering the best course of action for desperately ill children is that death could occur during prevarications.

> *"Choosing to take no action and deferring a decision is an active treatment decision"* [Doctor 3, Consultant]

Delays in potentially escalating treatment may result in an increased likelihood of complaint and/or doubt for families as to what may have been.

7.2.1.3 During treatment

Indeterminacy, when it was not possible to predict whether the outcome would be in a child's best interests, was particularly evident when decisions about how to proceed were being triggered. These deliberations involved efforts to pursue a 'reasonable' or 'justifiable' course of action, even if it is not possible to tell until later if this was the right one. Intensive care interventions can inflict burdens on persons that some may rationally decline, thus posing the question at what point in the scale of suffering and disability does the best interests of the child result in bringing to an end treatment.

> *“..essentially with intensive care, you either do it or you don’t. There’s no middle ground. You can't do a bit of intensive care, because that would be a tautology, the patient would die, so then there’s no point.”* [Doctor 3, Consultant]

Explicit consideration was given to what may be beneficial and appropriate for each child. This included evaluation of risks versus benefits of proposed interventions, prognostication about potential future and whether all treatment options had been exhausted. PIC therapies are acknowledged to be an extreme intervention, yet decisions must be made regarding what the team are prepared to do on behalf of each child and family.

In Amy’s case, uncertainty surrounding her clinical condition, in terms of definitive diagnosis and long-term prognosis meant that there was no universally acceptable determination of best interests. With no agreed hierarchy of the balance, benefits and burden of suffering, any balancing exercise was inescapably subjective and nebulous. Determining acceptable parameters of intervention varied according to how different ways of assessing risk and uncertainty were defined and from whose perspective these were being explored. There was recognition from Amy’s readmission to the PICU that both the duration of her seizures and the inability to control these through conventional medical means raised questions and divergent opinions about whether it was right to continue treatment.

> *“I’m not a neurology specialist, but my understanding is that after fitting for a certain amount of time then the chances of recovery are minimal….But then the neurology team were saying that they had examples of patients who after prolonged fitting had gone back to school. That certainly makes it difficult.”* [Doctor 2, Consultant].

> *“And in my experience sometimes people can go through a long period of status epilepticus and make a reasonable recovery, either back to their normal state or not 100% their normal state,”* [Doctor 4, Consultant].

A difficulty in PICU is that technology exists to keep children like Amy alive in extraordinary circumstances. However, there is little information available to know whether this is the right thing to do.

Views as to what is reasonable treatment do vary over time in such profoundly complex situations. Indeterminacy becomes more problematic when professional opinions diverge and consensus weakens. Whilst HCPs recognised the importance of attuning and accommodating different viewpoints and actions, this generated confusion for parents trying to understand opposing interpretations.

> *“But I could see that sometimes Dr …. would go through the drugs while the intensivists were there and they'd be thinking no. They thought different things than the neurologists and you could see that…And you don't really know who is doing the right thing really.”* [Alison]

Respecting the contribution of other professionals, irrespective of the difficulties in achieving a consensus decision, was stated to be based on protecting Amy’s best interests.

Similarly, for Edward, discussions centred on whether increased suffering would be caused by further intervention. This included reintubation should Edward fail to successfully maintain his own airway on a second occasion. Disagreement revolved around whether the benefits of undergoing a biopsy and potentially commencing aggressive chemotherapy treatment would outweigh the cost this treatment would impose. Simply because a treatment can be offered does not mean that it is right to put a child through it. The quandary was whether providing ongoing respiratory support whilst undertaking a tumour biopsy and initiating chemotherapy was the right thing to do.

Ben's situation was different. It was undisputed that he had enjoyed tangible and genuine benefits from life that outweighed the burdens of his existence prior to this admission. The challenge was establishing whether he would continue to do so.

> *"I think those (best interest decisions) are made on an individual basis. There are some important generic considerations. Are there any treatments you haven't tried that may be of benefit and there were no others that we could consider. What the output in terms of quality of survival is, if you persist in treatment. With Ben that's a difficult one, because clearly he is already very severely limited in what he can do. However, his quality of life for him is good when he's at home ...The difficulty at that moment in time…, he was not conscious and didn't look like that was going to improve. Given the underlying prognosis for which there is no treatment, and as he already has very limited abilities, it (best interests) was something we just had to consider."* [Doctor 6, Consultant]

The complexity of physiological, emotional, social and other dynamics, which underlie such decisions, means that the best interests of the child may be indeterminable. In order to assist a decision, there is a requirement for knowledge of all potential options including conceivable effects and consequences, together with the likelihood of those occurring. Furthermore, a means of assigning a value to these options is implicit. Whether it is feasible or realistic in this era of scientific and technological advancement to fulfil these requirements is debatable, with latitude in decisions inevitable.

7.2.3 Quality of life

The natural instinct is always to act to keep a child alive but this does need to be balanced against their overall welfare. Quality of life (QoL) was an intricately linked theme across all cases and a term frequently heard within the critical care setting when debating outcomes. Yet this nebulous concept, inescapably open to subjective appraisal, cannot be rigorously assessed in this context. It is problematic because, similar to best interests it is a commonplace, catch-all term, construed according to individual perspectives, society at large providing no clear consensus or hierarchy of values. It is not possible to balance the value of a life, since there are no objective measures. QoL was observed to incorporate subjective consideration of physical, psychological and emotional health and well-being, familial and social relationships, future prospects, level of independence, and environment personal beliefs and expectations.

7.2.3.1 Judging quality of life for another

Considerable debate exists as to how to define and measure QoL especially in children in the ICU whereby life can be prolonged but at the expense of adverse corollaries.

> *"It is always a phrase that I struggle with, because it's very difficult for anyone to judge anybody else's quality of life."* [Doctor 5]

> *"I am very pro in terms of not prolonging life at the cost of quality of life."* [Doctor 10, Consultant]

The quandary of how to judge another individual's QoL was recognised by HCPs as troublesome in rendering incorporation into determinations of best interests. HCPS acknowledged that individuals have their own unique viewpoint and ethical frameworks to guide their understanding and interpretation of QoL. The role of internalised knowledge and beliefs was recognised as impinging upon judgements.

> *"So that's something I find quite difficult, quality of life is often something that's said on here. I have always felt slightly uneasy about medics making a judgement as to what quality of life is, because in general we are all healthy. We have a certain standard of life, all fairly highly educated and used to using our brains and being able to think round problems. We thrive on that…..I always find it a bit difficult, to judge what is a quality of life for them. Because a lot of the things that we feel make our lives rich they*

> *don't have, which automatically puts us in a position where we think well they can't have any quality of life. But they obviously do. …….So it's a difficult judgement for us to make."* [Doctor 5]

> *"I remember thinking to myself, what is the best outcome here? I really struggled conscience wise with it. I am not a parent myself. I don't know what would be worse a child who is so impaired to what they were, or for the child to pass away. I don't know. I struggle with that because, is it terrible because I am thinking that?"* [Nurse 12]

Recognition by HCPs of the necessity to attune their values and beliefs to the needs of others was striking, as was the inherent emotional burden these subjective decisions impose.

In terms of health and treatments, it may be feasible to predict the outcome of interventions, with varying degrees of accuracy. Determining a child's QoL requires sensitivity and it can be difficult, to fully appreciate the complexity of the individual. This opinion is dependent upon "*the individual's perception of their position in life, in the context of culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns*." [World Health Organisation, 1947]. There was also acknowledgment that quality of life is an ill-defined and subjective concept.

> *"There is no definition. It is very subjective, it is a very variable, it's a social, it's a religious consideration, it is very complex."* [Doctor 10, Consultant]

> *"For me, the ability to communicate, enjoyment of food, it's, there's all sorts of things. There's the ability to have an emotional connection with someone. Yeah being able to have a wide variety of experiences and enjoyment."* [Nurse 8]

Within the high technological environment of PICU there is a real danger of focusing upon objective measures and it is easy to lose sight of the child that was and may yet recover to being.

> *"Well I think it is very much based on what you have to offer in terms of treatments, what the child's current quality of life, survival is, … what are the potential things that might happen in the future. Which are very difficult to quantify but have to play some small part in what you're thinking. Are there other options for treatment that are feasible? What will you be left with in terms of how that child will be, and how that child will function?. … That's when the dialogue with the family is so important, because to a family their child being alive is a blessing or whatever. To others a multiply handicapped child is not. And it is a very difficult, so knowing the family is very important. That's often very difficult early on, but as you move through a natural history of a child's disease you get a feeling for that."* [Doctor 6, Consultant]

When making best interest decisions, consideration of the consequences for the family was shown by HCPs.

Significantly, nursing staff generally request parents and family members to bring in photographs of the child. These act as an aide-memoire, conveying a more evocative insight into that child's life and QoL than words alone.

> "*That's very difficult for me to determine because I don't see him when he is at his most well, which is why I said you need the parents to bring a picture of him when he is really well. Then it keeps it in people's mind that they have a quality of life, that they don't dismiss them as much."* [Nurse 7]

Quality as opposed to quantity of life was a key determinant for parents and professionals alike. When Edward was initially admitted to PICU, it was to receive life-saving treatment whereby a good outcome, i.e. a reduction in ICP could be achieved. As a direct consequence of his acute deterioration during the first twenty-four hours of admission, it became apparent that separation of life saving and life prolonging treatment was crucial in determining the limits of interventions. The fundamental question being advanced by HCPs and to a more limited extent by his parents, was: at what point does Edward's acute deterioration including limited response to surgical intervention and high dose steroid therapy result in a decision to limit escalation of treatment and potentially withdrawal of artificial ventilation?

> *"It's very difficult, because the doctors were telling telling us that actually he might not breathe without a ventilator, and he might not walk or talk. And to me I don't think that that's a quality of life, I don't think that that is something people want as a life."* [Nurse 10]

In the PIC, reliance is placed on parents defining what QoL means for their child. Eric acknowledged quality of life is vulnerable to negative interpretation.

> *"Initially there were even some points in time where, if you can't have a completely normal life then we don't want to put him through this."* [Eric]

It must be questioned, as to whether parents and professionals can make a value judgement about quality of life, especially when, as additionally stated by Eric, viewpoints vary over time.

> *"And my view on that has changed again as well, because what is a normal life? Even with all the treatment that is going on and him not being able to fully be himself... it changed depending on which part of the series of events was going on. Initially quality of life was, if you are able to keep him on a ventilator and him never wake up, then that's not a quality of life. If he is able to be awake, interact, be aware and be happy, that's quality of life. But the parts were moving all the time. That definition of quality of life changes…It would be his level of happiness, and as a parent you can judge that, if he is better with whatever treatment he is getting. If you had a treatment that was so extreme and severe and he was just in agony and just debilitated all the time that would be it."* [Eric]

Eric's use of the term 'net benefits' is aligned to the use of best interests being a balancing exercise of benefits and dis-benefits to judge quality of life. Perceived suffering, without the possibility of reprieve or cure, and an inability to have a level of happiness are consistent themes along with the difficulty of trying to envisage what future life may be like. Emma made ad-hoc comments when faced with the initial diagnosis and prognosis, questioning whether it was worthwhile for Edward and the family to suffer the misery of treatment and attendant complications. Attempting to balance burdens and benefits in such uncertain circumstances is not straightforward. It was recognised by the social worker that initial parental comments may not represent the reality of subsequent appraisal.

> *"Quality of life is different for everyone in a way. A parent will keep a child, will still look after their child. Even if Edward had survived this but had been left with damage (names Edward's Mum) would have still looked after him. That wouldn't have been her choice but as a parent you do."* [Social Worker 1]

Nonetheless, the dilemma remains regarding the possibility of excluding treatment where the chance of recovery exists. There was unease about the perceived suffering and effect on QoL that both Edward and his family may experience if chemotherapy commenced. The difficulty in amassing evidence without a tumour biopsy (in itself a risky procedure) epitomises the struggle when there is limited diagnostic and prognostic information. This emphasises the difficulty of trying to weigh up future burdens and benefits and the uncertainty of prediction making an unequivocal assessment impossible.

For Beth, though, the focus on Ben achieving a similar level of health prior to the current illness episode and being able to remain at home was paramount.

> *"If he's at home and he's enjoying himself then I can do it. But if he's at hospital and we've been in and out and it's been unstable, then it's like no enough is enough."* [Beth]

Powerfully, she also quantified QoL in terms of not acquiring additional medical equipment.

> *"But then if we got him back and he was having to be on more machines, different machines than what I could have at home, then it would be like no, let's turn it off and let's take him away."* [Beth]

Beth described QOL in future terms identifying opportunities to enhance Ben's ability to communicate and thus integrate more fully.

> *"Him going to school, I mean in September we're looking at eye movement technology so he can start speaking through a computer. So that is one thing that I want to get there to."* [Beth]

7.2.3.2 Envisioning a child's future quality of life: outcome determines actions.

Competing interpretations of QoL were particularly evident when concern focussed on the potential longer term physical effects of diseases versus intellectual and psychological effects. Shortly after George's admission it was clear that should he survive he would likely undergo partial limb amputations of all four limbs. Physical disability per se was not a consideration in determining treatment.

> *"I think that a child that loses their limbs doesn't mean that they can't have a real fulfilment of life that anyone who has got four limbs could not have."* [Nurse 14]

> *"I don't consider physical limitation as a limitation of quality of life, if you can certainly enjoy some activity. It doesn't mean that if you are wheelchair bound that you have a quality of life that is wrong. ……. So quality of life that is very subjective because you can adapt to the new lifestyle, that doesn't mean that you take away the right to life, to live. Very variable, it is case by case, but physical limitations or any disability is not a consideration in that situation."* [Consultant 10]

For other medical and nursing staff, while concurring that physical disability should not be a consideration they did try to quantify understanding by considering the degree of disability.

> *"I think if his tissue damage was so much that it would have been above elbow and above knee for all four limbs. There was a waiver of a kind of question in me. How is that, what kind of quality of life would he have? But then actually in this country with the advances in prostheses and in so many areas, actually it felt like it was a fleeting thought."* [Nurse 14]

This dilemma epitomises the subjectivity of the concept. It is evident that HCPs are not just considering the child in isolation. Value judgements about how a family may be envisaged to adapt to a different future are only incidentally about the best interests of the child.

> *"And I think it is very difficult to make a decision about someone else's life and family. You don't know how they are going to cope with his amputations or how he's going to cope. But generally children do adapt really well."* [Nurse 14]

When considering the quandary of Fiona's future QoL, it was also evident that different people reached differing conclusions prior to her terminal decline. The most important factor influencing quality of life for some, was the prediction that Fiona would have sustained severe brain damage and be severely impaired.

> *"and the problem is that in PICU we think that an outcome is good when the brain is good."* [Doctor 8, Consultant]

Doctor 4 additionally recognised the dilemma posed by disability and the difficulty of identifying at what point a disability results in a determination to withhold or withdraw treatment

> *"Well I think there is a conflict because some people will say it's not in their best interests to survive disabled, whereas it's a matter of degree isn't it. It's also a matter about their other mitigating circumstances or aggravating circumstances. So it ends up being*

> *subjective. But I think the viewpoint of the Disability Discrimination Act is important too. I will remind the other doctors and nurses about that viewpoint regularly. I think in any negotiation you want everybody to be able to see other people's viewpoint as everybody is trying to do the best for the child."* [Doctor 4, Consultant].

The common presumption was that Fiona would not wish to survive in a profoundly disabled state. However, there exists a paradox that the more severe the neurological injury then the less likely the child would have insight or awareness of their incapacity and yet greater onus is placed on its measure. In contrast, the consultant neurologist challenged perceptions of intellectual disability, acknowledging the discrepancy across medical specialities as to how this may affect the provision of life sustaining treatment.

> *"Sometimes I think there is conflict between what I may think, what neurologists may think and what PICU think too…..a lot of my patients have quite severe neuro disability. Some people think that if a child has severe neuro-disability or we perceive that they will have and need 24 hour around the clock care that maybe that child should have care withdrawn and shouldn't survive with that degree of disability. That needs to be discussed with the family and the clinicians involved……….I think that is a really difficult decision."* [Doctor 9, Consultant]

It is doubtful whether it is ever possible to imagine what life with a neurological impairment would be like. The observed tendency of HCPs when attempting to envisage the child's future life was to base judgements about quality of life using their own personal values, beliefs and experiences. Nevertheless, the things that make life worthwhile in their eyes are likely to be different to parents and the child.

> *"But on the Thursday the doctors were talking about tracheostomy and ventilating (long term) which I felt quite strongly about. I didn't think it was appropriate. If it was me, I wouldn't want to be unable*

> *to do anything, not be able to cough or swallow, not be able to talk or do anything and just not be the same person. So I didn't think that that was appropriate. I know a few of the other nurses felt quite strongly about that as well."* [Nurse 11]

> *"I think that maybe it is to easier to answer now because I am not in a state where I am losing my vision or my hearing or anything. I believe that, for me, not for my loved ones, my wife or child, but for me, I believe I could not accept not being able to communicate and interact with my surroundings. This would be not acceptable………… At first, I don't think you have quality of life, but if you can communicate and interact then you can find ways to overcome this disability, not totally, but in a way that your life can be fruitful and creative and sharing things with others.* [Consultant 8]

Again, this reinforces the contentious nature of a best interest judgement.

Nursing staff, in particular, tended to consider QoL from a parental perspective. They recognised that it would be the parents, who would ultimately shoulder the burden of providing future care.

> *"but I think you see the impacts of that (decision) and it isn't just the yes they've survived it is the massive implications it has on the family. It just changes everything."* [Nurse 12]

Whilst there was awareness that they, as individuals, were unlikely to be able to conceive a life with a disability, the ability to benefit from things that are considered fundamental human characteristics was seen as essential. The ability to be able to communicate, interact with surroundings and have relationships were all believed by HCPs as key in having a QoL. This contrasts with Fiona's family who believed the fact that she was alive was sufficient and meant her life held value.

> *"But to my mind it was very simple. She was alive, in which case she is a human, irrespective of what state she is in and therefore deserves every bit of my effort. Or she wasn't alive."* [Finlay]

Determining QoL within a critical care setting is complicated. HCPs and parents alike wrestled with trying to make sense of what makes a life worth living and acting in the best interests of the child. Parents, when confronted with the initial uncertainty as to whether their child would survive, were frequently observed to make assertions that all that was important was for their child to survive, irrespective of outcome. At such a time, parents are likely to deny or overcompensate future impact as a consequence of a genuine desire for their child to survive. A fundamental parental duty is to support their child unconditionally. There are also strong social norms against saying, far less thinking, otherwise. It is therefore understandable for a parent to do anything to enable their child to survive. Attempting to balance the burdens and benefits when the future is unknown is impossible and parental comments may not represent the reality of future situations. Crucial is whether best interests are deliberated from a short-term or longer-term perspective. Whilst there is recognition that QoL may vary over time, it is not a static state and it must be questioned as to whether it is ever feasible to alter a trajectory later as intimated below.

> *"But I think you do everything you can to do that and if then you aren't achieving a quality of life that either the child or the family deem as being what they expect then you reassess. And I know you can't do that down the line."* [Doctor 10, Consultant]

HCPs realised that best interests offered limited and inconsistent assistance. There was recognition that they could only do what they could.

> *"..we have to accept that there may be a certain outcome, but that outcome we are not responsible for. We shouldn't take it personally. It's not, whatever happens the parents will have to accept and that's the nature of life. You know, to say that we produce a perfectly normal child at the stay of ICU care, we are not in that game. What we have to do is provide the best care for our patient, make sure that they do wonderfully well within the ICU*

> *and then the outcome depends on the underlying, what they came in with originally……What happens in the long run is a different, is not up to us."* [Doctor 11, Consultant]

7.2.4 Autonomy

While consideration of welfare underpins the best interest standard, autonomy relates to who is empowered to make such decisions (Section 2.5 page 23). Within the PICU, a child, whilst having interests and rights, is usually unable to take a decision-making role. The child is reliant on parents, or those with parental responsibility being empowered as proxy decision makers, albeit constrained by professional judgement and decisions, acting on their behalf. Rarely, if decisions become contentious and mediation fails, then the courts may become involved as arbiters and substitute their decision.

7.2.4.1 What weight to attach to a child's wishes?

Whilst the imperative is to act in a child's best interests, establishing their viewpoint is problematical in PICU. The Children Act 1989 requires that when important decisions are to be made there is a need to take into account '*the ascertainable wishes and feelings of the child concerned'*, considered in the light of their age and understanding (Children Act, 1989: S17; Article 12 Convention on the Rights of the Child, 1989). Even so, children's 'voices' were not generally observed to be taken into account despite these decision-making processes directly affecting their lives. Most children being cared for on PICU have limited capacity to contribute. Many are intubated, ventilated and receiving sedation and analgesia creating significant barriers to communication and profound cognitive impairment. Additionally, many children admitted to PICU, (including George, Edward and Carly), are not old enough and do not possess sufficient capacity to participate in decision-making. A danger in this situation is that the child's voice can be marginalised, with parents and HCPs assuming that the child has nothing to say.

The principle of respect for older children to make an autonomous decision was not universally applied, since children were deemed as incompetent by HCPs by virtue of their clinical condition. Significantly, a number of children admitted as a consequence of having chronic and (for some) life limiting illnesses had been permitted some involvement prior to admission. Amy had been actively involved in decisions about her renal management prior to transplant surgery, learning to take some responsibility. She had been assessed as of an age and maturity to participate and her voice had been listened to. She had previously expressed opinions about renal treatments she had undergone and had demonstrated understanding of the complexities and implications of medical interventions.

> *"..and going back to when she started with kidney failure, she said to me was if cats and dogs get kidney failure, the vet would put them to sleep wouldn't they? And I said yeah, and she'd say well why can't they do that to me?"* [Alison]

There is a real possibility that Amy may have changed her mind about deciding whether she wanted active treatment over time. This could be used as a justification for not acceding to Amy's previously expressed thoughts and wishes whilst in PICU. Alternatively, there was recognition that this situation could not have been predicted and that there had been no possibility to prepare her in advance. It was accepted and acknowledged by all HCPs, that it was untenable at this time for Amy's thoughts and wishes to have an active role in decisions about her ongoing care. However, the credibility of such expressed sentiments warrants further exploration. This is especially relevant for the many children with chronic and life limiting conditions who require admission to PICU.

Correspondingly, Fiona, whilst possessing a limited cognition of her pre-existing illness had been in the very preliminary stages of becoming actively involved in decisions about managing her cardiac condition prior to this episode. Fiona's level of cognitive functioning and the fact that this situation again could not have been foreseen meant that it was recognised that it was impracticable for her thoughts and wishes to be given a voice. Nevertheless, Fiona was known to have a needle phobia, a fear of medical procedures involving needles or injections. She became distressed and anxious when she was aware that she had to attend medical appointments. However, needle phobia in itself would not normally preclude aggressive treatment.

Ben had been actively involved in discussions about his care with the oncology team and was known to detest being hospitalised and had made his position understood.

> *"Because he obviously hated being here. In his more lucid moments he did not want to be here. I'd met him the Thursday before (admission) because he'd come in for an MRI. Even then he didn't want to be here, it was not where he wanted to be."* [Doctor 5]

Although his wishes were not always upheld they were afforded consideration. Ben previously expressed a wish not to undergo further chemotherapy but was persuaded by parents to acquiesce. It became apparent when interviewing Beth following Ben's discharge home that Beth and his named oncology consultant do proactively explore Ben's wishes. Attempts were made to include him in decisions about care at a level he felt able to participate, thus affording him a degree of agency.

> *"Yeah, he asks Ben what he wants. Ben's always in the room with us, we always include him, or try to include him as much as he can understand. He knows what's going on all the time. It's like I said it's his body at the end of the day, if he turned round and said enough's enough then enough's enough with him."* [Beth]

Remarkably, nothing was documented in Ben's medical notes signifying that discussions with Ben had taken place, rendering his voice unheard during his stay. This is despite all involved having acknowledged that his thoughts and wishes should influence decision-making. Further admissions to PICU should be anticipated given Ben's illness trajectory. If he is to have an active role in decisions about ongoing care then perhaps once he recovers from this episode the time has come engage in what undoubtedly will be a difficult discussion. There was recognition by nursing staff during ad-hoc conversations throughout the study that children frequently do not have a voice or choice.

7.2.5 Deciding for a child

As previously stated, construction of the child's best interests establishing their viewpoint as a rationale to guide treatment can be unrealisable. The norm is to assume that parents have the authority to make decisions on their child's behalf. This substituted judgement merits attention since the legal stance is to focus solely on the child, denying the interests of the family. Yet, their interests are inextricably linked. Two key themes emerged, parental capability to act on behalf of their child and the complicatedness of balancing the interests of the child whilst also accommodating interrelated family interests.

7.2.5.1 Parental role in determining a child's best interests

Opinions were varied as to the extent to which parents in such stressful situations can influence the decision making process. There was acknowledgement that parents are usually best placed to make decisions about their child's care because they know their child best and because they may be responsible for managing long-term care for their child if they survive PICU.

> *"They're useful in conveying the child's pre-PICU function and what their quality of life's like. Sometimes the parents won't want a child to survive with a very severe disability. They think that's cruel for the child and I would tend to go with their feeling if they felt that. But I might have a similar case where the parents felt if the child's disabled and handicapped that would still be better than the child dying. It's difficult for families because they don't really very often know what that really means. But then I think in everybody's life you don't really know what the outcome of the decisions you make are until it happens."* [Doctor 2, Consultant]

Significantly, the consultant infers that they would be comfortable about withdrawing treatment if parents wanted this.

There was unanimous agreement and appreciation across the whole team that it was undesirable to require parents to be solely burdened and responsible for making decisions.

> *"I believe that they have to be actively involved in this decision because it is their child. Their child is in a state they cannot take decisions for her/himself so parents are responsible and are legally and ethically responsible to take decisions regarding their children. They have to be actively involved because the burden of the care after leaving hospital is up to them so they have to, we have to be sure that they are accepting of this and that they are capable of taking this great weight. I think that parents must participate in decisions."* [Doctor 8, Consultant]

Whilst HCPs acknowledged parents should be involved in deciding their child's care, this existed within the confines of a strategy of guided paternalism, as discussed in the literature review, section 2.5.3. Though parental views were respected, parents were led into making a decision through HCPs agreeing in advance what choices about care would be offered to the family (Shaw, Stokoe, Gallagher et al, 2016; deVos, Bos, Plotz et al 2015).

> *"I think that they should have involvement in the decision making process. I don't think it is one or the other. Because I think they need to be guided. Families will tell you it's not fair if you ask me to make the decision, 'I am not a doctor I don't want to make the decision about my child. You are a Doctor you know best.' This is what families usually think."* [Doctor 9, Consultant]

> *"…it is not only not right, but it is cruel to expect parents to do that. I think that this is where we as a clinician need to lead them, give direction and help make that decision."* [Doctor 11, Consultant]

Nursing staff also commented, both in ad-hoc remarks to the researcher and during interviews, that parents may not be best placed to make some decisions. The suggestion is that it is untenable to expect parents to abandon hope because of their enduring love and commitment to their child.

> *"You are never going to make that decision for your child, however hopeless it is, unless someone tells you it is completely hopeless and allows you to finally not have that little bit of hope, you know."* [Nurse 5].

> *"There are very few parents who want to give up on their child, even if their child's going to be in a persistent vegetative state. Parents say I want them whatever, without realising the ramifications of the changes for their (child's) life and that the sentence involves themselves too."* [Nurse 6].

There was also recognition amongst some parents that they may not be best placed to determine what is in their child's best interests. Parental ability to participate in decision making about best interests is influenced by a diversity of factors including, age, gender and education. In Edward's case, Eric's disclosed experience and knowledge as a medical practitioner tended to influence relationships. Yet Eric, whilst wanting to pursue an active role in decision making, demonstrated insight recognising that his knowledge was limited and he was unable to act autonomously. He focussed on developing a collaborative relationship, accepting that he was reliant on others' professional expertise to enable Edward's best interests to be met.

> *"One thing I learnt very quickly was, and I am a medical doctor myself, but I was out of my depth almost from the very beginning. I was treating this as an intelligent lay person who can ask questions and process information, but who doesn't know. You just have to rely on the expertise of others."* [Eric]

Gaby also acknowledged that she may not have been the best person to voice George's interests during the early days of his admission. She perceived that her ability to assimilate and interpret information was limited at this time. Moreover, she acknowledged that her way of coping was to switch off, at least until she received news that she knew she could not ignore.

> *"It is quite a blur. They said its life threatening and I think I just switched off. I didn't accept it. You don't do you."* [Gaby]

Gaby recognised during ad-hoc discussion sometime later that, if she had been called upon to make any best interests decisions at this time, this was something that she would not have felt comfortable undertaking. It is not realistic to assume that parents can anticipate in advance what is best for their child. Gaby acknowledged that her default stance would have been to have been directed by the medical staff, her perception being that they would do the best for her child.

Equally, there was recognition amongst medical staff that Edward's parents were in an untenable position and it may not be reasonable to expect parents in such an emotional predicament to make such decisions. Relying on parents' instincts to know what will be best places a tremendous burden on parents.

> *"It has to be putting his interests first, above anything else really, and weighing up the nature of the treatment that's available. The outcome and how he deals with it. So, just doing what is right for him, which is really hard."* [Emma]

This was not a decision that Alison was prepared to take. Although she wanted to be involved and included in the decision making process she did not ultimately accept responsibility, delegating this to the consultant in charge.

> *"So when we were asked do you want us to carry on or stop now. I think I said I can't make that decision, so he said I can do it for you. Although, I knew I wanted to make that decision, I couldn't say it."* [Alison]

Alison later revealed that part of her rationale for not wanting to make the decision was due to conflicts within the wider family. The paternal grandmother had issued threats both to Alison, witnessed by the maternal grandmother, and additionally to nursing and junior medical staff. She had declared that withdrawal of treatment, specifically ventilator support, was tantamount to murder. This was a decision she threatened to challenge. The HCP team interpreted these threats as an expression of grief. For Alison, they were highly distressing and considered to impact upon her ability and desire to participate in decisions about her daughter's interests.

Greater recognition of the cognitive and emotional demands on parents is needed to enable a better understanding of how tensions and conflicts impact on the functioning of the best interest principle.

7.2.5.2 Family centred best interests

Each child, whilst unique and holding rights, is also a member of a family. Those with parental responsibility are afforded proxy decision-making responsibility. However, the findings demonstrate this presumption is precarious at best and little more than a fabrication at worst. The best interest standard does not take into account the complexity of looking at the child as part of a family mandating that parents do what is best for the child even if this overrides the interests of the parents and other family members. This creates tensions when trying to establish a child's best interests. To what extent any parent can divorce their child's interests from those of the family is dubious. Paradoxically, an underpinning tenet of paediatric care and the philosophical viewpoint within the PICU under study is that of a family centred approach to care. This creates a situation whereby the interests are seen as interconnected with those of their parents, siblings and wider family despite the legal actuality that they are separate. The challenge observed in practice was how to acknowledge and balance the best interests of the child whilst also considering the interrelated interests of the parents whose interests were also seen to be a responsibility to protect.

> *"what's the best treatment for the child and the family, particularly the parents, but sometimes other people in the family,"* [Doctor 4, Consultant]

> *“So I think the factors we need to consider includes the family’s quality of life as well.“* [Doctor 5]

Notably one of the consultants considered the distinction between a child’s and family’s best interests to be redundant, perceiving that a lack of consensus is the result of a failure of discussion and negotiation.

> *“I don’t think that there is that divide. I think what is in the interests of the child is in the interests of the family. And the divide happens when the parents are not on board with you.”* [Doctor 11, Consultant]

This denial of a distinction between the rights of the child and those of the family and the assumption that the doctor ‘knows best’ highlights the use of professional status, knowledge and expertise to control best interest outcomes.

Adoption of a family centred best interests approach means that parents may act against the interests of one child, to benefit themselves and/or other family members. Divergence was evident as to how to balance obligations and duties to do the best for the family as a whole. Edward’s parents were able to comprehend the considerable demands having a child with a brain tumour would place on the family dynamic, with added responsibilities and changes in family life. Eric had from his medical training and career some insight into what may be involved in future.

> *Comments during handover are that the parents have insight into the demands of chemotherapy and the impact that this will have primarily on their child but secondarily on their family life, including the older sibling*. [Extract observational notes].

However, not all parents are able to consider these things when faced with sudden and unexpected news that their child is critically ill and are reliant on others to guide them.

> *It was acknowledged by (Consultant PICU), following a comment from the nurse in charge, that the family are in a hopeless situation*

> *and that the team need to work with the family and support their (the family's) decision.* [Extract observational notes].

This in reality meant helping the family formulate their decision, although whether it would carry any weight was questionable.

Decisions about best interests were dynamic and did not occur in isolation. With the benefit of time and opportunity to reflect on events, Edward's parents appeared to recognise during interviews that best interest decisions are situation dependent and that their interpretation of what was best changed over time. They acknowledged that they were influenced by Edward's clinical condition, knowledge available to them including current prognosis, and the specific decision being made.

> *"Now it is for a, doing everything we can for a full recovery. Then it was initially it was making sure he was comfortable and everything was dignified."* [Eric]

7.2.5.3 Balancing the child and family's best interests

Even before Carly was transferred from another PICU, the need to protect her interests and dignity, whilst simultaneously balancing obligations and duties to do the best for the family was recognised by HCPs. Legally, there was a duty of care to Carly, to act in her best interests. Any duty of care owed to her parents was of lesser magnitude than that owed to Carly and should not be a deciding factor. The decision to accept Carly's referral could be considered the decisive turning point when, the psychological needs of her parents became of paramount importance. There was recognition by the involved HCPs that, despite every effort, there was a limit on what could be done to preserve Carly's life. The receiving PICU consultant could justifiably have made a decision not to admit Carly on the grounds that provision of further treatment, including transfer, would be contrary to her best interests.

The decision to admit intimated that the psychological needs of the parents justified the compassionate use of a non-beneficial treatment. This decision to give precedence to parental needs was not an isolated occurrence confined to this situation, but was observed throughout the period of ethnographic observation. The difficulty with adopting such an approach concerns how and on what grounds future parental requests for interventions are deemed non-beneficial and denied. Additionally, it raises the question whether it is ever appropriate for parental needs to be put above the child's needs. The rationale for accepting parental best interests is that it makes a very real practical difference to the way that these parents and families are ultimately able to manage the outcome of decisions to withdraw or withhold treatment.

When death seemed inevitable during end of life care, a shift of focus from the interests of the child to that of the family was evident throughout observations. This adoption of a family centred best interests approach was suggested to prevent the family from longer-term adverse psychological effects.

This was exemplified during discussions in a family meeting about how to manage a resuscitation should Fiona's condition deteriorate. A decision was documented whereby CPR could be initiated to allow Fiona's parents to be present when she died.

> *If …. Was to arrest we would try and keep her going for parents to arrive and then stop. This was discussed during the above meeting and parents did not have any objections.* [Extract from medical notes of family meeting]

It can be contended that such a decision conflicts with the best interests of the child. Initiation of CPR in such circumstances is for the benefit of the family to potentially assist family members in their grieving. This superiority of parental needs during end of life was justified by staff as adaptation of compassionate management of family members and promotion of future psychological and emotional health and well-being.

> *"I think it is very important that there are clinicians around to give children a good death. I think what I am trying to do is provide for the family. I know this child is going to die. What can I do along with the team to make that go as well as it possibly can so that in a year's time, in ten years' time that family will look back and go,*

> *there's nothing else that hospital could have done, they provided us with good care, it wasn't their fault that our child died."* [Doctor 9, Consultant]

The professional desire to ensure that the needs of the family were fulfilled when death was inevitable was unmistakeable. The importance of a 'good death' and a desire to fulfil parental wishes for organ donation resulted in a situation where it can be contended that for a brief period, Fiona's best interests were not paramount. HCPs recognised that decisions to escalate therapies to facilitate organ donation may prolong individual suffering but considered this legitimate as they were acting for to upholding parental and a greater societal best interest.

7.2.5.4 Managing competing interests during end of life care

Acting against Amy's best interests was also considered acceptable, once there had been clear agreement between the parents and medical staff to withdraw care and transfer her to the hospice for end of life management. In Amy's case there was recognition that it was neither appropriate nor in her overall interests to have an escalation of therapies once a decision had been made to progress to end of life care. A personal resuscitation plan had been established. However, when Amy's clinical condition deteriorated further two days later, HCPs desire to ensure a positive outcome for the family led to extraordinary circumstances. Amy's parents wanted her to die with her family around her in a pleasant environment and with a degree of privacy that could not be afforded in a PICU setting. A decision to escalate ventilator support therapies and commence IV antibiotics was taken in attempt to ensure that Amy could be transferred to the hospice to die as planned. HCPs, by prioritising family interests, chose to act in a way that could be construed as unreasonable.

> *"Once the decision had been made to try and get Amy to the hospice, ……..I thought that we owed it to them to do what we could within reason to get her there. And so the PRP had been written before they visited the hospice, and I felt that it was*

> *appropriate to override the PRP until we got her there…I think there's a perception that the PRP is set in stone, but actually if circumstances change, and they did because we weren't able to move her as quickly as she needed to be moved, we needed to put in a buffer. And just as well we did because otherwise she wouldn't have got there. So I feel quite proud of that."* [Doctor 2, Consultant].
>
> *"…we tried very hard to get her in there (the hospice) but they couldn't take her. And we started IV antibiotics purely to get her to the Hospice, because that's what the family wanted. I think if we'd been able to get her in on the Friday we possibly wouldn't have started those, but it's a very, very fine line just so we can get her to where her family wanted her to be…"* [Nurse 4].

There was acknowledgement by the consultant caring for Amy that this decision could be equivocal and steps were taken to ensure that PICU team members and the family felt that this was an appropriate decision. Significantly the family did not initiate the request for escalation, the staff initiated and directed the process. All involved were aware that this was a contentious decision.

> *"I felt that I was being a bit bossy that day when I said no we are bagging her, we are putting her onto the Evita (increased ventilatory support) if she needs to be etc., but I didn't find much resistance. I don't think anybody really would have argued with that."* [Doctor 2, Consultant].

When intervening, the consultant stated that there had to be consensus amongst all the team that they agreed the harm caused by prolonging Amy's suffering would be outweighed by the benefits of getting her to the hospice. The difficulty in this context is how to assess suffering, especially given the exceptional duration of Amy's admission. It could be challenged that Amy's best interests would have been met by a decision to not prolong her suffering, allowing her to die. The decision of those present were that Amy's interests were outweighed by the benefit of ensuring that this family’s perceived need for a ‘good death’ was met at this time.

> *“It’s a big shame that she wasn’t able to go (transfer) within the timespan that (names consultant) had wanted her to go. That might have stopped her needing the treatments, …… and you could say that that’s an unnecessary use of treatment. But I think from the family’s perspective of having ‘a nice death’ in an environment that’s totally un-orientated towards the intensive care arena, to give them some time as a family as a group together, including the dog, was good.”* [Nurse 6].

> *“I know that (names hospice) is where the parents wanted her to be. But you can’t help but feel, on the one hand, that’s what the parents want, whereas on the other hand, have we not put this poor young lady through enough….I suppose I agree with what we did, but a very small part of me feels who were we doing this for?”* [Nurse 4].

Both in ad-hoc discussion with HCPs and within some of the interviews, this transition to upholding the family’s best interests and acting against a child’s interests were justified. Some recognised the negative consequences of medical intervention. Others expressed a view that escalating treatment may reduce future complaints about care on PICU.

> *“So although the child’s, best interest is the primary outcome, I also feel a bit of a responsibility to the parents and how they’re going to be after the death. That involves managing the death and making it less bad for the parents and the family. And part of that is not having a battle and going to court, so I try and avoid that.”* [Doctor 4, Consultant]

> *“If you look at the complaints file in the unit manager’s office a complaint has come a year after the child’s death. That shows the parents haven’t moved on at any point in their grieving process. They are just very angry and a year after somebody’s death is a long time to be holding ill feelings and isn’t healthy.”* [Nurse 6]

A departure away from the best interests of the child, which is meant to be the defining standard, was observed at this time when death was recognised as inevitable. Best interests is supposed to be objective and disinterested but are revealed to be interconnected with family needs, dynamics and circumstances.

7.2.6 Gatekeepers to best interest determinations

Decisions about best interests, up to the point that death is considered inevitable and the focus moves to managing it, seldom result solely from parental wishes. Whilst the intent may be to work with parents to achieve an agreed interpretation of best interests, parental role and involvement is variable. The complex nature of decision making means that whilst parental involvement is seen as imperative, these decisions involve deep seated and strongly held values and are affected by feelings of anxiety, depression, grief and possibly guilt. Within contemporary practice, the paternalistic nature of HCPs' input is not certain or simple. While HCPs were seeking to secure agreement for what they thought was best, they were also trying to relieve parents who were not willing to accept the burden of being responsible for the decision. Clinical judgements were observed to be based on the knowledge and experience of the child and family's individual circumstances and background

> *"I'm very keen that parents don't make decisions about this kind of thing. I'm very happy for them to go home and shout and scream and hate me, because I can walk away and there'll be another patient along next week. But they will only ever have their child who's died. If they feel that it was their decision which caused the death, they'll have to live with that for the rest of their life. That's a horrendous thing to have to do. Whereas, they can blame the final act of death on me as opposed to blaming it on themselves. That is really important. But they have to accept the decision I've made."* [Doctor 3, Consultant].

Amongst HCPs appreciation of the need to guide parents to make the 'right' decision, the decision selected by the clinicians was evident.

> *"You want the parents to support you in that decision, you communicate with them all along about that decision. I don't think that you can make it their decision. I think that that is really unfair because they have got to live with that forever. They need to be guided by you, so you can discuss it with them, but you are actually the people making the decision. They are just agreeing with you in that decision…It is too much responsibility to give somebody."* [Nurse 5]

HCPs were seen to strive to achieve this aim of working across teams and with parents. Aligning parental and clinician viewpoints was fundamental. However, in practice, things were rarely that straightforward. Historically, the validity of professional judgements have rarely been contested. Yet, the prevailing demand for increased parental autonomy appears to conflict with medicine's paternalistic approach. Some parents were reluctant to relinquish decisions to medical staff. While parents have a duty to 'choose' in their child's best interest, parental perception sometimes resulted in conflict with HCPs. Parental choices will only be acceded to if the medical staff are in agreement that this is the right thing to do. Professionals were sometimes seen to manage the situation to give the appearance of respecting parental wishes whilst manipulating preferred outcomes.

Potential for conflict was evident throughout Edward's admission on PICU primarily because at times there was disagreement between both physicians and physicians and parents as to what was in Edward's best interests. Discussions centred on whether further intervention would cause suffering. One disagreement revolved around whether the benefits of undergoing a biopsy and potentially commencing aggressive chemotherapy treatment would outweigh the cost that Edward was being required to take. There was acknowledgment that Edward did not have a voice or choice, that any decision would be imposed. Though a treatment can be offered, this does not inexorably mean that we ought to put a child through it. The dilemma in this situation was whether undertaking a tumour biopsy and initiating chemotherapy, was this was the right thing to do.

> *It was acknowledged by Consultant PICU 3, following a comment from the nurse in charge, that the family are in a hopeless situation and that the team need to work with the family and support their (the family's) decision.* [Extract observational notes 15 August].

> *Parents are not currently willing for treatment as they do not want his quality of life limited, but Prof. xxxxx states they made the decision in a state of shock and state of mind was not best to make an appropriate decision.* [Extract from medical notes]

Ostensibly professional concern was evident, with acknowledgement of the desperate situation the family were experiencing, together with concern that the parents may change their mind. Nevertheless, when it was suggested that Edward's parents were considering whether or not to follow the second neuro-oncology team consultants guidance to establish a definitive diagnosis, the parental right to be able to decide for their child was challenged. In the extract from the medical notes above, the emotional competence of parents was questioned when they did not accord with prevailing medical opinion. At this point some medical staff attempted to suppress decision making, on the grounds that the parents lacked capacity. A collaborative decision-making approach appeared to exist only when parents concurred with medical decisions.

> *When one of the middle grade doctors commented that the parents were unwilling to consider a biopsy, Consultant PICU specifically remarked that consideration must be given to the rights of the child versus the rights of the parents and that perhaps legal guidance would need to be sought.* [Extract observational notes]

Particularly important was the PICU consultant's reference to legal guidance and the recognition that this may become a contentious case.

PIC professionals appeared to acknowledge the involvedness of the law. Early consideration of the potential for legal involvement was observed during ethnographic observations. The influence of the courts when determining best interests was mentioned on a number of occasions including when conflict between parents and HCPs was considered likely and when HCPs were meeting to try and establish inter-disciplinary unanimity. These meetings, which take place prior to family meetings with the parents, were frequently observed to have a legal and ethical undercurrent with reference made as to how the courts may interpret a situation and underline how professionals privilege the family's interests.

> *Consultant PICU restated that the parents had expressed that they do not wish to pursue active treatment. At this point Consultant Oncologist stated that he did not think this was in the best interests of the child. Consultant PICU responded that if the case became contested he was not convinced [that a court] would rule in favour of treatment given the size, location and limited efficacy of treatment. He further added that although treatment would buy some time, the child's quality of life may well be such that it would be of limited value to the family.* [Extract observational notes]

HCPs were also mindful that parents may pursue litigation against professionals. Difference and dispute are likely due to the qualitative and subjective nature of critical care decision making. Early consideration of legal involvement may be a tactic by which medical staff may counter dissent from colleagues and secure approval for their actions. Whilst the intention of the HCPs, and specifically medical staff, may be to encourage parental involvement for deciding what is right for their child, parental autonomy was limited by the exercise of professional expertise. For example, in Edward's case, best interests ultimately was what the medical team were prepared to do on behalf of Edward and his family.

Edward's parents recognised that they should in principle be making decisions about their son's treatment. When embroiled in the confrontation over whether Edward should undergo a tumour biopsy, Emma openly acknowledged the constraints on her parental rights to determine her son's best interests on two occasions. She possessed insight that medical staff may seek recourse to the courts to supervene parental rights.

> *Emma questioned whether they as parents would be allowed to decide what is best for their child. The consultant commented that the intention was to work with the parents to do what is best for their child.* [Extract Observational notes]
>
> *Emma commented about losing parental choice and asked at what point would they as parents not be able to influence the decisions. She then specifically referred to the Courts "if there is disagreement and we do not want to pursue treatment, at what point do you go to the court and will we then have to lose our child to the courts?" Consultant PICU stated their intent was to work together to achieve a decision all are happy with. Emma stated that she was concerned they (parents) were being bullied into a decision to go for a biopsy and that this would then force them into active treatment and that it would be their child and them that would have to endure prolonged suffering and distress for no ultimate gain.* [Extract Observational notes]

Emma's legal background may have been a crucial contributor affecting her viewpoint of parental role and involvement in decision-making. Her knowledge of previously contested cases within PIC settings, whereby courts were asked to adjudicate in determining best interests, may have prompted her concern that their parental rights may be limited or suspended. Emma conveyed a very real perceived fear that she and Eric may be excluded from determining Edward's interests if they did not acquiesce to the tumour biopsy. Significantly, as highly educated and articulate parents, the overwhelming maternal concern was whether their parental rights to decide for their child would be legally challenged. Edward's parents professional backgrounds in medicine and law, furnished them with far greater insight into the ramifications of treatment decisions than most parents. Emma recognised that she was having to challenge the power of the medical professionals. Observing this interplay of different and conflicting discourses around best interests, it was apparent that professionals do switch to and from a medical to a moral or legal discourse as a controlling strategy. Some actions undertaken in negotiating the ambiguities of this case were not necessarily meant to feature within legal interpretations of the best interest process. This demonstrated that best interests were discursively reframed by professionals in clinical, rather than moral, terms in order to neutralise challenges.

During interview, Emma acknowledged that whilst the intervention of the courts was extreme, the need for sensitive exploration of uncertainty of the potential harms and benefits of treatments was paramount.

> ***Interviewer: "You challenged, in terms of your role as parents, and questioned at what point would you (HCPs) override my parental authority."***
>
> *"I think that was only because we were thrown into a situation where we had been told that some doctors will treat and treat and treat. And we weren't told that it would be at the expense of the child, but it almost felt, that was the impression that we were given. However right or wrong that impression was that's how I interpreted it. I knew that from a legal point of view. This is where a little bit of knowledge is a dangerous thing. Children can be made wards of court, if the doctors feel that we are not acting in the best interests of the child. And that is an extreme consequence, but it can happen. We were in a really low place and still at that stage where we weren't a 100% on board with what the new team was telling us. We had to have time to take it in and understand everything that would be involved in that relationship*." [Emma]

Of particular note are comments which led parents to perceive that their child may be considered as a research experiment to explore the limits of treatment. Differences in determinants of optimistic and pessimistic outcomes across the multi-disciplinary teams were previously observed in earlier case studies and such discrepancies were, on this occasion, conveyed to the family. This did have a deleterious effect on the parent's relationships with some professionals. Nevertheless, although Eric was aware that parental rights could be challenged, unlike his wife this was not something that he considered as necessarily applying to them.

> *"I don't think it affected me as deeply. It was something that had been raised by (names neurosurgical consultant) and he was just kind of giving anecdotal, that oh I've had some situations, wasn't directing that at ourselves at all….He said that there are times when you have to take parents to court so that you basically take away their control from them. But in no way did he suggest that that was our situation."* [Eric]

It is difficult to ascertain whether parents generally have awareness and insight regarding the role of the law and parental rights in decision making or whether these parents were exceptional due to their professional backgrounds. Highly publicised events such as those surrounding the Charlie Gard and Alfie Evans cases have heightened public awareness that parental rights to determine treatment may be challenged through national and international law. Media discussion of other cases may have increased awareness and understanding for some, and confusion for others surrounding parental rights. The discussions generated included questioning whether HCPs act in the best interests of the child or are complicit in rationing therapies.

There was awareness across HCPs that with another family the outcome of events may well have been different.

> *"It is amazing actually, because any other family would have been very angry. I think in a way they are one of the easiest families*

> *that I have worked with, in the fact that they are not unrealistic.”* [Social worker 1]

Whilst the majority of parental views about treatment and care are respected, this situation brings into question the level of decision making parents may be reasonably involved with. Parents’ right to exercise choice and make decisions about their child’s care is shrouded in uncertainty. When conflict occurs, the circumstances are highly fact sensitive and the practical level at which the clinicians operate is grey. HCPs interpretations are, to a large extent, disconnected from the legal construction of best interests. To involve parents in all clinical decisions is unrealistic. In practice, challenge to parental responsibility and reference to the law is triggered only when parents appear to disagree with medical opinion. For parents this amounts to them having to venture to challenge the power of the professional.

7.2.7 The role of the law

Medical and nursing staff were aware of legislation and also some specific legal cases, although the extent to which this impacted on the decision making process was unclear.

> *“I think having the legislation about the best interests of the child helps because you can always look to that. And having a legislation that you don’t do anything to kill the person is very helpful. So we can treat symptoms and try and make their life comfortable and as nice as you can. If that happens to shorten their life as a side effect, that’s legal, but not deliberately with the intention of shortening someone’s life.”* [Doctor 4, Consultant].

On one occasion during a MDT meeting, debate centred on whether Amy’s best interests were being met during discussion about proposed treatment changes. It was evident that, should the choices made by the parents be perceived by one of the consultants as being against what he truly believed was in Amy’s best interests, he would be willing to supervene parental wishes.

> *Consultant X commented that although he would work with the family it is not their choice. This comment appeared to anger Consultant Y who commented that need to consider best interests and that the law would look at things differently.* [Extract from observational notes]

Such reference to the role of the law by HCPs may arise out of personal experience, observation of other cases, and media reporting or through use of tacit knowledge developed through custom and practice. Threat of the court as an arbiter of professional behaviour and conduct may be a tactic by which medical staff may seek justification for their actions as opposed to the driver for decision-making.

However, the threat of legal involvement could also be construed as an attempt to limit parental autonomy. Senior HCPs were cognisant that whilst they cannot override parental decisions, should the courts be required to make judgements, they rarely override professional judgments. Yet, there was recognition that the longer term effect of adopting a legalistic approach to best interest determinations was detrimental for parents with expressed concern for parental emotional and psychological adjustment following legal adjudication. HCPs were observed to go to considerable lengths to mitigate such action, legal involvement being viewed as a last resort when negotiation and mediation may have irrevocably broken down.

7.3 Chapter summary

Throughout this chapter, complexity and uncertainty have underpinned a struggle to do the best for children in the context of determining whether to persevere, withhold or withdraw treatment in these cases. The notion of best interests presupposes that there is, theoretically, a right answer to the question: ‘is this intervention in the best interests of child?’ What this chapter has demonstrated through exploration of the cases, is that this can never be achieved. Parents and professionals construct and negotiate best interests in different ways according to the unique context of each case and individual perspective and values.

Different accounts about balancing of interests, values and quality of life encountered highlight the risk that these decisions are likely to result in stand-off. As seen throughout, nuanced interpretations of best interests were used to justify decisions made by HCPs and as a bargaining tool. The need for child and parental viewpoints to be included was evident. Yet discourses of professional status were used as a means on occasion to control parental involvement and on others with beneficient intent to relieve parents from decisional responsibility. The cases presented emphasise the need to inculcate realistic expectations of the rights and ability of parents to participate in these difficult decisions. Likewise, HCPs must be appropriately respectful and reflective in their negotiations and to ensure opposing viewpoints are not overlooked. Honouring and incorporating the voice of the child is interlinked and warrants additional critical exploration.

The inability to accommodate all competing values and wishes means that each unique set of circumstances is ripe for dispute. Clinicians and families were trying their best and working hard to find the right thing to do. However, best interests as a decision-making tool has been shown to contribute little to the pre-existing tools of medical diagnosis and prognosis, and ethical considerations regarding sanctity and quality of life. Instead, best interests simply offers a different discursive frame for the same substantive quandaries and decisions to treat or not to treat.

Chapter Eight

8. Discussion and Conclusion

8.1 Introduction

The aim of this study was to explore how the construct of best interests is understood when making difficult decisions to persevere with, withhold and/or withdraw life sustaining medical treatment in children. Adoption of ethnographic approaches permitted in-depth contextual understanding, as befits the sensitive and emotive nature of a critical care setting, of decisional processes when choices about treatment/non-treatment had to be made.

This chapter will present a critical examination of the major findings with reference to existing knowledge and theory.

8.2 Overview of principal findings

At the outset, the study aimed to address gaps within existing knowledge (section 3.1, page 57) by:

- Exploring what is meant by the concept of 'best interests', and how it is perceived, described and experienced by parents and HCPs.
- Reviewing how decisions to persevere, withdraw and/or withhold treatments in critically ill children are reached.
- Considering the roles of parents and healthcare professionals in interpreting and applying best interests for surrogate decision-making in the PICU.

These aims were addressed through exploring experiences by:

- Undertaking an extended two-year case study of a single PICU.
- Application of a collective (multiple) case study approach which enabled comprehensive observation of care and interventions given to six critically ill children and their parents.

Rich and complex data were generated allowing in-depth exploration, analysis and representation of individual experience and group interaction within its social context. Chapters 6 and 7 presented the themes generated from qualitative analysis of data.

As the first UK prospective, qualitative study to explore the immediacy of the decision-making process as it happened in the PICU, the study has provided numerous insights into the construct of best interests. Despite the singularity of each of the six embedded case studies, common themes concerning the intricacies of how difficult decisions about a child's best interests were made have been derived. These included:

- how parents and professionals constructed best interests in different ways according to the unique context of each case and individual perspectives, values and beliefs.
- parental ability to exercise choice and make decisions about their child's care was shrouded in ambiguity and reliant upon how parental and professional relations were shaped.
- parents' and professional approaches to try to contain uncertainty and difference in order to determine a course of action.
- the impossibility of accommodating all competing values and wishes meant that each unique set of circumstances was ripe for dispute.
- the impracticality of trying to impose a rigid structure or framework of how decisions can be constructed.

The PICU was an incredibly challenging decision-making environment due to the sheer density of decisions and environmental milieu. Particularly striking were the ways in which professionals and parents endeavoured to work out approaches to adapting to the demands of complex decision-making. Each actor was seen to be grappling to realise his/her own formulation of best interests from a personal or professional perspective. Actors were trying to do their best in very difficult circumstances. Nevertheless, during observations and interviews, it was apparent that parents and professionals were trying to resolve different conceptualisation of the child's best interests and indeed, sometimes struggling themselves to work out what these may be.

On the surface, the process of best-interests decision making appears relatively uncomplicated. However, as these study findings establish this is decidedly not the case. Decision-making was observed to be fraught with difficulties, confusion and inconsistencies. Consideration of best interests was situated in the complex diagnostic, and clinical decision-making process of determining whether to initiate treatment, whether to withdraw treatments that have already been commenced or to impose limitations on escalation of treatments already started. At the commencement of the PhD it was anticipated that the law would be central to the decision-making process in these difficult cases. In the event, what has emerged has been much more about relations between parents and professionals, between professionals and across disciplines. The law, although situated in the background, was still relevant. HCPs had their own varying awareness of the law that influenced their decision-making. The law became another tool in the rhetorical repertoire of making arguments, and on rare occasions was even used as a threat. HCPs, and to a much lesser extent parents, nonetheless identified an imperative to forestall legal involvement and most of the time managed to contain conflict, even if the process of this did not always work to the child’s advantage. Issues of relational autonomy versus a child’s autonomy were revealed.

Core findings will be discussed in light of three key areas:

- The complex and, on occasion, conflicted interplay between HCPs and parents: Parents’ understanding mediated by professionals.
- The intricate manoeuvrings and negotiations observed amongst HCPs to engineer professional consensus as to how to proceed: Intra and inter-professional dynamics.
- The multiple and discontinuous enigmatic qualities of best interests.

8.3 Parents’ understanding mediated by professionals

In the unnatural world of PICU, the predicament for parents, as demonstrated throughout the findings, is that they find themselves attempting to adjust to a very abnormal situation at a time of great personal vulnerability. Although the convention existed for parents and HCPs to work in partnership, how this translated into practice was varied. Isolated individuals did not make these intricate health decisions. Collective thinking and actions, arising from complex professional networks and parental social and emotional partnerships evolved into decisions.

Parental ability to participate in decision-making links to the concepts of autonomy and professional expertise. Within contemporary healthcare, autonomy in decision-making is fostered through the provision of information (Coulter and Collins, 2011; Department of Health, 2010) and this featured to varying extents within all cases. However, as indicated within Chapter 7, establishing the child's viewpoint for these complex cases was unrealisable, and so the norm was to work with parents as surrogate decision-makers. Therefore, discussion will focus upon parents, initially exploring how parents participated and were supported to be involved in decision-making.

8.3.1 Parental participation: a dynamic and relational process

That the views of the parents were important in shaping decisions is incontrovertible. What the study has demonstrated is that in conceptual terms, there was a discrepancy when the concept of parental autonomy was employed. The perceived notion is that parents are going to act in a rational manner (Dubov, 2015). That parents are going to be able to assimilate complex information, weigh up the pros and cons of results and treatment choices, be able to function in an analytical and dispassionate manner and reach a considered decision based on the needs and interests of their child (Orfali 2004; Orfali and Gordon 2004). Such an idealised representation of parental participation in decision-making does not capture the experiences or wants witnessed. Autonomy was observed to be aspirational and temporal (Fineman, 2008). It was aspirational in that parents sometimes thought that they ought to be able to decide for their child. Professionals notionally wanted parents to be involved. However, the interplay between actors was unpredictable and varied. Autonomy was a temporal and shifting characteristic, dependent upon the subtleties of people’s opinions, circumstances and positioning. The findings demonstrate that the dynamics of parental relationships with professionals cannot be simplistically reduced to HCPs moving between paternalistic, informed or shared models of decision-making. This does not capture the phenomena found, with each situation unique and complex.

8.3.4 Diversity of parental engagement

Although promoted as a central tenet of care, within the real world setting of PICU, parental engagement and involvement in decision-making was observed to be a fragile concept. Perceived social norms and healthcare policy recommendations are that parents wish to be involved in deciding for their child and that HCPs want parents to be involved (Larcher et al 2015; Gillam & Sullivan 2011; Department of Health, 2010, McHaffie 2001). The cases involved in this study exemplified a whole gamut of parental preferences, demonstrating how little is really known about people’s desire and capacity to be involved.

Parental participation was seen to occur at any point along poles of a continuum, ranging from nominal, assenting to what was going to happen, to full collaboration (Anspach, 1993; Gillam & Sullivan 2011). Parental participation could be likened to an adapted version of Hart’s Ladder of Participation (Figure 2 p45). However, although parents moved between various levels of participation, most did not metaphorically ‘climb’ the ladder towards increased participation. Neither did all participate in the same way or level at similar points during their child’s admission to PICU. The ladder presumes an ordered hierarchy in which participation occurs and progresses. However, parents were seen to ‘hop on and off’ at different levels dependent upon their emotional, psychological and physiological needs at that moment in time. Hart’s ladder implies that professionals are controlling involvement and to a certain extent that was the case, with HCPs exerting power particularly over what information to release and manipulating situations behind the scene. Nonetheless, it was apparent that both parents and professionals were active, choosing to participate in multiple ways and with various approaches, which could be co-occurring. Parents and professionals did not necessarily hold one opinion at a time about an issue. They were seen to move very suddenly between one viewpoint and another, even over the course of a matter of minutes reflecting the fragile and unpredictable nature of paediatric critical care. Both were observed to constantly revise, reappraise and modify their opinions and assessments. It was quite stunning at times, how quickly decisions could be overturned. This related directly to the situations that parents and professionals found themselves in, where there are very few, if any, guidelines or references available as to how to progress care.

Parental capacity and desire for autonomous and rational decision-making could not and should not always be presumed. Parental involvement is often simplistically portrayed as parents choosing either to be involved or not involved, being at opposing ends of a spectrum. Involvement was seen to be an all embracing term, which extended from an awareness that decision(s) were happening, to collaborating with HCPs, to a parental belief that they had made the final decision (Shaw et al 2016; deVos et al 2015; McGraw et al 2012; Ames et al 2011). Parental decisional autonomy is not a static concept, being complex, involving dependent, interdependent and independent variables, many criss-crossing pressures and uncertainty.

8.3.4.1 Parental incapacitation

Connecting with previous studies investigating parental role alteration and professional relationships when a child dies, parents were seen to recognise that initially admission to the PICU environment required them to relinquish their normal parental function of deciding for their child (Butler et al, 2018; Ames, Renwick & Baillargeon, 2013, Yorke 2011; Colville, Darkins, Hesketh, et al 2009). Parental incapacitation particularly at times of crisis, including admission to the PICU and acute deteriorations in a child’s condition, was witnessed throughout (Butler et al 2018; Carnevale et al, 2016; Latour et al, 2011). Whilst differences between circumstances for admission existed, all parents were discerned, to begin with, to be in a state of shock due to the shifting nature of their relationship with their child. Some were visibly acutely distressed, others appeared numb and incapacitated. For HCPs, the focus at this time was to prioritise the child's survival. Accordingly, HCPs were seen to intervene in necessarily paternalistic ways with parents, to act as gatekeepers of information. Within the dynamic and fluctuating circumstances surrounding each child's case, as Foster (2014:50) identifies

> *"autonomy, to be rightly understood and exercised, has to be seen in the light of the fact that humans are necessarily embedded in a social matrix."*

At these critical times parents willingly conceded that HCPs were the experts who possessed the skills and knowledge to potentially 'save' their child, acquiescing to decisions being made. Butler et al (2018) describe this as a phase of 'welcoming expertise'. Accordingly, within this study, HCPs were seen to intervene in a paternalistic manner in the short term. Yet, significantly, findings indicate that HCPs recognised this authority as transient, as revealed by the considerable efforts undertaken to persevere in including parents, with a view to enhance parental autonomy in the medium or longer term. Furthermore, parents acknowledged the need for HCPs to act in genuine emergency and life-threatening situations. During interviews, parents were able to differentiate and understand the temporal nature of their participation (Section 6.4.2 p169). They recognised that acts of benevolent paternalism were not inevitably about devious professionals attempting to seize power and disempower them but due to practical exigencies of life-threatening situations.

8.3.4.2 Reconstructing the parental role

Most commonly, the anticipated trajectory described within the literature is parents moving on, reconstructing their parental role, wanting to become actively involved in care practices and working in partnership with HCPs to determine treatment choices (Shapiro et al, 2017; Ames et al., 2011; Noyes, 1998). Similar to this study's findings, Wirtz et al's

(2006) exploration of the limitations of models of decision-making revealed a temporal gap between theories of involvement and the intricacy of determining which decisions parents should be involved in and how parental engagement could be facilitated. Wirtz et al. claim that professional, legal and ethical accountability inevitably renders relationships inequitable, the professional narrowing of options considerably restricting parental autonomy. These complicated phenomena of participation and empowerment are oversimplified when conceptualised as models. Dynamic and ever-evolving processes are required to allow methods of involvement to be shaped to meet individual need and enable change over time. Recognition existed that parents needed to be able to trust in relationships and processes so that they could articulate their desired degree of participation (Ames et al., 2011; Shudy et al 2006). There is a need to view involvement beyond the representation of inclusion and exclusion and work with parents continuously in ways that they desire and fostering agency to access alternative methods of involvement at different times.

8.3.4.3 Prior knowledge and experience of PICU impairs participation

Significantly, this study highlighted that the extent to which parents wished to be involved in decision-making did not appear to be determined by prior exposure to the PICU setting or duration of a child's admission. This study's sample contained a mix of parents of children admitted for a one-off admission as well as those with children with underlying chronic illnesses who had experienced prior PICU admissions. Ad-hoc conversations revealed assumptions by some HCPs that lack of exposure to an intensive care setting was considered to predispose parents to decision avoidance. The assumption was that parents who had experienced previous admissions were more familiar with the environment, the workings of the unit. Additionally, these parents possessed considerable knowledge, skills and expertise, regarding their child (Graham, Pemstein & Curley 2009) and therefore were presumed to be better equipped to be active in decisions. The episodic nature of admissions and the enforced disconnect from parental primary care giver role was seen to expose parental vulnerabilities and fears together with a dislike of relinquishing control. Although varied in their experiences, parents wanted continuity of care both within the PICU and with the individual speciality services that would in all likelihood continue to provide care following discharge. This added an additional layer of complexity to communication of information and parental involvement. The potential for communication failures, relationship breakdown and conflict significantly heightened. These parents recognised that they found it harder to cope and adapt with each subsequent admission, the antithesis of HCPs expectations.

8.3.4.4 Choosing not to make a decision

Although a general acceptance that parents, may be initially incapacitated exists (Butler et al 2018; Madrigal et al 2012; Ames et al 2011), there remained a presumption that parents will conform to anticipated norms of behaviour and start to want to take a more active role. This literature is however limited, being mostly based on maternal perspectives. Yet, the study identified that the emotional demands of decision-making may lead a parent to choose the third option of not making a decision in this emotionally laden milieu. Models of participation do not acknowledge that some parents may be ambivalent and others may choose not to participate. Parents in this study exhibited degrees of unwillingness to participate in decision making extending beyond initial admission. Responsibility was then delegated to their spouse or significant other, or to physicians, or they chose only to contribute on an intermittent basis. This lack of desire to participate lacks acknowledgement within the PICU literature, but is recognised within wider neonatal and adult literature exploring highly consequential decision-making (Orfali & Gordon 2004; Weiss et al 2015; Wong & King 2008; Pavia & Mason, 2004). The 'right to not know' was explicitly recognised in *Re Montgomery* (2015) and is also found in Article 10.2 of the Bioethics Convention (1997). Yet, there is a presumption amongst some HCPs that all parents will want to be involved.

Being unwilling to participate in decision-making does not necessarily imply risk aversion but may in fact be an effective information management tool adopted by some parents. The psychological burdens of decision-making, including the pressure of being a ‘good parent’ and making the right choices are recognised (Madrigal & Patterson 2018; Carnevale, Teachman & Bogossian, 2017; October et al 2014; deVos et al 2015; Botti and McGill 2006). Parents may feel overwhelmed by the responsibility of being asked to make decisions which have momentous consequences and which they do not feel technically competent to make judgements about. Eschewing determinations may additionally enable shielding from the reality of the information, allowing hope for a better outcome for their child to be maintained. This was unsurprising, given the emotionally charged and highly consequential nature of decisions involved (Orfalli, Botti. Iygenor 2009; Orfalli 2004). By opting not to make decisions about treatment plans, the parent delegates responsibility to HCPs as informed ‘agents’ to evaluate proposed options effectively. This was particularly apparent when the consequences of courses of action were uncertain and emotionally laden, and things may work out well, gravely, or somewhere in between. Deflecting a decision, therefore may signify a manifestation of emotional and psychological turmoil (Botti et al, 2009), a means by which parents, principally mothers within the existing body of literature, may manage information overload, emotional conflict and indeterminate preferences (Orafali, Iygenor and Botti 2009; Botti & Iygenor 2006; Botti & McGill 2006). Nonetheless, as Herring and Foster (2012) report, the right not to know can be interpreted in a patronising manner by HCPs who may consider the parent to be acting irrationally and feed into the ‘patient deficit’ model of assumed incompetence (Welie &Welie, 2001) .

When one parent opted not to know, tremendous burden was placed on the other parent and the dynamic of communication with HCPs was altered. Under these circumstances HCPs were unsure of their overall responsibility to each of the parents. Continuing to attempt to give knowledge to a parent who has stated they do not wish to receive information may have further incapacitating effect on the decision-making ability of that person (Herring and Foster, 2012). Despite this awareness, the need to continue to engage with both parents was acknowleged. Emphasis, however, was placed on connecting with the parent who was better able to interact and participate in information exchange. Although in the main effectively managed by HCPs, incompatibility between parents generated ethical tensions and led on one occasion to dispute. There was an ensuing temporary breakdown of communication between parents and HCPs with resulting tension and loss of trusting relations. The shifting fragility and volatility of relationships between HCPs and parents was highlighted.

The difficulty facing professionals was in assessing, reconciling and meeting the needs for the level of involvement that was apposite for each individual. That parents' reactions were individual, subtle and nuanced were recognised as a potential challenge by HCPs, particularly when there was difference between the parents. Significantly, HCPs were located in exquisitely problematical positions, being forced to make active decisions about whether or not to continue to inform and promote parental participation. When HCPs recognised the nature of the parents' dilemma occurring, considerable professional sensitivity was exercised. Physicians understood that relieving parental burden and responsibility for making difficult decisions was an integral part of their role. As Orfalli et al (2009) acknowledge, parental autonomy has been idealised and does not reflect the nuanced reality of 'tragic choices' in practice. Information avoidance diverges from perceived cultural and societal norms. Further exploration and evaluation of how the choice not to know or be involved in these highly consequential decisions, influences outcomes, together with how it influences relationships and emotional welfare of all actors, is warranted.

8.3.5 Learning to work the system

While alteration and acclimatisation in parental roles have been identified within the literature (Ames et al 2011; Colville et al, 2009; Just 2005), new insight has emerged from this study about the evolving nature of relationships between parents and HCPs. Little is known about how the power imbalance impacts upon parental transition and adaptation to being in the PICU setting. Evidence from studies highlights that parents, principally mothers, want to be involved in their child's care but that this is dependent upon how HCPs facilitate this (Geoghegan et al, 2016a; Botti, et al, 2009; Shudy et al, 2006). Reflecting Butler et al's (2018) findings, parents within this study not only constructed a role for themselves, but additionally some were observed to fashion a role for HCPs. Several parents in this study were not passive, acquiescing to a role that was apportioned to them. Rather, they were also manoeuvring and positioning themselves, 'learning to work the system'. Both ends of the parent-HCP relationship were active, not just the HCPs.

8.3.5.1 Parents acquiring knowledge and skills

Parents' construction of their parental role varied (Ames et al., 2011; Roden, 2005). Parents, specifically those with professional backgrounds, were better equipped to 'work' to achieve their needs and wants. They were observed to operate in a tactical manner which appealed directly to professional temperament and enabled them to transcend traditional role boundaries. Two specific strategies were witnessed: targeting and focusing on two or three key HCPs, together with an acknowledgement that, as a parent they were insufficiently knowledgeable to assess what was right for their child. These parents were seen to rapidly identify key HCPs, commonly consultant medical staff, who would be central to the decision making process. By focussing almost exclusively on these senior and key personnel for communication of their child's condition and exchanges of information, less emotional 'cost' was incurred. Rapid identification that a very limited number of key personnel were able to help them understand and prepare for treatment decisions meant that these parents were able to circumvent becoming embroiled in the differences of opinion arising from professional debate. Additionally, through adoption of what superficially appeared to be an acquiescent and subservient role, but which in actuality centred on the care delivered to their child being grounded in an evidence based approach, parents required HCPs to explain and justify decisions based on available research and clinical evidence. Fundamental to this relationship was a recognition by these parents that they could never possess the same level of knowledge, understanding or expertise as the HCPs. Nevertheless, what they realised they could do was ensure that they could play a collaborative role in how decisions were determined. These parents were able to appeal to professionals' desire to search for answers and provide the best clinical care whilst being simultaneously able to incorporate their parental values and preferences into the decisions made. Whilst focussed on protecting their child's interests, they exhibited polished and confident communication skills, adroitness and understanding of professional etiquette, together with a level of self-composure that enabled them to foster a collaborative role. Specifically during family meetings, they were not intimidated being in the company of experts and demonstrated self-confidence and poise during interactions and this offered increased possibilities to influence the decision making process. Further exploration of the influence of parental educational and employment status including whether this dynamic alters allocation of resources is warranted.

Failure to align parental opinions and observations on care and HCP expectations resulted in increasingly strained, damaged and, on more than one occasion, confrontational relations. As reported by DeLemos et al (2010), some parents were reluctant to express dissent for fear of being considered difficult and believing that this may detrimentally affect their child's care. Unhappiness centred on HCPs' failure to fully consult or alert parents to changes. Affiliating with previous research, two parents expressed that they were not able to participate in decision making in the way that they desired (Ebrahim et al 2013; Carnevale et al 2011; Carnevale et al 2007). Although evidence of staff soliciting parental opinion was witnessed, together with mutual reciprocity of information exchange on many occasions, the difficulty remains as to how parents perceive the power differential embedded within all interactions. Parental expectations centred on a belief that their expertise ought to be solicited by HCPs. They felt aggrieved if they felt that HCPs were not taking sufficient account of their unique knowledge of their child and expertise in providing care during consultations (McPherson et al 2011; Graham et al 2009).

8.3.5.2 Parental response and coping

Parents were rarely openly adversarial in their approach. Similar to the findings of Geoghegan et al (2016b), the potential for conflicting relations was more likely amongst those families whose child experienced a prolonged admission and/or who had previously experienced admissions to the PICU environment, because of their child's antecedent condition(s). Parental desire to continue with aggressive and invasive life support therapies may be associated with the emotional, physical and psychological investment that have preceded the decision to consider EOL options. At the commencement of treatment, it is reasonable to assume that parents perceived that the prospect of survival and potential recovery through successful treatment was achievable. They then witness their child enduring and surviving, sometimes against the odds, the rigours of treatments and for some they experience this pattern during repeated admissions to PICU. These parents, and some HCPs, may well overestimate the body's capacity for recovery. Social and media portrayal of illness sets up an expected normative role for parents, which they may find difficult to deviate from. The use of military language, intensive therapies depicted as a battle, can present challenges. Battling implies a continuous active process and, although frequently used to evoke positivity, such rhetoric can place an unrealistic burden on the children and their families who may not be able 'to win the battle'. Acknowledging their child may not survive might imply that in some perverse way the family has failed to achieve something that is wholly beyond their control and over which they have no choice. The need to accommodate the time it takes for a family to agree to decisions to limit and/or withdraw treatment, was recognised and has been previously acknowledged in studies (deVos et al., 2015 & 2011; Verhagen et al., 2009). Gerstel et al (2008) describe a 'stuttering' withdrawal of care being associated with increased family satisfaction of end of life (EOL) care, whilst additionally acknowledging that the more protracted withdrawal of care in these circumstances benefits the surviving family members but may prolong the suffering of the child. The challenge for HCPs was managing the distinctiveness of each interaction. As a child’s condition became more desperate, parental interpretations and understanding of frequently, very complex information, was explicably skewed by their hope and desire for a positive outcome.

8.3.6 Professional sharing and openness

Throughout the study it emerged that parents possessed a tremendous amount of goodwill towards HCPs, who were perceived to be doing the best they could in almost impossible circumstances. Within these extraordinarily complex scenarios, parents start off being disposed to be trusting and open, but as things go on they may follow many different trajectories.

Autonomy within PICU pertained to parents being sufficiently informed, to be able to participate in decision-making. This study has shown a stark divide between ‘theory’ (guidelines) and ‘practice’ (real world). The difficulty for parents was that their participation in decision-making in these unimaginably difficult circumstances, however, can never be truly informed nor autonomous. Some parents were able to recognise that they had diminished cognitive ability to process complex and frequently ambiguous information. Parental understanding was observed to be temporarily impaired by the emotional impact of the situation in which they found themselves. Equally, others lacked insight into their own cognitive limitations and preconceptions. Such mutability was not unique to parents. Some HCPs also lacked awareness of their own biases and limitations. However, parents required input from trusted individuals to enable them to navigate a way through the decision making process (Botti et al. 2009; Cassell, 2007).

8.3.6.1 The fallacy of an equal partnership

From analysing the case studies, it was clear that parents, despite the rhetoric, were not automatically included as equals in the process to determine a child's interests. Parental agency was frequently compromised. Autonomy in these emotionally laden circumstances was inevitably shaped by how it was conceptualised and operationalised by HCPs (Botti et al., 2009; Orfali 2004). Decision-making during such intense circumstances necessitated parental reliance on others, specifically HCPs, to provide information, assist them to think, feel and find a way through. An almost limitless amount of information could be provided to parents. The difficulty for HCPs, when conceivably experiencing uncertainty themselves, was how to tailor to the demands and needs of the individual and provide the right amount of information.

Parents were acknowledged to require assistance to process and recall information (Shaw et al, 2016). Information sharing and informed decision making has complex moral implications with much written about parental, mainly maternal, emotional and psychological needs within the PICU setting (October et al, 2014); Madrigal et al 2012; Michelson et al 2006). Emerging from the study is the lack of preparation for parents to enable them to participate at a level of their choosing. Parents have to learn many implicit as well as explicit rules about how they conduct themselves (Alderson et al 2006), so as not to alienate themselves from HCPs. This occurs at a time when they are emotionally burdened and vulnerable. Several parents expressed dissatisfaction and frustration when they perceived information was being withheld from them.

8.3.6.2 Pre-configuration of information

Where families accept medical staff recommendations, decision making is relatively straightforward. However, when a family opposed medical staff recommendations and proposals for management it was far less clear-cut as to what should be done. At what point should a unilateral decision be made to provide, withhold or withdraw treatment if it may be against parental wishes? Implicit within decision making in the contexts of family centred care is an expectation that parents will be able to choose for their child and that parents will decide what is in the best interests of their child, even when their child is in a critical care setting. It is usually only when the parents is in conflict that this generally accepted moral and legal right is challenged. For parents, this situation is emotionally fraught. Not only may they not possess the same level of understanding as professionals of their child's condition and potential treatment options, but their values, beliefs and views may be radically different to clinicians. For parents, whilst attempts were made to involve them in decision-making, it is apparent that the stress and the upset of their situation may render them unable to assimilate information in a way that is both objectively and subjectively meaningful for them. Whether it is realistic to expect parents, to be able to fully comprehend and act upon medical advice must be questioned.

The misconception exists that a decision to act in a child's best interests decision occurs as a discrete event. Yet as seen throughout, decision-making was a process. It is the cumulative effect of many choices and judgements, which superficially may appear inconsequential. Singly and collectively, the case studies demonstrate the need for continuous renegotiation of parental engagement to determine boundaries for participation. The ideal to which participants aspire, but rarely achieve, was open and honest communication of what was known (October et al. 2014; Madrigal et al 2012; Power, 2012; Michelson et al 2009 & 2011.). Informed and autonomous decision-making implies that all options are shared and that HCPs would justify why they are proposing specific choices and ruled out others prior to an agreement being negotiated. Communication and information sharing with parents was nevertheless, observed to be mediated (Shaw et al 2016; Michelson et al 2011; Carnevale, 2012, 2011 & 2007). Parents were not provided with everything that was known about their child's clinical condition and care. As previously discussed, many parents acknowledged that they did not necessarily want to know everything. Rather, HCPs selected information that parents accessed via them, as if to say 'here is everything that we as HCPs think you need to know'. This prefiguration of information inevitability can be argued as having constrained parental autonomy. Equally, selective choice can be argued as reducing information overload and decisional paralysis and, in so doing, to facilitate participation (Botti & Iyengar, 2006; Botti and McGill, 2006).

The use of a selection process, through framing of options by HCPs during MDTs, manifests as to what choices are going to be offered to parents during the family meeting and underlines the significance of parental exclusion from most ward rounds. HCPs' action of portraying a team recommendation to foster a superficially collaborative approach parallels findings of previous studies discussing end of life care (deVos et al 2015; Michelson et al 2013; Curtis 2004). Inevitably, these discussions were dependent on professional judgement, discretion and subjective interpretation. Explicitly selecting a limited menu of treatment options, with some alternative treatments disregarded, has been widely reported within the literature across neonatal, paediatric and adult settings (Shaw et al, 2016; Harrison, 2008; Carnevale, 2007; Melia 2004 & 2001; Orfali 2004). Shielding parents from divergent opinions was stated by professionals to be primarily motivated by benevolent intent. Exposing emotionally encumbered parents to debate was deemed a cruel and unreasonable burden. Similar to Shaw et al (2016), HCPs did not wish to handicap parents with responsibility. HCPs, even though they recognised parent's entitlement to shared decision making, steadfastly believed that they held final accountability and responsibility for whatever decision was taken. This professional view, also expressed by some of the parents in the study, was that it is not reasonable nor appropriate to expect parents to make decisions in these complex situations which they were grappling with. The strategy of providing less information may genuinely be more beneficial in assisting some parents to participate since parents were seen to encounter cognitive limitations, including difficulties processing and retaining information generated by the situation and setting (Michelson et al., 2013). Yet this presentation of a unified approach during these more formal communications with parents is ethically problematical. For some parents, the presentation of a single unified evaluation as to how best to proceed whilst restricting their possible choices may well be a welcome release from the responsibility of choosing. For these parents it may be reassuring to feel that professionals have a united stance, whereas awareness of disagreement may be troubling. For others, imposition of this paternalistic approach, restricting access to full information, irrespective of benevolent intent, would be a dubious strategy, which may well bring about parental mistrust. Conflicts are assumed to have a negative impact, inhibiting effective relations, coping and trust both amongst professionals, and between parents and professionals. Yet across several cases within this study and similar to Shapiro et al's (2017) findings, parents were aware, and recognised the value, of professional debate. Some parents suggested that these disputes enabled them to become more informed and clarified their own positions. Others were, however stressed and upset by what they perceived to be contradictory information.

Many instances were witnessed where due to the imperative of rapid clinical decision making it would have been impracticable to delay this to allow parents to be fully involved. A fundamental part of professional practice within this environment is balancing of risks, anticipating outcomes and taking action with parents necessarily dependent on HCPs. There additionally appeared to be acceptance that the full consequence of a decision only emerges once taken and tolerance that HCPs may not always get the decision right.

Restricting the range and volume of information shared outside of crisis management is contentious. The standpoint of professionals was that parents should be involved in decision-making, but provision of information was selective and circumscribed. It was only as HCPs began to engage in discourse with parents that they were able to begin the process of trying to establish what information and in what detail parents wanted, together with assessing parental ability to process and assimilate. This inevitably rendered the process faltering and potentially disorganised. Considerable skill was required, and in the main evidenced by HCPs who continuously renegotiated boundaries of participation with parents.

Whilst the majority of parental views about treatment and care were respected, to involve parents in all clinical decisions was considered unrealistic. Decision-making is dynamic and preferences have to be contextualised, as circumstances are highly fact sensitive. The practical level at which parents and clinicians operate is grey. If HCPs are required to inform parents about everything, this would place a considerable burden upon already pressured resources and may result in the practice of defensive medicine.

8.3.6.3 Changing dynamics: internet and social media

HCPs understood their relationships with parents to be unpredictable and evolving. The information revolution, including the ever increasing role of the internet and social media as information sources and putative loss of public confidence in the authority of medicine has changed the dynamic of parental and HCP relationships (Plantin & Daneback, 2009). The majority of parents within the PICU setting did not solely rely on HCPs as their source of information. The accepted, and indeed the professionally encouraged norm as revealed in Edward, Carly and Amy's cases, was that parents would seek additional and corroborating sources of information. Inevitably, the balance of power then shifts some parents seemingly empowered to question and challenge the authority of a clinician's professional judgement. The challenge then becomes how to manage increasingly frequent situations when desperate parents, as realised in this study, seize upon any chance of hope (Pré & Brierley 2018).

8.3.6.4 Ensuring the child's interests remain at the forefront of care

Ensuring the child's interests were paramount was seen to be a constant challenge. Although, within the PICU setting, the preferred resolution is shared decision making, it brings to question as to how far the interests of the parents should be taken into account. To what extent should the wishes of parents, as occurred in Carly's case, to extend treatments against the professional judgement of a medical team prevail? Inappropriate care does prolong suffering and fails to achieve a good outcome for the child. As exemplified by Carly's case, there are intrinsic weaknesses in allowing parents to vet clinical decisions in situations where consensus is fragile or elusive, since it infers that they have an expertise and an ability to make such judgements to the same or higher level than the clinician. There is need for open debate as to what extent the wishes of parents to extend treatment against the wishes of the treating medical team should prevail. An emergent role for HCPs, witnessed during the course of the study, was that of an interpreter of parentally sourced information, assisting parents to fathom and appraise material. HCPs acquire knowledge through rigorous education, clinical experience and practice to make good enough decisions. Therefore, it would be unreasonable when encouraging parents to use all resources open to them not to then assist them to acquire balanced information.

While the law upholds that parents are unable to demand treatments not considered by the clinical team to be in the child's best interests, there remains a duty to assist parents to locate others who may do so. HCPs did encourage parents to seek second opinions though this was mostly in the context of channelling the search in the direction of colleagues they anticipated would support their own judgement. This driver, whilst seemingly supportive, is in practice difficult to implement especially when an impasse has been reached between parents and HCPs. There are no criteria for determining the efficacy of these therapies nor who is financially responsible for any treatment. Accommodation of parental wishes was particularly problematical when transitioning from maximal intervention to an end-of-life pathway. The globalisation of access to information is generating increasing dilemmas about managing parental expectations and understanding of rights (Linney et al, 2019: Brierley et al 2018). During the period of ethnographic observation, conflict involving the courts did not arise. However, when parental decisions may be considered outside the goals of good medicine, and may be incongruent with the interests of the child, as occurred in Carly's case, the question remains: is it morally and ethically acceptable to make decisions to meet the interests of the family in an attempt to be compassionate? There is a very real and urgent need for open, honest and transparent debate as to how to manage parental expectations. As highlighted in the recent legal cases involving Alfie Evans and Charlie Gard, parents are being placed in invidious positions when international health care facilities offer treatments that courts have stated are not in the best interests of the child.

This study underlines that no ‘one size fits all’ approach or guideline about the process of communicating and consulting between HCPs and parents can be championed. Recognition of potentially competing preferences (Section 7.2.5.4. p232) respects parents as being autonomous in a relational sense, but does not provide an answer as to how individualistic notions of autonomy in a practical sense can be taken into account by HCPs. A central feature in all cases was the extent to which conflict was contained and avoided when disagreements arose. Parents and professionals made considerable efforts when there was a disconnect between parental expectations and desire for continued treatments and what HCPs perceived to be the limits of their actions to avoid dispute. For parents engaging with the reality that their child may not survive may be unbearable. The dilemma explored by this study was that at a time when there was a need for transparency and openness in communications, HCPs became more defensive, selective and circumscribed in their interactions. Dissatisfaction and complaints about care arose when parents felt excluded from the process of decision-making. Equally, clinicians are very vulnerable to parental impulses when providing information that a parent does not wish to hear. Yet, there is a tacit expectation that they will be able to work through these. Generally, this seems to be accomplished with an agreed decision as to how best to proceed is brought into being.

8.4 Intra and inter-professional dynamics

It rapidly became evident that the care decisions for children in the PICU were constructed around the intra and inter-professional dynamics and management of these professional and organisational boundaries. This collective responsibility for the decision embodies the micro-politics of decision making in this semi-public arena. The handling and flow of information to determine acceptable parameters of care occurred as a multidimensional process. The need for constructive engagement to manage gaps of information and knowledge within and across teams emerged as a continuum of ever-changing alliances and repositioning of stances. In the majority of the situations studied, the generation of a collegial inter-professional decision was influenced by two key factors. The first pertains to the subjective and emotive dimension of collegial relationships. The second was the lack of objective data and validated medical evidence as to how to proceed. Connecting with previous studies, differences amongst professionals were seen to occur (Archambault Grenier 2018; Michelson et al, 2013; Meert, Thurston & Sarnik, 2000). Yet, emerging from this study was the significance these differences had on patient management and team working. This section acknowledges the multiplicity of dynamics which impinged upon professional relationships in the PICU including emotional impact of the decision making process factors, technical factors of treatment but is going to focus upon impact on collegial relationships. Focus will centre on power, hierarchy and interdependency amongst senior physicians; the need to create an impression of a democracy focusing on distributed decision making and interplays of influence; and how difference and conflict was contained.

8.4.1 Collegial relationships

The benefit of an integrated care approach was in terms of access to knowledge and expertise to inform decision-making, patient outcomes and support for these vulnerable families (Donovan, Aldrich, Gross et al 2018; Shapiro, Donohue, Kudchadkar, Hutton & Boss, 2017). Professional relationships across medical specialities were largely characterised by informality, mutual respect and professional courtesy (DeRoubaix, 2017). Nonetheless, in this very charged atmosphere, these collaborative interplays exposed divergent values and behaviours, together with different interpretations of how best to proceed. Achieving synthesis to try to ensure that the right decisions were made for each child at the right time was a problematic and uneven process, as shown in Amy, Edward and Fiona's cases. Synthesis was observed to rest on a fragile and pragmatic consensus of how intensivists and specialist consultants worked with and alongside each other.

With patient care so complex within PICU and increased specialisation across health care, no one individual or specialist team could meet all the complex needs of these children (Stocker, Pilgrim, Burmeister, et al., 2016). HCPs were unanimous in their understanding that doing the right thing equated to a consensus approach to decision making. Idealised as a collective and cooperative search for a best decision, albeit within the confines of professional hierarchies, individual professional perspectives were embraced, ideas generated, developed and agreed (Shapiro et al 2017). This reflects prevailing professional opinion whereby adoption of a consensus decision-making paradigm is promoted: the General Medical Council (GMC 2010) proposed that clinical teams should aim to reach a consensus prior to initiating any limitations to treatment. Yet, no definitive definition of consensus is provided within professional guidelines (GMC 2010; Larcher et al 2015). Furthermore as Shapiro et al (2017) report, there is a dearth of literature exploring the practicalities of consensus decision making. Consequently, the role and responsibilities of individuals and teams were ill defined and based on the erroneous assumption that two or more people can achieve a common understanding of what is best for the child. The data as revealed in all cases suggests however, that professionals were ostensibly committed to achieving a consensus.

8.4.1.1 Power and hierarchy

The configuration of those involved in decision-making was profoundly hierarchical, the traditional dominance of medicine was manifest. The authority and jurisdiction of HCPs means that doctors, specifically consultants, continued to be positioned at the top of the hierarchy in determining parameters of care as reported in previous studies

(Archambault-Grenier et al, 2018; Richards et al 2018; Shapiro et al, 2017; TenHave & Nap 2014; Power, 2012; Carnevale 2007). Medical dominance was employed through all facets of decision making, consultants leading informal and formal communications, deciding actions to be undertaken.

It is beyond the scope of this study to explore in depth inter-professional hierarchies, since consultants were the ones in possession of the power, beyond stating that corresponding to previous studies (Archambault-Grenier 2018; Carnevale 2007) the role of junior medical and nursing staff in decision-making was constrained. Junior medical staff expressed a reluctance to openly challenge decisions for fear of negatively impacting career progression and the enduring need for ‘good’ relationships. Nurses consistently recounted accounts of marginalisation. Replicating previous studies, they perceived their contributions during team discussions to be less influential (Carnevale et al 2012; Hoy et al 2007).

8.4.1.2 Professional engagement and boundaries

Although each child was admitted under the auspices of a named PICU consultant, a complex, fluid and heterogeneous professional and social network of medical specialists were seen to be intricately involved in these problematical cases (Paradis, Reeves, Leslie et al, 2014; Lingard, Espin, Evans et al 2004). This study has demonstrated that whilst medical staff continue to possess the power to make decisions the considered necessary involvement of doctors from different disciplines and expertise introduced dysfunction (Sorensen and Iedema, 2008). The ever-changing nature of large medical teams throughout a child’s admission is widely recognised within the paediatric and neonatal critical care literature (Shapiro, et al 2017; Wilkinson & Truog 2013; Randolph, Zollo, Egger et al 1999). No formal rules existed, as to how professional boundaries and roles would be managed across the involved and continually evolving extended team membership.

Tacit rules of engagement pertaining to individual jurisdiction and seniority, in the context of ever-changing team membership, resulted in tensions, inadequate communication, erroneous messages and a lack of agreement as to how to approach difficult decisions. As Stocker et al (2016) identified, there are no published studies exploring cultural differences amongst the PICU team, nor how these differences may affect decision management. Consultant intensivists were noted, in this study, to be very reluctant to challenge more senior physicians from within the children's hospital, possibly symbolic of a culturally and organisationally sanctioned configuration of roles. The high prevalence of locum intensivists (as detailed Section 5.2.1, p105) feasibly skewed the dynamics with increased subjugation, acquiescence and reduced negotiation observed. The lack of strong leadership by the intensivists also correlated to intensivists' personal leadership style, professional experience and on occasion status as locums. Stocker et al's (2016) review exploring inter-professional team management in paediatric critical care acknowledged that the role of the consultant intensivist is to facilitate multi-disciplinary collaboration. However, managing the heterogeneity of individual consultant values, beliefs and experiences was a complicated and frequently protracted process (Sorensen and Iedema 2008). Aligning to previous research, this study reveals that intensivist and specialist consultants did not agree about their responsibilities when approaching difficult decisions (Shapiro et al 2017). The problem then was, who leads care to avoid mixed messages and ensure care trajectory remained on course?

Traditionally, the consultant role has been associated with professional autonomy and independent authority (Stocker et al 2016) and these behaviours were observed on occasion to impede collaborative working. Each consultant held their own professional opinion as to treatment options and recommendation. Each also had their own sense of responsibility and 'ownership' for the child's care. When patients were transferred to the PICU, traditional disciplinary boundaries persisted, with clinicians ostensibly 'owning' some patients. Principally this occurred with patients with long standing chronic illnesses and conditions. These situations made specialist consultants more likely to communicate directly with parents and sometimes in direct conflict with the intensivists. The need to improve communication and share decisions through group discussions has previously been identified (Carnevale et al 2012). Existing research across PICU, acute paediatric oncology settings and end-of-life care emphasises the importance of designating a principal physician to promote continuity of care and improved psychosocial support for parents and families (Linney et al 2019; Johnston et al 2017; Nadeau et al 2016; Haggerty et al 2013; Abbot et al 2001).

The fluidity of the medical team and inconsistency in individual decision making has been demonstrated across these cases to increase divergence. Variable patterns of working and the rapidly rotating daily consultant intensivist cover impacted adversely upon parental and professional perceptions of the effectiveness of decision-making (Archambault-Grenier et al 2018). Simplistically, it may be proposed that altering consultant intensivists rotas, to work for a period of consecutive days could feasibly increase continuity of care for the majority of acute patients. However, there is a dearth of research about how shift patterns impact continuity of care, patient outcomes or the consequences for the intensivists. Non-consecutive working days, despite the concomitant reduction in continuity of care may benefit the child and family with ‘a fresh pair of eyes’, offering new insight for care management. However, for long stay patients, physician rotation resulted not only in sporadic involvement resulting in fragmented and extended decision-making, but also exposed parents to inconsistencies in individual physician standpoints which was observed to undermine trusting relationships (Michelson et al 2013; Studdert et al 2003b; Meert et al, 2000). Wilkinson & Truog’s (2013) analysis of physician variability during end-of-life (EOL) decision making, identified that this can result in a ‘roster lottery’ whereby decisions occur by chance depending on who is coordinating care. This was particularly problematical in children with pre-existing illnesses when a lead professional role was frequently indeterminate. This resulted in genuine misunderstandings and breakdown in communications with a tendency for conflicting information.

8.4.1.3 The false impression of democracy in decision-making

Intra-professional collaboration was revealed to be a complex sub-culture where boundaries were seen to be ill-defined and negotiable (Shapiro et al 2017). Management of the resultant intra-disciplinary heterogeneity resulted in consultants continually having to navigate and negotiate ways of working together (Stocker et al 2016), whilst simultaneously trying to promote the interests of the child. Variations were visible with regard to, and in respect of, degrees of collaboration and conflict. Decision-making did not occur in a vacuum but was entrenched within a cultural climate of professional socialisation, historical tensions and organisational leadership While intra and inter professional participation in decision-making was promoted, values, behaviours and cultures were revealed to be very different. Tensions resulted from perceived differences or incompatibilities especially when functioning beyond traditional scientific and evidence based approach.

8.4.1.4 Distributing the decision

Decisions were seldom taken unilaterally. As previously highlighted, a number of intra and inter-professional teams were involved in each child's care bringing substantial skills in assessment and risk management. Such a strategy is unsurprising, given these terribly difficult circumstances where clinicians were having to justify everything they were trying to do. In a sense, professionals were actively managing possible future scrutiny and openly expressed trepidations about the potential for legal action. Carnevale, Benedetti, Bonaldi et al (2011) likewise reported that physicians struggled with the weight and solitude of decisional responsibility, a consequence of uncertainty and fear of making an error. This use of a consensus approach can act as a protective mechanism for the individual clinician and feasibly also for the organisation. Distributing the decision across medical teams is a tactic, which enables risk to be underwritten through the adoption of what could be construed as being an insurance-based model. Achieving a kind of conferred consensus accordingly not only diffuses risk to the individual, but also blurs responsibility for the decision (Wilkinson, Troug & Savulescu 2016). Although not witnessed in this study, Shapiro et al (2017) postulate whether the desire for a consensus decision may also be associated with individual difficulty to make personal treatment recommendations. HCPs have been identified to experience lingering worries that they did the right thing when there is a lack of certainty as to how to progress care (Carnevale, Farrell, Cremer et al., 2012). By seeking other colleagues' opinions, should a case be subject to review or be contested and eventually come before the courts, then medical staff could state that they had sought the opinion of others who also reached the same decision. This struggle to achieve professional unanimity could correlate to a professional desire to transfer some of the decisional responsibility. Such action resonates with Birchley, Gooberman-Hill, Deans, Fraser and Huxtable's (2017) commentary that clinicians protect themselves from the risks associated with 'individualized' clinical decisions. As Long, Forsyth, Iedema & Carroll (2006) acknowledge, such clinical democracy, while reflecting organisational values, has particular implications for the negotiation and brokering of decisions.

Finding an incontrovertible 'best' decision, which could be uniformly accepted was, in practice, extremely difficult and nearly always unachievable. In line with Wilkinson, Truog and Savulescu (2016), consensus embraced a spectrum of levels of agreement: ranging from a simple majority decision, to near unanimity, to unanimity. Significantly, when contemplating decisions about persevering, withholding or withdrawing treatment, unanimity is acknowledged to be reasonably impracticable in all situations, the RCPCH guidance stating that "unanimity on the part of the health team is not essential" (2015:19). Nevertheless, the dominant ethos manifest across all cases was that professional unanimity was requisite prior to approaching parents. By seeking consensus decisions through the use of tacit agreement, as opposed to explicit use of voting, unanimity amongst HCPs was not necessary. Frequently witnessed was a partial unanimity whereby all actors agreed to let a decision to be made, following a process of deliberation and negotiation, despite not necessarily personally sharing it. During this process, decisions were understood to have been taken when there was an absence of expressed dissent during discussions and acceptance of proposals to confirm actions. In these circumstances, normative behaviours and etiquette imply a prior agreement and commitment to be bound by the agreement (Shapiro et al 2017).

8.4.2 Interplays of influence

8.4.2.1 The use of persuasion

The employment of persuasion amongst professionals was a key feature within the decision making process. Persuasion was used as a means of communicating reasoned arguments in justification for an action.

> "*persuasion is a form of influence when one person intends to produce a change in the behaviour or opinions of another using words to convey information, feelings or reasoning or a combination thereof while leaving enough freedom to choose otherwise*." . Dubov (2015:497)

Physicians were sophisticated and adept in their use of persuasive appeal. Although a legitimate strategy, it was inevitably combined with individual physician beliefs and views regarding the presentation of the best option. Persuasion within NICU and PICU settings has previously been reported, both in respect of professional to parent and between professionals (Verhagen et al 2009; Power 2012). The reality of the situation was incredibly complex since the use of persuasion, aimed at influencing the choice of a particular course of action, is endemic within the culture of HCP negotiations. Rather than necessarily being viewed as a fight for supremacy, this strategy was seen to be an ongoing process, to try and establish agreement for a preferred course of action. Debates were candid and ranged from being amiable to adversarial with disputes occurring mainly but not exclusively away from parents. These displays of competitive power were not unidirectional or static and highlighted the continually evolving order within PICU, communication being embedded in social practices, cultures and values (Dubov, 2015).

Within the MDT and as previously identified by Long et al (2006) physicians dominated MDT discussions. Effective decision making in PICU entails the presentation of and understanding of information including the presentation of reasoned arguments in defence of options (Dubov, 2015). Within this study, there was evidence that some consultants were able to exert greater influence in decisions made with power wielded in shrewd ways through use of a form of subtle coercion particularly during MDT meetings. Lutzen (1998:103), defines subtle coercion as '*an inter-dynamic involving one person or several exerting his or her will upon others*.' The use of clandestine professional influence, whether intentional or not, is contrary to an open approach with decisions determined more by how support for individual viewpoints was mobilised. Throughout the study, the difficulty of trying to assemble involved professionals to discuss and agree how best to proceed was problematical with organisational constraints restricting democracy in decision making. MDT meetings were often convened with very little notice, restricting attendance, with nurses and other professionals tending to be present less often. This was not always the consequence of a deliberate strategy but may reflect differential value afforded to medical time (Long et al 2006) and the practical exigencies of releasing nursing staff from nursing care activities (Street et al 2000).

The introduction of a best interests discourse was seen to be deployed by some consultants within MDT meetings as a mechanism to promote compliance amongst the team and exert control with a proposed course of action. The calculated and controlling use of reference to best interest legislation during debates invoked an element of fear, generating emotional responses and swaying attitudes about the choice made. The inference that there was a legally right or wrong decision, a desirable way to act. When invoked, the effect, as occurred in Edward's case, was to obfuscate discussion, sufficient to provoke professional unease (Dubov, 2015; Powers 2007). Corresponding to Verhagen et al (2009), this tactic was utilised when there was diagnostic and prognostic uncertainty. Junior medical and nursing staff perceived such action to actively discourage free and open expression of opinion. Such behaviour appeared counterintuitive, since a collaborative approach is necessary to enable the collation of information from all involved parties to enable effective and fully informed decisions to be made.

The use of persuasive tactics was not however limited to medical staff. Senior and experienced nursing staff were also observed to ‘coach’ parents as to what to ask within family meetings, inevitably shaping their preferences (Section 6.4.2.3. p174-5). Whilst this may have been a consequence of a genuine belief to act with benevolent intent and empower parents, nurses also recognised this as a means to exert influence over the decision-making process. The danger when using these persuasive strategies is that parents may be steered into accepting decisions which are inconsistent with their own values and beliefs, although this was not witnessed. Yet, this process of shaping parents agreement had an added consequence. Whether consciously or unconsciously, it was an effective way for nursing staff to avoid direct conflict and antagonistic encounters with medical staff enabling the preservation of good working relationships beyond the case.

8.4.2.2 Use of veto power

There was recognition that managing an agreement could be protracted, over many days or weeks and incremental. Yet, while there was expressed willingness to make concessions to reach a compromise witnessed, this did not avert the formation of competing factions with subsequent lack of harmony and dissonance across and within medical and nursing teams. Contrary to unanimity, whether partial or total, is the option of individual veto which was seen to be exercised when disagreement about how best to proceed arose. Whilst the diversity of interests and values may suggest that exercise of veto power may be commonplace, the strong consensus culture at an organisational level incentivised the securing of a compromise. Use of veto, is divisive and within the relatively small and close-knit medical community within the children's hospital employment was restricted in the main by social and norms.

8.4.3 How difference and conflict was contained

Achievement of a consensus decision amongst HCPs and specifically the medical staff were seen as a necessary pre-requisite prior to approaching parents to discuss how best to advance care. This replicates McHaffie et al's (2001) NICU study, Power's (2012) PICU, and Seymour's (2001) adult ICU findings of consultants conferring and achieving consensus as to when to withdraw treatments prior to supporting parents through the process. Analogous to Whitney (2003) and Wirtz et al (2006), a key focus for HCPs throughout was depicting an impression of unanimity. Yet, despite HCPs attempting to manage situations by determination of medical best interests prior to initiation of more formal discussions with parents, the façade of a unified approach was not always portrayed or cultivated as demonstrated in Amy's case

Throughout the study, divergence and tension was common and difficult to manage (Linney et al 2019; Richards et al 2017; Birchley et al 2017). Yet, inherent diversity does not automatically result in disagreement. The study also identified the immense team effort to try and avoid dispute by of attempting to contain difference, even if this was not always successful. HCPs acknowledged that conflict amongst professionals was damaging (Forbat and Barclay (2018); moral distress among team members as a consequence of conflict has been reported widely within the literature (Dzeng and Curtis 2018; Field Deeming and Smith, 2016; Embriaco, Papazian, Kentish-Barnes et al 2007). Dissonance across and within medical teams, nursing and allied health professionals was exposed in Amy, Carly, Edward and Fiona's cases. This mirrors findings from Archambault-Grenier et al (2018) who identified that conflict between paediatric HCPs was commonplace when making and managing end-of-life decisions in a children's hospital. In the present study, as revealed extensively in Amy and Edward's cases, disagreement over how and when to progress care combined with poor communication amongst specialist medical teams were the principal sources of conflict witnessed. This corresponds to DeVos et al (2015) Baines (2010) and Holm & Edgar's (2008) findings whereby the imprecise nature of treatment decisions was observed on numerous occasions to be a source of great tension. Comparable levels of conflict of between 25% - 58% of all cases about treatment decisions amongst HCPs are furthermore reported within adult and neonatal ICU settings (Arhcambualt-Grenier et al., 2018: Fazzier & Azoulay, 2010; Studdert et al 2003; Breen, Abernethey, Abbott et al. 2001). This is despite obvious differences in demographics and differing illness aetiologies. Specific research exploring the epidemiology and effects of constructive and destructive conflict on HCPs is required. Additionally, little is currently known about how HCPs reconcile obvious conflicts, how this shapes practice within the PICU and the extent to which conflict is burdensome or informing for parents.

8.4.3.1 Accommodating difference

The agonising decisions revealed across Amy, Carly, Edward and Fiona's cases, which involved the exercise of professional and moral judgement, were distinctive, taking into account the uniqueness and intricacies of each case. Considerable sensitivity and respect for individual professionals' need to exhaust all treatment options and combinations on a case-by-case basis was observed. Accommodation of professional viewpoints to secure unanimity was a protracted process slowing down the decision- making (Laurent, Bonnet, Capellier et al 2017). However, a significant problem for HCPs is the practical difficulty of what then constitutes a reasonable allocation of time to enable appropriate accommodation, compromise and agreement to be reached. Unsurprisingly, individual professionals' beliefs and understandings could either change more rapidly or trail behind the team. This can, as was witnessed in several of the cases (Amy, Edward and Fiona), result in a desire to progress care faster than was able to be managed or result in the adoption of strategies to delay decisions. For individual consultants and specialist teams, this resulted in a distancing and isolation, forced to either comply with the collective level, or as frequently occurred, adjust and delay decision making, until agreement was achieved. For parents, the consequence was confusion with erosion of trusting relations, While HCPs anticipated tensions due to their different viewpoints and stances, determination of what information could be shared with parents became a messy, non-linear and micro-political process. This study clearly reveals the need for the maintenance of good professional working relationships beyond the individual case. Physicians identified a need to respect colleagues' expertise to enable longer-term good will and cooperation as they will be required to seek assistance from speciality colleagues for future cases. This reflects McNeil, Mitchell and Parker's (2013) findings of inter-professional practice within healthcare, which identified that conflict occurring amongst teams not only reflects current circumstances but also the effects of historical tensions.

Precedence was given to the negotiation process between the specialist medical teams and the achievement of an agreed decision. This was despite the risk that suffering for both the child and family may be prolonged. The role and use of the strategy of protracted discussions with parents to secure agreement has previously been recognised in the literature (Birchley et al 2017; DeVos et 2015). However, the use of such by clinicians to resolve professional impasse has not previously been identified.

8.4.3.2 Timing of decisions

Two distinctive time sequences which influenced the modification of professional cultures and behaviours emerged from this study. Concurring with results from previous research (Shapiro et al, 2017; Marcus, Henderson & Boss 2016), differing decision-making practices were distinguished when urgent decisions were required compared to non-urgent situations, when decision-making could span days or even weeks.

When time was of the essence and urgent clinical decisions were requisite, there was tacit acknowledgement amongst the team that decisions made by the consultant intensivist present at the time of the crisis would not be openly challenged or censured. As reported by Shapiro, Donohue, Kudchadkar et al (2017), professional etiquette was to uphold a decision, unless a safety issue was apparent. HCPs displayed commendable sensitivity, appreciating the practical dilemma of having to make decisions under conditions of uncertainty, time pressures and concomitant limitations on negotiating with other experts in these extremely stressful situations. Yet, physicians frequently have to assume responsibility and manage the consequences of inherited decisions, which they may not necessarily be in accord with, as has previously been identified within the literature (Archambault-Grenier et al, 2018; Shapiro et al 2017; Power 2012). The difficulty, then, is that there was a reliance on all actors being in accord about their professional responsibilities to employ this approach and not advance personal recommendations or agendas.

When decision-making was non-urgent, increased time was afforded following stabilisation and ‘new normalisation’ of the child’s condition and greater divergence in decision-making amongst HCPs was evident. This may well link with a desire for increased certainty as to how to proceed. The concomitant decrease in urgency meant that additional tests and interventions, together with results from trials of treatments could be more reflexively considered. Wilkinson and Truog (2013) question whether physician variability is necessarily bad, suggesting that it enables review of the evidence and debate about the right course of action. Uniformity of opinion would generate increased parental and public concern about physician integrity and trustworthiness. The changing epidemiology of PICU patients with increasing numbers of patients admitted having underlying, chronic complex illnesses and medical complexity (Rennick and Childerhouse, 2016) challenged HCPs’ culture and organisation of care delivery. PICUs traditionally focus on acute care curative models (Graham, Pemstein, Curley 2009; Geoghegan et al 2016b). Where multiple paediatric specialities are involved in a child’s care and there is a need for decision making about complex issues, including end-of-life decision making, intra-team conflict and between HCPs and parents was more likely to be prevalent (Odeniyi, Nathanson, Schall & Walter 2017; Forbat, et al 2015; Studdert et al 2003b).

8.4.5 Professionals managing uncertainty

Healthcare professionals have a legal and ethical duty to continually consider what is best for each child (Children Act 1989). Accordingly, determination of best interests from a medical perspective occurred as an intricate recursive process throughout the duration of all cases. Evaluation of treatment options were based on each child's unique circumstances and individual clinical needs. In theory, effective decision-making encompassed what was known about the issue, what evidence existed to support a treatment pathway, following a traditional hypothetico-deductive model. Yet, notwithstanding the current emphasis on best practice, the reality within the critical care setting is that HCPs were frequently confronted by diagnostic and prognostic uncertainty. Medical uncertainty within the cases studied frequently rendered application of the principles of evidence-based medicine impossible. Decision-making in this context could not be reduced and simplified to deliberation of physiological and empirical data. Treatment decisions evolved in response to a continuous cycle of administering aggressive interventions, evaluating effectiveness and further tweaking to counteract any adverse effects. This infers a linear and orderly process whereas decisions were seen to be interdependent, incorporating multiple feedback loops, data from monitoring and investigations and communication across the multiple team members. The relationship between cause and effect was incredibly complicated and frequently could not be distinguished.

8.4.5.1 Trials of treatment

The possibility of a single 'best' and objective determination in these exquisitely difficult cases was seen to be implausible and misrepresentative. Decisions taken and actions instigated in a child's 'best interests' were recognised as leading to a range of potential outcomes. The ambiguous nature of this concept is widely acknowledged

(Carnevale, 2013; Baines 2008 & 2010, Brazier, 2005; Studdert, et al; 2003a; Kopelmann, 1997 & 2010). Yet, it is unfeasible in the clinical situation not to provide an answer as to how to proceed. In these circumstances, when working at the limits of medical knowledge and ethical uncertainty, the corollary was that diagnostic tests and therapeutic interventions were used in the absence of knowing what was effective. Use of such an approach attempted to provide a temporal and conceptual boundary, since it enabled a disputed treatment to be tried, even though some may have expressed concern that it was medically inappropriate.

All the way through the study, the difficulties of determining whether a treatment is efficacious or in the best interest of the child was epitomised by decisions to initiate therapies on a tentative basis. This mechanism, a trial of treatment, typifies the quandary of amassing the evidence to support the introduction of an intervention. It further highlights the value judgements made by HCPs determining whether an intervention is perceived as beneficial or not. The challenge, then, was how best to manage these clinical decisions where outcome is uncertain. Decisions were not made with good or bad intentions in mind, but by necessity became highly contextual practical experiments. Accordingly, it was not feasible to judge how well or badly the notion of acting in a child's interests was being played out. This resulted in on-going tensions between individual clinicians and team professional judgements with decision-making seen to be both active and constrained. Active in the sense that team agreement was normally secured for a course of action. Yet, constrained in that the action may not reflect the intra and inter-disciplinary heterogeneity. Although efforts were made to pursue and stage a reasonable or justifiable course of action, throughout the study the lack of certainty in diagnosis and resultant difficulty in prognostication meant that this was not a straightforward process (Gill, 2005). The effect was that it was much harder for parents to engage effectively in decision-making (Meert et al 2008). Such a strategy additionally risks overlooking the wider notion of how a trial of treatment may impact upon a child's future and wider quality of life. Within the high technological environs of PICU, there is a very real danger of focussing upon objective measures, since it is easy to lose sight of the child and what recovery may entail. Throughout, it was evident that HCPs were more comfortable, decisions less demanding and relatively straightforward when there was certainty in diagnosis. As Fortune (2006) similarly identified, it is not hard to see why individuals struggled. Findings emphasise the inconsistency and unpredictability of what is deemed reasonable. Differences across speciality medical teams revealed a complex interplay as to how chance and prognosis impacted on decisions taken.

External to critical care settings, medical disciplines tend to function in semi-isolated silos generating distinct interpretations and culture, with sharing of practices limited. Similar to Konstantara et al's (2016) and Baggs et al's (2007) adult ICU studies, physicians' approaches to initiating difficult decision making were varied. Paediatric intensivists were observed to be more likely, explicitly or implicitly, to consider a move towards withholding or withdrawing care in advance of other medical specialists. Neurologists and oncologists, in all observed cases, were more likely to try to exhaust all treatment options prior to deliberating the goals of sustaining treatment. This may result in part from differences in professional subcultures. Furthermore, it could be explained by intensivists' increased presence on the unit. Their greater familiarity with the child's current clinical condition involved greater exposure to the challenges of life sustaining therapies. Predictably, the range of reasonable professional interpretations as to what was in a child's best interests exposed the diversity of individual consultants' values, beliefs and experiences and inexactness of paediatric critical care medicine. This plurality of outlooks, as Carnevale (2007) proposed, could be considered to increase convergence as to a course of action but more commonly coexisted problematically and other times in conflict.

8.4.5.2 Satisfying the desire to do everything possible: experimental treatments

Whilst hope for a miraculous cure is recognised as a relatively common theme amongst parents (Gill, 2005), it was also seen to materialise in some HCPs. Desire to continue with aggressive, on occasion high risk and experimental therapies typified the quandary of whether it is possible to determine if any treatment with a possibility of success could or should be excluded. This included treatments where the risks versus the benefits made the prospect of recovery unlikely and could even precipitate death. Whilst HCPs suggested that they were acting with benevolent intent, the value judgments made by staff in determining whether an intervention was perceived as beneficial or not revealed variance in assessment and differential valuing of risk. Moreover, such action may result in a child benefiting, given access to finite physical, staff and financial resources during the attempt to sustain their life to the detriment of others who may credibly possess a more realistic prospect of recovery (Birchley, 2015; Fortune 2006).

The desire to initiate experimental therapies may well be a manifestation of a physician's reluctance to accept the failure of modern medicine, together with an assumption that parents will want to carry on. Initiation of ground breaking treatments may also relate to the intellectual challenge, anecdotal comments suggested a professional curiosity to push the bounds of science. Decisions taken may on occasion generate unanticipated and astonishing results (Fortune, 2006). Physicians are acknowledged to gain respect and repute for extraordinary successes and rare diagnoses (Hall 2005). Conversely they are extremely vulnerable, their professional reputation at stake, should their decision be contested. Complex personal (and parental) agendas may preclude objective consideration as to the harms and benefits of experimental treatment (Fortune, 2006). The risk, as revealed in the findings (Section 6.3.2.2. p150), is the arbitrariness of physician judgement and exercise of authority, when ostensibly the democratic process of decision-making was abandoned, contrary to the political etiquette to work as a team.

Such action raises concerns about the limits of individual professional judgement in these exceptional cases, together with ethical, moral and common good concerns. Problematically experimental therapies may have been used as a strategy to manage parents, providing them comfort in the knowledge that everything that can be done has been done and concurrently assuage HCP self-reproach. Analogous to Caplan (2007), parents were perceived to view experimental therapies with excessive optimism. Nursing staff especially expressed doubts, about parental capacity to give meaningful consent in these situations. This mirrors Harrison's (2008) concerns that parents are susceptible to manipulation. It additionally draws attention to the polarised opinions and potential for variation as to how parental requests to access experimental with equally uncertain outcomes may be managed (Birchley 2018; Dare 2009; Erickson, 2010). Emerging from this study and reflecting the findings of Birchley (2018), when therapies with a low probability of success are being explored, there is a need for professionals to adopt a circumspect approach.

8.4.5.2 The pursuit of further knowledge and expertise

Commonly in these difficult cases, when treatment options were diminishing and there was recognition that poor outcome was to be anticipated intensivists and other consultants were witnessed opening out to their external professional contacts, in pursuit of knowledge and understanding as to how best to address a specific issue. This occurred through the extensive use of formal means, including second opinions and informal professional and social networks. The consultant is, as Kincheloe (2001) identifies, distinctively positioned because of their intimate understanding of the child's circumstances and knowledge of the professional political, sensitivities and politics, to innovate in these highly complex situations. These networks varied tremendously in composition, from individual specialists in the subject field, to virtual expert panels, to long-standing peer support systems.

This quest for knowledge was mainly discussed with parents, with consent usually sought to involve others. Some parents found considerable solace that HCPs were going to considerable lengths to access opinions from other experts. The use of such networks could reflect the globalisation of medicine and be an effective use of limited resources in these uncommon situations. It could also relate to the burdens felt by individual clinicians, the expectations and demands they place on themselves and may relate to feelings of inadequacy in addition to defending their actions. Quality of information may be variable, and is likely to be subject to nuanced interpretations. It can also be postulated that, within these professional networks and virtual groups, individual consultants identify and position with like-minded individuals, reducing heterogeneity of ideas and enhancing consistency of approach and outlooks. Nevertheless, accessing a variety of opinions can and did result on occasion in greater confusion as to the possible options for treatment. Resultant delays may not be in the best interest of the child, potentially prolonging unnecessary suffering.

8.5 The multiple and discontinuous enigmatic qualities of best interests

8.5.1 The illusion of best interests

In conventional discourse, there is an assumption that best interests are, in a way, obvious and compelling. The impact of fluctuating clinical conditions exposed in this study show the disconnect between the representation of best interests and the reality. Decisions were made based on what was known at that moment, with best interests and best decisions frequently observed to be intangible and temporal, too transient, in terms of time and too complex in terms of the uniqueness and forces at work in each case, to isolate. The revealed difficulty was then how to divine which amongst a range of options was best? This study has provided fresh insight that the more complex the situation is, then the further removed is the likelihood of making a clear-cut determination.

Although HCPs were trying to pursue best interests, despite holding different interpretations and assessments, it must be questioned as to how best interests can be persuadably promoted because nobody really knows if they are doing the right thing. Evaluation of treatment options was based on each child's unique circumstances and clinical needs. Decision-making, in this context, could not be reduced and simplified to deliberation of physiological and empirical data. Consequently, best interest determinations functioned by being reinvented as the unknowable but potentially discoverable, enabling HCPs to produce a level of agreement as to how to proceed. This finding aligns with Baines' (2010) standpoint that objective agreement as to what is best may not be possible, since there are no balances or frameworks which can be applied in all circumstances. As Huxtable (2013) postulates this inherent flexibility in interpreting best interests is a both a strength and a vulnerability. It allows the notion of best interests to still have a function in terms of guiding HCPs' actions and structuring behaviours. It enables intra and interdisciplinary interactions, since people can apply it in many different ways and contexts. However, the vulnerability is that it offers little practical guidance and is open to manipulation. Whilst in an abstract sense there is a best interest, within the PICU setting it was seen to be an ideal that is frequently, in these exceptional cases, unknowable, but upheld as potentially discoverable. Identification that the notion of best interests is illusory is not exceptional (Huxtable 2013; Baines 2008 & 2010; Herring 2005). However, the cases within this study illuminate the difficulties of disentangling these diverse professional and parental views and efforts to achieve a shared understanding of the child's best interests.

Best interests is an elusive striven for goal. Theoretically it exists, but practically it has been seen to be unobtainable. Consequently, the notion of best interests is useful as a tool: it has a function in terms of guiding action, structuring behaviour and enabling the intra and inter disciplinary interactions that HCPs have with each other and with parents. Yet, the flexibility of how it can be applied means that it can be used in many different ways and contexts, each case being singularly unique.

8.5.2 Blurring the boundaries: balancing the child’s best interests with parental and family-focused interests.

Navigation of the decision-making process within this study illuminated the difficulties encountered by HCPs when balancing the duty to prioritise the child’s welfare whilst also recognising the intertwined interests of the parents. Medical decision-making within the PICU encompassed appreciation of the need to explore the consequences of actions for parental and family interests. Recognition that clinicians are sympathetic to the interests of the family is evidenced within the literature (Birchley & Huxtable 2016; Blustein 2012; Gillam & Sullivan 2011; McDougall & Notini, 2013). This study, however, revealed that a specific transition point, when physicians altered the balance, occurred when it became apparent that a child’s death was inevitable. Focus shifted, albeit for relatively brief periods, to ensure the needs, wishes and interests of the family were upheld as paramount, even when it could be contended that this was to the detriment of the child’s interests their suffering extended. Prioritising parental interests was undertaken predominantly with benevolent intent, HCPs believing that the risk to bereaved parents’ mental health and well-being should be avoided (Archimbault-Grenier et al 2018). Parents having an element of choice as to timing and place of death has been demonstrated to be significant in both parental perceptions of experience, morbidity and mortality (Gillam & Sullivan, 2011; Meyer, Ritholz, Burns et al, 2006; Woical, 2000).

Timing of decisions is a balancing of actions. Despite the natural instinct always being to act to keep a child alive, for some children prolonging life by technological means may not be right, with death inevitable. Parents and some HCPs acknowledge this was found to be a complex and conflicted process, balancing duties and responsibilities to the child and their family was frequently difficult to achieve. Timing was observed to be particularly problematical for parents of children who had experienced prolonged admissions to PICU and those who had underlying chronic illnesses. Death in these cases occurred as a result of a stuttering withdrawal of care. Parents possessed a more positive view of their child's prognosis, and appeared to have lost perspective about just how sick their child's condition was (deVos et al 2011; Verhagen et al 2009). Parents in the current study were not being intentionally testing. They were existing in a living nightmare and trying to do their best for their son/daughter. The quandary of determining another individual's quality of life combined with the difficulty of attuning values, beliefs and understanding with parents was appreciated by HCPs. Carnevale et al (2007) similarly found that differing opinions of what makes a life worthwhile contributed to conflict between parents and HCPs. The principal stratagem used to resolve these differences was, as also reported in paediatric and neonatal literature, to allow parents more time, enabling them to witness the physical deterioration in their child's condition (De Vos et al, 2015; Verhagen et al 2009 and Meert, Briller, Schim et al 2009). Simultaneously, communications and discussions between HCPs and parents were intensified, including offering referral for further expert opinions to avert conflict escalating. An unintentional corollary of these actions was that HCPs' moral distress was sometimes also alleviated. Novel insight emerged from this study that temporalisation and prioritisation of parental needs and interests was adopted as an approach to potentially minimise and counterbalance future complaints about care received (section 7.2.5.4 page 234). Whilst possibly not overtly commonplace, the introduction of such a tactic is concerning and may well risk prolonging suffering and increase moral distress amongst HCPs.

8.5.3 Collective best interests

Conspicuous throughout the study was the complete lack of reference to resource management. The strategic focus on the child's interests seen within these cases suggests that the child is privileged, their interests portrayed as inviolable. Yet, there was also recognition that competing interests were involved. These were specifically discussed in terms of the interests of the individual child versus the interests of children (society) generally (Wilkinson 2016; Baily, 2011); allocation of available PIC beds; and determining what treatments may be reasonably offered.

In the recent legally contested cases of Charlie Gard and Alfie Evans, their parents argued that futility had been used as an excuse to ration treatment. Their parents perceived benefits from proposed treatments, which would extend their child's life, and found international physicians to support them. However, the value placed on life extension must be balanced with the risk of harm and suffering to the child, the economic burdens of treatment and the challenge of accommodating minority viewpoints. Resource management does not mean that there should not be choice about treatments, rather that there is not unlimited choice to the detriment of others (Wilkinson, 2017). The dichotomy of advocating for the individual child and children generally is an area, which requires future public and political consideration. Resource limitation is ethically complex and morally controversial and beyond the scope of this thesis. However, there is a need for debate to explore how the boundaries of finite resources should be managed when providing treatments where there is a low chance of benefit and also in respect of the longer term costs of on-going care provision should the child survive (Larcher, Turnham & Brierley 2018; Wilkinson, 2017).

8.5.4 The legal enigma: the elephant in the room

There was recognition that each case, for differing reasons, had the potential to transcend everyday medical decision-making and move into a more legal and potentially public arena. Disagreement leading to argument between HCPs and parents about treatment did occur in one of the cases. The extent to which parental wishes to extend or limit treatment against the professional judgement of a medical team should be accommodated remains indeterminate and contentious. Even though no cases were referred for judicial deliberation throughout the duration of the study, it was apparent that all HCPs, especially medical staff, acknowledged the relevance of the law. The possibility of legal intervention was never far from thoughts and commonly voiced during ethnographic observations (Section 7.2.6. p237-9). Professional interpretations of the role of the law were multiple, inexact and sometimes misplaced. While it was evident to the researcher that interpretation of the law was generally vague, its use particularly during MDT discussions left some members of the team very uneasy. Legal knowledge is accepted to be generally poor amongst HCPs. White et al (2014) examined doctors' level of knowledge of the law on withholding and withdrawing life-sustaining treatment in Australia and found significant gaps in knowledge. While some caution is required in application of these findings may due to differences in legislation, they however do reflect anecdotal and observational findings. HCPs expressed considerable trepidation about legal intervention, although, mirroring the findings of Birchley et al (2017), only a very few had direct experience. Birchley et al discovered that professional concerns centre on the acrimonious and taxing nature of any dispute requiring legal intervention, with suspicion additionally expressed about conceivable challenge to professional judgement, integrity and conduct. Ostensibly, and perhaps erroneously, medical staff perceive an adversarial relation between law and medicine when determining a child’s best interests. Yet, legal precedent would suggest that this is not the case. Although medical action and expertise is subject to examination and challenge when best interest determinations come before the courts, prevailing professional practices are rarely contested. It is undeniable that usually the court will normally defer to medical opinion, medical evidence dominating the decision-making process as indicated within *Portsmouth NHS Trust v Wyatt [2005] EWCA Civ. 1181; [2005] 1 W.L.R. 3995 and Re L (A Child) (Medical Treatment: Benefit) [2004] EWHC 2713 (Fam); [2005] 1 F.L.R. 491* and more recently *Great Ormond Street Hospital v Constance Yates, Christopher Gard and Charles Gard [2017] EWCA Civ. 410; [2017] EWHC 972 (Fam)*. Unless medical staff have been clearly negligent, when the law would intervene, the law does not function in a punitive manner. The predicament observed for parents, located in the frightening world of PICU, is that they find themselves attempting to adjust to a very abnormal situation at a time of great personal vulnerability. From being wholly responsible for their child’s welfare, they are plunged into a situation whereby they are dependent upon the PICU team (Gillis and Rennick 2006). Some parents were cognisant that, contrary to the ethical principle of parents' possessing autonomy, deference would normally be given to medical opinion if challenged via the courts as revealed by Emma (Section 7.6.2 page 239). On the surface, the law-medicine alliance makes it incredibly difficult for parents to contest decisions based upon medical judgement. Should such an event occur, in all likelihood parental preference of the child's interests would be overridden. HCPs were sensitive to the potential profound effects disagreements about care decisions can have and the vulnerability of the situation for all concerned. This may well explain the considerable lengths undertaken to achieve unanimity in care decisions both amongst medical staff and with parents.

8.5.5 Resolving differing opinions

This study identifies, in common with prior studies, that the critical care environment is prone to differences of opinion (Fassier & Azoulay, 2010; Azoulay et al 2009;Studdert et al, 2003a). Determining the course of action, which would best serve a child's medical needs was rarely straightforward. Yet, whilst disagreement is prevalent within the decision-making milieu of PICU, management of difference in this context is an under explored phenomenon.

This study makes an important contribution since distinctively and corresponding with the employment of a two-stage approach to decision making, a staged approach to resolving differing opinions has been evidenced. This predated, but in the main played out, some of the key proposals contained within the recently published RCPCH guidance on conflict recognition and management for those involved with WLSMT in paediatrics (Linney, Hain, Wilkinson et al., 2019). Formal intervention, arbitration, although not employed in these cases was anecdotally reported to be employed for disputes amongst professionals. Senior 'neutral' consultants, employed within the children's hospital, were described as leading negotiations amongst HCPs. Simply, their stated role is to help the involved teams to understand their differing perspectives and provide support and practical advice to enable a consensus decision to be generated. Yet, whilst this process may enable some exploration of the causes of the dispute, this process of negotiation comes asunder in both practice and principle. The lack of separation of powers, specifically the independence of the facilitator, who was employed and influential within the organisation, was problematical, rendering the process unbalanced and inhibiting truly open discussions. Furthermore, although a consensus agreement was reached formally, the decision implemented may not have the support of one or more of the HCPs involved.

The RCPCH have recently undertaken a six month test of a conflict management framework, originally developed in Australia, across four UK trial sites (Forbat and Barclay, 2019). This structured framework has proved effective in reducing the incidence of conflict in these sites, by 64% over a 6 month period. The framework focuses on de-escalation and early intervention. This reflects that the primary reported cause of conflicts in complex cases was a breakdown in communication (Linney et al 2019; Forbat, 2016; Larcher et al 2015; Studdert et al 2003). The Nuffield Council on Bioethics (2019) has emphasised the importance of training on ethics, communication, and conflict management for paediatric HCPs. They suggest that training should be widely available or even compulsory. Previous work focused on resolving disputes between HCPs and parents has also acknowledged the use of mediation as a tool to avert escalation of conflict and to generate a mutually agreed approach (Larcher et al, 2015; Meller & Barclay 2011; Brazier 2010; Nuffield Council on Bioethics, 2006). Externally facilitated mediation and referral to clinical ethics committee was not observed to occur throughout the duration of study. Agreement was eventually reached in all cases. However, analogous to Birchley et al (2016), professionals were seen to go to considerable lengths to attempt to prevent escalation of conflicts. As detailed within the findings (Section 6.4.1.2. p158), and exemplified by Amy, Carly and Edward’s cases, this included the provision of additional time and investigations, including the use of second opinions and external experts to consider the issues to resolve divergence amongst professionals, and/or between professionals and parents, mirroring previous research findings (deVos 2015).

Mediation can support and assist all parties to attain a better understanding of each other’s position, when attempting to resolve difference in these ethically complex cases (Larcher et al 2015). Significantly, in *Great Ormond Street Hospital v Yates [2017] EWHC 1909 (Fam)* Francis J suggested

> *that mediation should be attempted in all cases, such as this one even if all it does is achieve a greater understanding by the parties of each other’s positions.* (Paragraph 20)

Conspicuously, within this study, professionals tried hard to make use of strategies to avoid the need for mediation. However, as indicated above mediation does not always provide a definitive answer as to what is best for the child. Huxtable (2018) identifies that mediation may, in some cases, effectively manage conflict by enhancing understanding and trust amongst participants and by potentially avoiding legal costs. However, it may still be insufficient to effectively address the intricate ethical nuances in these challenging circumstances (Huxtable, 2018). Specialist ethical advice, a clinical ethics committee (CEC), was available at the study site to provide support and advice to HCPs and parents. Although a relatively recent development, Hajibabaee et al (2016) state that one of the functions of CECs is to provide a forum for discussion, analysis and advice for individual referred cases (Larcher et al, 2015; UKCEN 2018). Further work is required to understand parents’ perspectives of the use of CECs. This needs to be undertaken together with a full economic evaluation of their benefit in terms of cost savings including time spent managing conflicts, legal fees and other expenses such as HCP sickness and absence.

8.6 Chapter summary

Findings illuminate the complexity and shifting nature of negotiations, which underpin the production of decisions about best interests affecting critically ill children. The production of a single best option, which parents and medical staff will agree upon, was seen in the main to be illusory. Whilst acknowledging that best interests do theoretically exist, in the PICU studied there were, only very rarely, circumstances where there were singular decisions, with unanimity about what is best for the child. Within the exquisitely complex cases illustrated, determining a child’s best interests was seen to be inherently abstract and subjective, with broad and varied understandings.

Chapter 9:

9. Conclusion

9.1 Conclusion

To conclude, this study has explored how the construct of best interests is understood when making difficult decisions to persevere with, withhold and/or withdraw life sustaining medical treatment in children within the context of a single PICU. There is a paucity of existing research investigating the relational and temporal nature of difficult decision-making in the PICU and what does exist is retrospective. This study is compelling and evocative, the cases advancing novel and rich insight into what has been a largely hidden process through exploration of the immediacy of the decision-making process by undertaking a multi-perspectival inquiry using ethnographic approaches. In the real world setting of the PICU studied, the dynamics of best interests and autonomy were shown to be applied in distinctive ways in different contexts as a form of pragmatic framing to justify the decisions made.

The construction and manipulation of best interests from a medical perspective occurred as an intricate recursive process. Best interests were revealed to be initially negotiated across complicated intra-professional dynamics in advance of discussions with parents. The complex and hierarchical nature of professional interactions, underpinned by diagnostic and prognostic uncertainty have been shown to be used as control mechanisms amongst involved HCPs and parents. Evaluation of treatment options were based on assessment of each child's unique circumstances and individual clinical needs. Treatment decisions reflected the difficulty of the environment. Rather than following a linear and orderly process, decisions were interdependent, some rapid, others involving longer processes of deliberation and uncertainty. All decisions incorporated multiple feedback loops, data from monitoring and investigations and communication across the multiple team members. Harnessing knowledge, clarifying acceptable medical options and choosing a preferred course of action across the complex and fluid team of involved HCPs was extraordinarily difficult to achieve. Findings have revealed that best interests as a PICU decision-making tool adds little to the pre-existing repertoire of medical diagnosis and prognosis, and ethical considerations regarding sanctity and quality of life. Instead, it simply offers a different discursive frame for the same substantive quandaries and decisions of whether to continue to treat or not.

While inter and intra professional practice was endorsed, disciplinary values, behaviours and cultures were revealed to be very different. Significantly, the study has demonstrated the importance and general efficacy of mechanisms to contain conflict, to enable decisions and actions to be implemented between HCPs and between HCPs and parents. Tensions between professional teams resulted from perceived differences or incompatibilities especially when functioning beyond a traditional scientific and evidence based approach. Achieving synthesis to try to ensure that the best decisions were made for each child, at the right time, was a problematic and uneven process. Co-production rested on a fragile and pragmatic consensus of how intensivists and specialist consultants worked with and alongside each other. Intricate manoeuvrings amongst HCPs, principally managed by consultants, were observed to engineer professional consensus as to how to proceed. Partly, this arose to manage the indeterminacy of situations occurring and in part circumspection was exercised to avoid dispute within the team to enable professional relations to be maintained beyond the individual case. However, the drawback of working for a consensus decision was slowness of decisions and treatments that could have an adverse impact on the child. Best interests therefore served as a mechanism to transcend the sensitivities of professional etiquette and furthermore allowed consultants to distance themselves from occupying sole responsibility for a decision.

A complex and, on occasion, conflicted interplay between HCPs and parents has been demonstrated. HCPs endeavoured to work with parents and involve them in decision-making, but this effort was revealed to be shrouded in ambivalence. HCPs anticipated that parents would want to carry on treatments, that parents may adopt a demanding stance and demonstrated wariness as to what parents may request. This exposed an interesting dichotomy as HCPs also expected and encouraged parents to search for information and second opinions. A largely collaborative process was promoted. HCPs exercised exceptional sensitivity in reaching out to parents, trying to support them within the context of a clinical situation where HCPs held privileged professional knowledge. Even though HCPs attempted to manage parental involvement, guiding parents to work towards implementing the decisions that professionals thought best, parents recognised the moral work that HCPs undertook. Comprehension of the parental role has almost been idealised within society, that it is the parent's job to ensure that everything that can be done for their child has been done. This made it incredibly difficult for parents to give themselves permission that they could give everything up and accept that their child would not survive. HCPs perceived a moral duty on these occasions, which parents found so difficult, to help them out by taking responsibility for the decision to withhold or withdraw treatments. Even within an ethos of shared decision-making, not all parents wanted to exercise this choice, to take on the responsibility to decide what is best for their child. The multidimensional nature of shared decision-making, the complex interplay of motives and interests, which enable the containment of disagreement and maintenance of relationships, has been revealed. It is not a simple opposition between parents and HCPs.

While the construct of best interests of the child was ever-present when making decisions, discursive shifts were observed. The pivotal nature of the transition point from active intervention to end of life care demonstrated. The psychological needs of parents, and to a much lesser extent HCPs, took precedence at this juncture, with the importance of a 'good death' justifying the use of compassionate and non-beneficial treatments, even though this may prolong suffering. Legal formulation of the best interest standard does not take into account the complexity of looking at the child as part of a family, that their interests are intricately intertwined with those of others. Yet, the challenge in practice was how to acknowledge and balance the best interests of the child whilst also considering parental and family interests. The inviolable nature of the child's interests are demonstrably inappropriate when trying to arrive at a satisfactory compromise around conflicting interests. Best interests cannot be considered in the context of individual autonomy, decision-making determined to be a relational endeavour. The potentially damaging consequences of considering anyone's interests as paramount and to the exclusion of others must be questioned. The challenge then is how to arrive at a satisfactory compromise around the frequently conflicting interests of the child and the family.

Best interests was uncovered to be a very pragmatic working concept, which was temporally balanced according to peoples opinions, dynamics and circumstances to find a way forward. The potential for dispute, with differing understandings, varying values and beliefs was considerable. Remarkably though, this system of decision-making, which functions under extraordinary strain and circumstances, was seen to work comparatively effectively. All determinations, across these cases, were made without any recourse to legal system. This study has shown that HCPs and parents manage, most of the time, to contain and avoid conflict even though the process for this may not always work to the child's advantage.

Each case was intrinsically a tragic situation, especially for the parents. The decisional process observed to be fragile, volatile and pressured, but actors did not avoid conflict or unhappiness. Decisions may often be open to alternative judgement, especially in retrospect: the point, surely, is that actors do not have the benefit of hindsight. This study has highlighted the opaqueness of best interests and that need for HCPs to approach every single case with an open mind. There is no panacea when making these heart-rending decisions.

9.1 Strengths and limitations

As far as I am aware, this is the first study to use an ethnographic research design to explore how these exquisitely difficult decisions about whether to continue to treat or not are made. Ethnographic approaches enabled exploration within this very complex and constantly shifting clinical environment of the intricate and highly situational specific facets of decision-making. As Orton, Halliday, Collins et al (2017) reported, this has allowed me to be adaptive and responsive, within the pre-agreed boundaries of the study. Interviews or documentary analysis alone would not have allowed a meaningful understanding or provided insights into the multiplicity of perspectives. The research process, using multiple data sources and prolonged observation of the unit, allowed nuanced and deep contextual understanding of how best interest decisions were constructed as they occurred and from the perspective of the different actors involved. Furthermore, utilisation of embedded case studies supported in-depth sensitive scrutiny of the diversity and complexity of these individual cases together with understanding of the commonalities across cases (Stake, 1995).

A strength and limitation of the study is that fieldwork was only undertaken in a single site. Findings are entrenched within the cultural and organisational context in which this study was undertaken. However, being situated as a qualitative researcher, the imperative was to gain in depth qualitative insight into a difficult to access area and generation of rich knowledge to enable complete contextual understanding of this sensitive issue (Hardin and Clark, 2012; Hammersley and Atkinson 2007). Findings may not be directly transferable across every PICU setting but there is no reason not to believe that these findings will not be valuable and applicable as exemplars of wider practice in comparable contexts.

Due to the difficulties in predicting and capturing opportunities within this patient population, there were methodological challenges to ensure representativeness. Recruitment bias is a limiting factor as parents who were not invited to participate, or who chose not to participate, or who were withdrawn from the study, may have provided differing insights. This is particularly significant since the study has identified a reluctance on the part of some parents to participate in communication and decision-making. The study also found that the experiences of all parents in the PICU setting are individual and distinctive with social, cultural, spiritual, emotional and psychological issues shaping the context of their experience and participation. Exclusion of non-English speaking participants, due to resource constraints to undertake translation[17], may also limit understanding of other pertinent factors. Although the recruited cases did reflect the ethnicity of the local population, transferability of findings may not be feasible or can only be tentatively applied to unrepresented populations.

Considerable attention was placed upon ensuring the trustworthiness and rigour of the findings through researcher reflexivity and methodological rigour as detailed throughout the thesis. To ensure theoretical insights emerged from the data, computerised technologies were used to assist in the analysis, particularly of patterns emerging from this large dataset. Additionally, the continued refinement of computer-assisted technology including coding and retrieval functions together with inductive linguistic computations may in the future further assist management of large datasets (Abramson, Joslyn, Rendle et al., 2018).

A major limitation is that the voice of the child was unheard and in the main absent from the decision-making process due to the life threatening nature of their illness. Thus, their role in deciding what is best for them was not able to be explored. There is a pressing need for further research into the child’s perception with the changing epidemiology of PICU patients with increasing numbers of patients admitted having underlying, chronic complex illnesses and medical complexity (Rennick and Childerhouse, 2016) and opportunities for future planning (Popejoy et al, 2017).

---

[17] As stipulated by ethics committee

9.2 Recommendations for future empirical work

This study has provided rich and nuanced insight into how difficult decisions were constructed and enacted. It contributes to the body of knowledge that health and social care HCPs, lawyers and policy makers require when engaging in providing support and developing guidance for those involved in these intricate and tragic situations. However, it has generated many areas which would benefit from further empirical study.

This thesis offers a powerful tool for HCPs reading it, by extending their insight into what and how they are doing things and parents' behaviour, which may subsequently inform and may perhaps change their practice to be more skilled at managing decisions in future. This research has compellingly demonstrated that how decisions are made comes down to personalities and very specific situational dynamics. From a professional perspective, this research has highlighted and further endorses the necessity for HCPs to engage in active critical reflection at both individual and organisational levels to promote awareness of the complexities of decision-making, emotional and moral intricacies. HCPs need to ensure they approach every single case they are involved in with an open mind and not make assumptions about what parents (or the child) may want or anticipate how they may respond in these tragic circumstances. A number of HCPs across professional groups commented on the benefit of participation in the study (section 4.5.4 p101). Their description of participation as cathartic, providing a safe environment and opportunity to explore difficult and distressing events and comment on service related issues affiliates to clinical supervision. There is acknowledgment that some HCPs may struggle to recognise their needs or acknowledge the impact this may have on decision-making processes (Miller-Smith et al 2019; Larcher et al, 2015). Further exploration of why some individuals choose to access support and why others do not is required. At an organisational level, consideration needs to be given, as part of clinical governance strategies, as to whether, when any difficult decision about whether to persevere with, withhold or withdraw treatment are made, this process should be subject to a formal review. Such a process may assist in ensuring transparency but might also provoke, rather than enable containment of conflict. It would also contribute to continuing learning about how best to manage these difficult and complex cases. However, the challenge and practicality of capturing parental feedback is not under-estimated and also warrants future consideration.

Parental ability to cope with distressing information and their ability to participate in decision-making warrants additional in-depth research. This should be centred on the practicalities of how to identify parents within the PICU who may require additional assistance to enable them to adapt, if desired, to the demands of participation. Focus will be needed on ways of facilitating participation during informal and formal communications and decision-making processes, including ward-rounds, family conferences and mediation in the PICU. Reasons why parents choose not to participate in decision-making is under-researched. Further exploration of diverse parental attributes including, but not limited to, ethnicity, gender, educational level, occupation and how these may influence relations with HCPs, how viewpoints are negotiated and consensus achieved is recommended.

Although not the focus of this study, the influence of the globalisation of access to information, including social media, and how this influences relationships and the management of parental and professional expectations is a relatively under-researched area. Two distinct strands warranting investigation have emerged. Firstly, how parents and HCPs utilise web technologies and social interaction platforms as information tools to assist decision-making. It is important to review how parents, who have in the main grown up and consider the internet an integral part of their daily lives, access medical information. This should include how and what information parents access, how they appraise the value of and use the information to assist in decision-making, and how they are supported (or not) to do so by HCPs. Similarly, from an HCP perspective, we need to know more about how HCPs use IT applications to support decision-making. This should include the use of conferencing applications (audio/videoconference, web based or not), and collaborative working systems such as file sharing applications for the improvement of clinical decision-making. Secondly, in the wake of the Evans and Gard cases, how social media is mobilised and utilised by parents. Further research should seek to understand whether any changes or strategies could, or should, be pursued to prevent conflicts arising/promote conflict resolution and limit HCPs being compromised in undertaking their roles is a further topic for investigation.

HCPs in the present study did not give prominence to resource constraints and allocation. Further guidance from professional bodies and politicians on how to approach and manage the changing epidemiology of PICU patients is warranted to avoid future damaging conflicts. Debate and transparency about how finite resources should be managed and on what basis they should be denied is necessary and becoming increasingly pressing.

9.3 Concluding remarks

Overall, the study subjects the constructs of best interests and best decisions to critical scrutiny, contributing to the body of knowledge surrounding parental participation in best interest decisions. This study exposed the difficult reality and complexity of the interplay between parents and HCPs. Best interest emerges as an elastic construct used by clinicians and families who are struggling to do their best to validate and justify decisional processes according to diverse and shifting standpoints. It was used as a mechanism to validate and justify the reasoning process according to diverse and mutable perspectives.

References

Addington-Hall, J.M., Bruera, E., Higginson, I. and Payne, S.A. (eds) (2005) *Research Methods in Palliative Care*. Oxford: Oxford University Press.

Advanced Life Support Group (2011) *Advanced Paediatric Life Support: The practical approach*. Oxford. BMJ Publishing (Wiley-Blackwell).

Alderson P., Hawthorne H. & Killen M. (2006) Parents' experiences of sharing neonatal information and decisions: consent, cost and risk. *Social Science & Medicine* 62, 1319– 1329.

Alvesson, M. and Skoldberg, K. (2000) *Reflexive Methodology: New vistas for qualitative research*. London. SAGE Publications.

Ames, KE., Rennick, JE. & Baillargeon (2011) A qualitative interpretive study exploring parents' perception of the parental role in the paediatric intensive care unit. *Intensive and Critical Care Nursing*. 27: 143-150

Angrosino, MV. (2005). Recontextualizing Observation: Ethnography, Pedagogy, and the Prospects for a Progressive Political Agenda. In N. K. Denzin & Y. S. Lincoln (Eds.), *The Sage handbook of qualitative research* (pp. 729-745). Thousand Oaks, CA, : Sage Publications Ltd.

Anspach, RR. (1993) *Deciding who lives: Fateful choices in the intensive care nursery*. Oxford. University of California Press Ltd.

Appleton, JV. & King, L. (2002) Journeying from the philosophical contemplation of constructivism to the methodological pragmatics of health services research. *Journal of Advanced Nursing*. 40(6): 641-648

Archambault-Grenier, MA., Roy-Gagnon, HL., Gauvin, F., Doucet, H., Humbert, N. et al (2018) Survey Highlights the need for specific interventions to reduce frequent conflicts between health care professionals providing paediatric end-of-life care. *Acta Paediatrica*:107: 262-269.

Aspesberro, F., Mangione-Smith, R. & Zimmerman, J.J. (2015) Health-related quality of life following pediatric critical illness. *Intensive Care Medicine*. 41(7) 1235 -1246.

Atkinson, S., Bihari, D., Smithies, M., Daly, K., Mason, R. & McColl, I. (1994) Identification of futility in intensive care. *The Lancet*. 344 (8391): 1203-6

Aull-Davies, C. (2012) *Reflexive ethnography: A guide to researching selves and others.* London. Routledge.

Aull-Davies (2008) *Reflexive Ethnography*. 2nd Edition. London. Routledge.

Austin, W., Kelecevic, J., Goble, E. & Mekechuk, J. (2009) An overview of moral distress and the paediatric intensive care team. *Nursing Ethics.* 16(1):58-68.

Avis, M. (2003) Do We Need Methodological Theory To Do Qualitative Research? *Qualitative Health Research*. Vol. 13 No 7: 995-1004.

Azoulay, E., Timsit, J-F., Sprung, C.L., Soares, M., Rusinová, K., Lafabrie, A., Abizanda, R., Svantesson, M., Rubulotta, F,. Ricou, B., & Benoit, D. (2009) Prevalence and Factors of Intensive Care Unit Conflicts; The Conflicus Study. *American Journal of Respiratory and Critical Care Medicine*:180 (9): 853-860 https://doi.org/10.1164/rccm.200810-1614OC accessed 03/06/2019

Baez, B. (2002) Confidentiality in qualitative research: reflections on secrets, power and agency. *Qualitative Research*. 2(1):35-58

Baggs, JG., Norton, SA., Schmitt, MH., Dombeck, MT., Sellers, CR. & Quinn, JR. Intensive care unit cultures and end-of-life decision making. *Journal of Critical Care*. 22:159–168

Baggs, J. G. Schmitt, M. H., Mushlin, A. I., Mitchell, P. H., Eldredge, D. H., Oakes, D. & Hutson, A.D. (1999). The association between nurse-physician collaboration and patient outcomes in three intensive care units. *Critical Care Medicine,* 27(9): 1991-1998.

Bagheri, A. (2008) Regulating Medical Futility: Neither excessive patient's autonomy nor physician's paternalism. *European Journal of Health Law*. 15:45-53

Baines, P. (2010) Death and best interests: a response to the legal challenge. *Clinical Ethics*. 5(4): 195-200

Baines, P. (2008) Death and best interests. *Clinical Ethics*. 3(4): 171-175

Bailey, S. (2004) The concept of futility in health care decision making. *Nursing Ethics*. 11(1):77-83

Baily, M.A. (2011) Futility, autonomy and cost in end of life care. *Journal of Law, Medicine and Ethics*. Summer 2011: 172-183.

Bate, L., Hutchinson, A., Underhill, J. & Maskrey, N. (2012) How clinical decisions are made. *British Journal of Clinical Pharmacology*. 74(4) 614-620.

Baxter, P. & Jack, S. (2008) Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*. 13(4): 544-559

Bazeley, P. (2013). *Qualitative Data Analysis: Practical Strategies*. London. Sage.

Bazeley, P. & Jackson, K. (2013). *Qualitative data analysis with NVivo London*. Sage.

Beauchamp, TL. & Childress, JF. (2013) *Principles of Biomedical Ethics*. 7th edn. Oxford: Oxford University Press.

Beresford, B. & Sloper, T. (2008) *Understanding the Dynamics of Decision-Making and Choice: A Scoping Study of Key Psychological Theories to Inform: The Design and Analysis of the Panel Study*. Social Policy Research Unit, University of York.

Birchley, G. (2018) Charlie Gard and the weight of parental rights to seek experimental treatment. *Journal of Medical Ethics*. 44:448-52

Birchley, G. (2016a) Harm is all you need? Best interests and shared decision-making in paediatric intensive care. *Health Care Analysis*. 22:203-22

Birchley, G. (2016b) The harm threshold and parents' obligation to benefit their children. *Journal of Medical Ethics*. 42: 123-126.

Birchley, G (2014) Deciding Together? Best interests and shared decision-making in paediatric intensive care. *Health Care Analysis*. 22(3):203-222

Birchley, G. (2010) What limits, if any, should be placed on a parents' right to consent and/or refuse to consent to medical treatment for their child? *Nursing Philosophy*. 11:280-285

Birchley, G. & Huxtable R. (2016) Critical decisions for critically ill infants: Principles, processes, problems in Stanton, C., Devaney, S., Farrell, AM. & Mullock, A. (Eds) (2016) *Pioneering healthcare law: Essays in honour of Margaret Brazier*. London. Routledge.

Birchley, G., Gooberman-Hill, R., Deans, Z., et al (2017) 'Best interests' in paediatric intensive care: an empirical ethics study. *Archives of Diseases in Childhood*. 102:930-935.

Blaikie, N. (2007) *Approaches to social enquiry: Advancing knowledge*. Cambridge. Polity Press.

Blustein J. (2012) Doing the best for one's child: satisficing versus optimizing parentalism. *Theoretical Medical Bioethics* 33:199–205.

Boeije, H. (2010). Doing qualitative analysis. In H. Boeije (Ed.), *Analysis in qualitative research* (pp. 93–121). Thousand Oaks: SAGE.

Bonner, A. & Tolhurst, G. (2002) Insider outsider perspectives of participant observation. *Nurse Researcher*. 9(4): 7-22.

Boss, R.D., Donohue, P.K., Larson, S.M., Arnold, R.M., and Roter, D.L. (2016) Family conferences in the neonatal ICU: Observation of communication dynamics and contributions. *Paediatric Critical Care Medicine*. 17(3): 223-230

Bosslet, GT., Pope, TM., Rubenfeld, GD., Lo, B., Truog, RD., Rushton, CH., Curtis, R., Ford, DW., Osborne, M., Miskak, C. & Au, DH. (2015) An official ATS /AACN /ACCP /ESICM /SCCM policy statement: Responding to requests for potentially inappropriate treatments in intensive care units. *American Journal of Respiratory Critical Care Medicine* 191: 1318–30 doi/full/10.1164/rccm.201505-0924ST#readcube-epdf (last accessed 26/06/2019)

Botti, S., Orfali, K. & Iyengor, S.S. (2009) Tragic choices: Autonomy and emotional responses to medical decision making. *Journal of Consumer Research.* 36 (13): 337-352.

Botti, S. & Iyengar, SS. (2006) The dark side of choice: When choice impairs social welfare. *American Marketing Association*. 25(1):24-38

Botti, S. & McGill, AL. (2006) When Choosing Is Not Deciding: The Effect of Perceived Responsibility on Satisfaction. *Journal of Consumer Research* 33(2):211-219

Brannick, T. & Colgan, D. (2007) In Defense of Being “Native”: The Case for Insider. *Academic Research Organisational Research Methods*. 10(1):59-74

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*. 3(2):77–101

Brazier, M. (2005) An Intractable Dispute: When Parents and Professionals Disagree. *Medical Law Review*13:412–418.

Brazier, M. (2003) *Medicine, patients and the law*. 3rd Edition. London. Penguin Books.

Breen, CM., Abernethy, AP., Abbott, KH. & Tulsky, JA. (2001) *Journal of General Internal Medicine*. 16(5): 283-9.

Brewer, JD. (2000) *Ethnography.* Buckingham. Open University Press.

British Transplant Society (2016) *Guidelines relating to solid organ transplants from non-heart beating donors.* London. British Transplant Society

Bryman, A. (2008) *Social Research Methods*. 3rd Edition. Oxford. Oxford University Press.

Bryman, A. and E. Bell (2004). *Business Research Methods*. Oxford University Press, Oxford.

Burns, JP. & Mitchell, C. (2011) Ethical Criteria for allocation of scarce resources in Diekema, DS., Mercurio, MR & Adam, MB. *Clinical Ethics in paediatrics: a case based textbook.* Cambridge. Cambridge University Press.

Burns, J. P., Sellers, D E., Meyer, E.C., Lewis-Newby, M., Troug, R.D. (2014) Epidemiology of Death in the Pediatric Intensive Care Unit at Five U.S. Teaching Hospitals. *Critical Care Medicine*. 42(9): 2101–2108

Butler, A. Copnell, B. Willetts, G (2014) Family-centred care in the paediatric intensive care unit: an integrative review of the literature. *Journal of Clinical Nursing*. 23:2086-2100

Butler, A., Hall, H. & Copnell, B. (2018) The changing nature of relationships between parents and healthcare providers when a child dies in the paediatric intensive care unit. *Journal of Advanced Nursing*. 74(1): 89-99

Butterworth, C. (2005) On-going consent to care for older people in care homes. *Nursing Standard*. 19(20):40-45.

Caplan A. (2007) Is it sound public policy to let the terminally ill access experimental medical innovations? *American Journal of Bioethics*. 7(6):1–3.

Carnevale, F. A., Farrell C., Cremer R., Seguret S, Canoui P, Leclerc F Lacroix, J & Hubert, P (2016) Communication in pediatric critical care: A proposal for an evidence-informed framework. *Journal of Child Health Care*. 20(1):27–36.

Carnevale, F.A., Farrell, C., Cremer, R., Canoui, P., Seguret, S., Guaderault, J., Brune de Berail, Lacroix, J., Leclerc, F. & Hubert, P. (2012) Struggling to do what is right for the child: Pediatric life support decisions among physicians and nurses in France & Quebec. *Journal of Child Health.* 16(2): 109-123.

Carnevale, F.A., Benedetti, M., Bonaldi, A., Bravi, E., Gaetano, T. & Biban, P. (2011) Understanding the private worlds of physicians, nurses and parents: A study of life sustaining treatment decisions in Italian paediatric critical care. *Journal of Child Health*. 15(4):334-349.

Carnevale FA, Canoui P, Cremer R, et al. (2007) Parental involvement in treatment decisions regarding their critically ill child: a comparative study of France and Quebec. *Pediatric Critical Care Medicine* 8(4):337–342.

Carnevale, FA., Canoui, P., Hubert P., Farrell, C., Leclerc, F., Doussau, A., Seguin, MJ. & Lacroix, J. (2006) The moral experience of parents regarding life-support decisions for their critically ill children: a preliminary study in France. *Journal of Child Health Care* 10(1):69–82.

Carnevale, FA. (2005) Ethical care of the critically ill child: a conception of a 'thick' bioethics. *Nursing Ethics*, 12, 239-52.

Carter, P. (2006) Straddling boundaries: Identity, culture and school. *Sociology of Education*. 79(4):304-28

Cassell, EJ. (2007) Unanswered Questions: Bioethics and Human Relationships. *The Hastings Centre Report* 3(5): 20-23

Charmaz, K. (2005) Grounded Theory in the 21st Century: Applications for Advancing Social Justice Studies. In Norman K. Denzin and Yvonna E. Lincoln (eds.), *Handbook of Qualitative Research* 3rd ed. (pp. 507-535). Thousand Oaks, CA: Sage

Charmaz, K. (2003) “Grounded theory”. In *Qualitative psychology: A practical guide to research methods*. Smith, JA. (Editor) 50–57. London: Sage.

Chen, S. & Chaiken, S. (1999) The Heuristic-Systematic Model in Its Broader Context. in: Chaiken, S. & Trope, Y. (eds.) *Dual-process Theories in Social Psychology*. New York: Guilford Press.

Chen YY, Li CM, Liang JC, Tsai CC (2018) Health Information Obtained From the Internet and Changes in Medical Decision Making: Questionnaire Development and Cross-Sectional Survey. *Journal Medical Internet Research*: 20(2):e47 doi: 10.2196/jmir.9370 (last accessed 24/08/2019).

Chen YY, Chen L, Kao YH, et al: (2014) The over-optimistic portrayal of life supporting treatments in newspapers and on the Internet: A cross sectional study using extra-corporeal membrane oxygenation as an example. *BMC Med Ethics* 15:59 doi.org/10.1186/1472-6939-15-59. (last accessed 24/08/2019).

Children Act, 1989 (c.41) [online] Available from http:// www.legislation.gov.uk/ukpga/1989/41/contents (last accessed 24/08/2019)

Chin, J.J. (2002) Doctor-patient relationship: from medical paternalism to enhanced autonomy. *Singapore Medical Journal*. 43(3): 152-155.

Chwang, E. (2009) Futility Clarified. Law Medicine and Ethics. 37(3):487-495.

Clarke-Pounder, JP., Boss, RD., Roter, DL., Hutton, N., Larson, S. & Donohue, PK. (2015) Communication intervention in the neonatal intensive care unit: can it backfire? *Journal of Palliative Medicine*. 18(2):157-61

Colville, G. & Pierce, C. (2012) Patterns of post-traumatic stress symptoms in families after paediatric intensive care. *Intensive Care Medicine*. 38(9): 1523-1531.

Colville, G. Darkins, J. Hesketh, J. Bennett, V. Aalcock, J & Noyes J. (2009) The impact on parents of a child’s admission to intensive care: Integration of qualitative findings from a cross-sectional study. *Intensive and Critical Care Nursing*. 25(2): 72-78

Corbin, J. & Morse, J. (2003) The unstructured interactive interview: issues of reciprocity and risks when dealing with sensitive topics. *Qualitative Inquiry*. 9(3): 335-354.

Cormack D (2000) *The research process in nursing*. 4th Ed. Oxford. Blackwell Science.

Coggan, J (2008) Best interests, public interest, and the power of the medical profession. *Health Care Analysis.* 16:219-232.

Coombs, M. & Ersser, SJ. (2004) Medical hegemony in decision-making: a barrier to interdisciplinary working in intensive care? *Journal of Advanced Nursing*. 46(3):242-252

Corden, A. & Sainsbury, R. (2006) Corden, A. and Sainsbury, R. (2006) *Using Verbatim Quotations in Publications Reporting Findings from Qualitative Social Research: A study of recent texts.* York. Social Policy Research Unit, University of York.

Coulter, A. & Collins, A. (2011) *Making Shared Decision Making a Reality. No decision about me, without me*. London. The Kings Fund.

Council of Europe (1997) *Convention for the Protection of Human Rights and Dignity of the HumanBeing with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine*. European Treaty Series No. 164

Creswell, J.W. (2009) *Research Design: Qualitative, Quantitative and Mixed Methods Approaches*. 3rd Edition. London. SAGE Publications Ltd.

Creswell, J.W. (2007) *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. 2nd Edition. London. SAGE Publishing Ltd.

Crotty, M. (2009) *The foundations of Social Research: Meaning and perspective in the research process*. 2nd Edition. London. SAGE Publications Ltd.

Cudmore, H. & Sondermeyer, J. (2007) Through the looking glass: being a critical ethnographic researcher in a familiar nursing context. *Nurse Researcher*. 14(3): 25-34.

Dare, T. (2009) Parental rights and medical decisions. *Pediatric Anesthesia.* 19(10):947-952

Data Protection Act 1998 (c.29) HMSO, London.

Davis, P., Stutchfield, C., Evans, TA. & Draper, E. (2018) Increasing admissions to paediatric intensive care units in England and Wales: more than just rising a birth rate. *Archive Diseases in Childhood*. 103:341–345

Delamont, S. (2004) Ethnography and Participant Observation In: Seale, C., Gobo, G., Gubrium, J & Silverman, D (2005) *Qualitative Research Practice*. London. SAGE Publications Ltd.

DeLemos, D., Chen, M., Rommer, A., Brydon, K., Kastner, K., Benjamin, A. & Hoehn, SK. (2010) Building trust through communication in the intensive care unit. *Pediatric Critical Care Medicine*. 11(3): 378-384

Dent, M. (2006) Disciplining the medical profession? Implications of patient choice for medical dominance. *Health Sociology Review*. 15: 458-468.

Denzin, K. & Lincoln, YS. (2011) *The SAGE handbook of qualitative research*. London. Sage Publications.

Department of Health (2010). *Equity & excellence: Liberating the NHS*. London: HMSO.

Department of Health (2005). *Research governance framework for health and social care*. London: DoH.

Department of Health (2003) *Getting the right start: The National Service Framework for Children, Young People and Maternity Services – Standard for Hospital Services.* London. Department of Health.

Department of Health (2002) *High Dependency Care for Children – Report of an expert advisory group for Department of Health 2001*. London. Department of Health.

Department of Health (1998) *A First Class Service: Quality in the New NHS.* London. Department of Health.

de Roubaix, M. (2017) Dare we rethink informed consent? South African *Journal of Bioethics and Law*. 10(1):25-28

de Vos MA, Seeber AA, Gevers SK, Bos AP, Gevers F, Willems DL. (2015) Parents who wish no further treatment for their child. *Journal of Medical Ethics*. 41(2):195–200

de Vos, M.A., Bos, A.P., Plotz, F.B., van Heerde, M., de Graaff, B.M., Tates, K., Truog, R.D., and Willems, D.L. (2015) Talking with parents about end-of-life decisions for their children. *Pediatrics*.135: 465-76

de Vos, MA., van der Heide, A., Maurice-Stam, H., Brouwer, OF., Plötz, FB., Schouten-van Meeteren, AY., Willems, DL., Heymans, HS. & Bos, AP. (2011) The process of end-of-life decision-making in pediatrics: a national survey in the Netherlands. *Pediatrics*. 127(4):e1004-12.

Devictor, D.J. & Nguyen, D.T. (2004) Forgoing life sustaining medical treatments in children: A comparison between Northern and Southern European paediatric intensive care units. *Pediatric Critical Care Medicine*. 5(3): 211-5.

Dewing, J. (2007) Participatory research: A method for process consent with persons who have dementia. *Dementia.* 6(1): 11-25.

Diekema, DS. (2011) Revisiting the best interest standard: uses and misuses. *The Journal of Clinical Ethics*. 22(2):128-133

Dietz, A.S., Pronovost, P.J., Mendez-Tellez, P.A., Wyskiel, R., Marsteller, J.A., Thompson, D.A., and Rosen,M.A. (2014) A systemic review of teamwork in the intensive care unit: What do we know about teamwork, team tasks, and improvement strategies? *Journal of Critical Care*. 29: 908-914.

Dilthey, W. (2003). The development of hermeneutics (1900). In: Delanty, G. and Strydom, P. (eds.) *Philosophies of social science: The classic and contemporary readings*. Maidenhead: Open University Press. pp. 99-101.

Donovan, AL., Aldrich, M., Gross, AK., Barchas, D., Thornton, K., Schell-Chapple, H., Gropper, M., Lipshultz, A., (2018) Interprofessional Care and Teamwork in the ICU. *Critical Care Medicine*. 46(6): 980-990

Doyal, L. & Larcher, V.F. (2000) Drafting guidelines for the withholding or withdrawing of life sustaining treatment in critically ill children and neonates. *Archive of Diseases in Childhood, Fetal and Neonatal Edition*. 83:F60-F63.

Dresser, R. (2003) Standards for family decisions: Replacing best interests with harm prevention. *The American Journal of Bioethics*. 3(2):54-55

Dubov, A. (2015) Ethical persuasion: the rhetoric of communication in critical care. *Journal of Evaluation in Clinical Practice*. 21: 496-502.

Dwyer, SC. & Buckle, JL. (2009) The Space Between: On Being an Insider-Outsider in Qualitative Research. International Journal of *Qualitative Research*. 8(1): 54-63

Dyregrov, K (2004) Bereaved parents’ experience of research participation. *Social Science & Medicine*. 58 (2): 391-400

Dzeng, E. & Curtis, R. (2018) Understanding ethical climate, moral distress, and burnout: a novel tool and a conceptual framework. British Medical Journal. *Quality & Safety*. 27:766–770 27(10)

Earle, RJ., Rennick, J., Carnevale, F. & Davis, GM. (2006) ‘It's okay, it helps me to breathe’: the experience of home ventilation from a child's perspective. *Journal of Child Health Care*. 10(4):270-282

East, L., Jackson, D., O’Brien, L. & Peters, K. (2010) Storytelling: an approach that can help in developing resilience. *Nurse Researcher*. 17(3) 17-25.

Ebrahim, S., Singh, S. & Parshuram, CS. (2013) Parental satisfaction, involvement, and presence after pediatric intensive care unit admission. *Journal of Critical Care.* 28(1): 40-45

Eccles, MP., Grimshaw, JM., Shekelle, P., Schunemann, HJ. & Woolf, S. (2012) Developing clinical practice guidelines: target audiences, identifying topics for guidelines, guideline group composition and functioning and conflicts of interest. *BMC Implentation Science*. 7.60 doi 10.1186/1748-5908-7-60 (last accessed 29/06/2019)

Edwards, J.D., Houtrow, A.J., Vasilevskis, E.E., Rehm, R.S., Markovitz, B.P., Graham, R.J Adams Dudley, R (2012) Chronic conditions among children admitted to U.S. PICUs: their prevalence and impact on risk for mortality and prolonged length of stay. *Critical Care Medicine*. 40(7): 2196–2203. doi: 10.1097/CCM.0b013e31824e68cf (last accessed 29/06/2019)

Edwards, M., Davies, M. & Edwards, A. (2009) What are the external influences in information exchange and shared decision making in healthcare consultations; a meta-synthesis of the literature. *Patient Education and counselling.* 75:37-52.

Ellis, P. (2010) *Understanding research for nursing students*. Exeter. Learning Matters Ltd.

Elliston, S (2007) *The best interests of the child*. London. Routledge.

Embriaco, N., Papazian, L., Kentish-Barnes, N., Pochard, F. & Azoulay, E. (2007) Burnout syndrome among critical care healthcare workers. *Current Opinion in Critical Care*. 13(5): 482–488

Epstein, D. & Brill, JE. (2005) A history of pediatric critical care medicine. *Pediatric Research*. 58:987–996

Erickson, SA. (2010) The wrong of rights: the moral authority of the family. *Journal of Medical Philosophy*. 35:600–16.

Esserman, L., Belkora, J., Lenert, L. (1995) Potentially ineffective care: a new outcome to assess the limits of critical care. *JAMA*. 274:1544–1551

Fassier, T. & Azoulay, E. (2010) Conflicts and communication gaps in the intensive care unit. *Current Opinion in Critical Care;* 16(6): 654–665

Feudtner, C., Schall, T. & Hill, D. (2018) Parental Personal Sense of Duty as a Foundation of Pediatric Medical Decision-making. *Pediatrics* 142 supp 3: s133-141

Fetterman, D.M. (2010) Ethnography: Step by step. 3rd Edition. London. Sage. *Archive of Disease in Childhood*.101(8):686-7

Field, D., Deeming, J. & Smith, LK. (2016) Moral distress: an inevitable part of neonatal and paediatric intensive care? *Archive of Diseases in Childhood.* 101(8):686-7.

Field, MJ. & Lohr, KN. (1990) *Clinical practice guidelines: directions for a new program.* Washington. National Academic Press.

Fineman, MA. (2008) The Vulnerable Subject: Anchoring Equality in the Human Condition*. Yale Journal of Law & Feminism*. 20(1):1-23

Finlay, L. (1998) Reflexivity: an essential component for all research. *British Journal of Occupational Therapy*. 61(10): 453-456.

Flyvbjerg, B (2004) Five misunderstandings about case-study research In Seale, C., Gobo, G., Gubrium, J & Silverman, D (2005) *Qualitative Research Practice*. London. SAGE Publications Ltd.

Forbat, L. & Barclay, S. (2019) Reducing healthcare conflict: outcomes from using the conflict management framework. *Archive of Disease in Childhood*. 104(4):328-332

Forbat, L., Sayer, C., McNamee, P., Menson, E., Barclay, S. (2016) Conflict in a paediatric hospital: a prospective mixed-method study. *Archives of Disease in Childhood*. 101:23–27 doi:10.1136/archdischild-2015-308814 (last accessed 23/06/2019)

Fortune, PM. (2006) Limiting and rationing treatment in Paediatric & neonatal intensive care. Best Practice & Research Clinical *Anaesthesiology*. 20(4): 577-588

Foster, C. (2014) Autonomy in the medico-legal courtroom: a principle fit for purpose? *Medical Law Review*. 22(1):48–63

Foster, C. (2005) Baby Charlotte – the end of intolerability. *Solicitors Journal* 1240-1241.

Frankish, K. (2010) Dual-process and dual systems theory of reasoning. *Philosophy Compass*. 5(10):914-926.

Gabbay, J. & Le May, A (2004) Evidence based guidelines or collectively constructed ‘mindlines’ Ethnographic study of knowledge management in primary care. *British Medical Journal*. 329:1013.

Gair, S. (2012) Feeling their stories: Contemplating empathy, insider/outsider positioning and enriching qualitative research. *Qualitative Health Research*. 22(1): 134-143.

Gampel, E (2006) Does professional autonomy protect medical futility judgments? *Bioethics* 20(2)92-104.

Garros, D., Rosychuk, R.J., Cox, P.N. (2003) Circumstances surrounding end of life in a pediatric intensive care unit. *Pediatrics;* 112(5): 371.

General Medical Council (2010) *Treatment and care towards the end of life: good practice in decision-making*. Manchester. GMC.

Geohegan, S., Oulton, K., Bull, C., Brierley, J., Peters, M. & Wray, J. (2016a) The Experience of Long-Stay Parents in the ICU: A Qualitative Study of Parent and Staff Perspectives. *Pediatric Critical Care Medicine.* 17(11) e496-e501

Geoghegan, S., Oulton, K., Bull, C., Brierley, J., Peters, M. & Wray, J. (2016b) The Challenges of Caring for Long-Stay Patients in the PICU. *Pediatric Critical Care Medicine*. 17(6)e266-e271

Gerrish, K. (2003) Self and others: The rigor and ethics of self-reflexive ethnography in Latimer, J (Ed) *Advanced Qualitative Research for Nursing*. Oxford. Blackwell Science.

Gerrish, K. (1997) Being a 'Marginal Native': Dilemmas of the Participant Observer, *Nurse Researcher*. 5(1): 25-34

Gerstel, E., Engelberg, A., Koepsell, T., and Curtis, J.R. (2008) Duration of withdrawal of life support in the intensive care unit and association with family satisfaction. *American Journal of Respiratory Critical Care Medicine*. Vol. 178: 798-804.

Gill, VT. (2005) Patient "demand" for medical interventions: exerting pressure for an offer in a primary care clinic visit. *Research on Language and Social Interaction*. 38(4): 451-479

Gillam, L. & Sullivan, J. (2011) Ethics at the end of life: Who should make decisions about treatment limitation for young children with life-threatening or life-limiting conditions? *Journal of Paediatrics and Child Health*. 47(9):594-598

Gillis, J. & Rennick, J. (2006) Affirming parental love in the pediatric intensive care unit. *Pediatric Critical Care Medicine*. 7(2):165-168

GMC (2010) *Treatment and care towards the end of life: good practice in decision making*. Manchester. GMC

Gobo, G (2008) *Doing Ethnography*. London. SAGE Publications Ltd.

Goethals, S., Gastmans, C. & Dierckx de Casterlé, B. (2010) Nurses' ethical reasoning and behaviour: A literature review. International *Journal of Nursing Studies*, 47(5), 635-650.

Goh, A.Y. & Mok, Q (2001) Identifying Futility in a paediatric critical care setting; a prospective observational study. Archives of disease in childhood. 84:265-268.

Goodwin, D,. Pope, C,. Mort, M. & Smith, A. (2003) Ethics and Ethnography: An Experiential Account. *Qualitative Health Research* 13(4):567-577

Graham, RJ., Pemstein, DM. & Curley, MA. (2009) Experiencing the pediatric intensive care unit: perspective from parents of children with severe antecedent disabilities. *Critical Care Medicine*. 37(6):2064-70

Green, J. & Thorogood, N. (2014) *Thematic content analysis. In: Qualitative methods for health research.* London. SAGE Publications Ltd. p. 209–18

Guillemin, M. & Gillam, L (2004) Ethics, reflexivity, and 'ethically important moments' in research. *Qualitative Inquiry*. 10(2): 261-280.

Haggerty, JL., Roberge, D., Freeman, GK. & Beaulieu, C. (2013) Experienced Continuity of Care When Patients See Multiple Clinicians: A Qualitative Meta summary. *Annals of Family Medicine*. 11(3): 262–271.

Hajibabaee, F., Joolaee, S., Al Cheraghi, M., Salari, P. & Rodney, P. (2016) Hospital/clinical ethics committees' notion: an overview. *Journal of Medical Ethics and History of Medicine*. 9: 17.

Hall, P. (2005) Interprofessional teamwork: Professional cultures as barriers. *Journal of Interprofessional Care*. 19:188-196.

Halse, C. & Honey, A (2005) Unraveling Ethics: Illuminating the Moral Dilemmas of Research Ethics. *New Feminist Approaches to Social Science Methodologies Special Issue*. 30(4):2141-2162

Hammersley, M. & Atkinson, P (2007) *Ethnography: Principles in practice.* 3rd Edition.London. Routeledge.

Hammond K.R. (1996) *Human Judgement and Social Policy: Irreducible Uncertainty, Inevitable Error*. Oxford. Oxford University Press.

Hammond-Browning, N. (2017) When doctors and parents don't agree: The story of Charlie Gard. *Bioethical Inquiry*. 14: 461-468.

Hartmann M, Saeed M, Bennett TD, Typpo K, Matos R, Olsen M. (2017) Readmission and Late Mortality after Critical Illness in Childhood. *Pediatric Critical Care Medicine.* 18(3):e112-e121.

Harvey, J. (1997) The Technological Regulation of Death: With Reference to the Technological Regulation of Birth. *Sociology*. 31(4)

Herring, J., Fulford, KMW., Dunn, M & Handa, A. (2017) Elbow Room for Best Practice? Montgomery, patients' values, and balanced decision-making in person-centred clinical care. *Medical Law Review*. 25(4):582–603

Herring, J. & Foster, C. (2012) ‘‘Please Don’t Tell Me’’ The Right Not to Know. *Cambridge Quarterly of Healthcare Ethics*. 21: 20–29

Herring, J. (2005) *Medical Law and Ethics*. Oxford. Oxford University Press.

Hewitt, J. (2007) Ethical Components of Researcher—Researched Relationships in Qualitative Interviewing. *Qualitative Health Research*. 17(8): 1149-1159

Heywood, R. & Miola, J. (2017) The changing face of pre-operative medical disclosure: Placing the patient at the heart of the matter. *Law Quarterly Review*. 133:296-321

Heywood, R. (2012) Parents and medical professionals: Conflict, cooperation and best interests. *Medical Law Review*. 20 (Winter) 29-44.

Higginbottom, G., Pillay, J. & Boadu, N. (2013) Guidance on Performing Focused Ethnographies with an Emphasis on Healthcare Research. *The Qualitative Report Volume* 18, Article 17, 1-16

Hoehn, K.S., Wernovsky, G., Rychik, J., Gaynor, J.W., Spray, T.L., Feudtner, C. & Nelson, R.M. (2005) What factors are important to parents making decisions about neonatal research? *Archives of Disease in Childhood, Fetal and Neonatal Edition*. 90: F267-F269.

Holloway, I. & Biley, F.C (2011) Being a qualitative researcher. *Qualitative Health Research.* 21(7): 968-975.

Holloway, I. & Todres, L. (2003) The Status of Method: Flexibility, Consistency and Coherence. *Qualitative Health Research.* 3(3): 345-357

Holloway, I. & Wheeler, S. (2010) *Qualitative research in nursing and healthcare.* 3rd Ed. Oxford: Wiley-Blackwell.

Holm, S., and Edgar, A. (2008) Best interests: A philosophical critique. *Health Care Analysis*. 16: 197-207.

Horne, R., Weinman, J., Barber, N., Elliot, R. & Morgan, M. (2005) *Concordance, adherence and compliance in medicine taking. Report for the national coordinating centre for NHS service delivery and organisation R & D.* London. NCCSDO.

Huxtable, R. (2018) Clinic, courtroom or specialist ethics committee: in the best interests of the critically ill child? *Journal of Medical Ethics*. 44:471-475

Huxtable, R. (2013) *Law, ethics and compromise at the limits of life: to treat or not to treat?* London. Routledge.

Hynson, I.L., Aroni, R., Bauld, C. & Sawyer, S.M. (2006) Research with bereaved parents: A question of why not how. *Palliative Medicine*. 20(8): 805-811.

Illich, I (1974) The political uses of a natural death. *The Hastings Center Studies*. 2(1):3-20.

Inwald, D. (2008) The best interests test at the end of life on PICU: a plea for a family centred approach. *Archives of Disease in Childhood.* 93:248-250.

Jacobs, BB. & Taylor, C. (2005) Medical futility in the natural attitude. *Advances in Nursing Science*. 28(4)

Jones, S. R. (2002). (Re)Writing the word: Methodological strategies and issues in qualitative research. *Journal of College Student Development*. 43(4), 461-473.

Johnson, LM., Snaman, JM., Cupit, MC, & Baker. JN. (2014) End-of-Life Care for Hospitalized Children. Pediatric Clinics of North America. 61:835–854.

Johnson, B & Macleod Clarke, J (2003) Collecting sensitive data: The impact on researchers. *Qualitative Health Research*. 13(3):421-434.

Johnston, DL., Halton, J., Bassal, M., Klaassen, RJ., Mandel, K., Ramphal, R. (2017) Pediatric Oncology Clinic Care Model: achieving better continuity of care for patients in a medium-sized program. J Pediatric Hematology and Oncology. 39: 476– 80.

Jones, C. & Lyons, C. (2004) Case Study: Design? Method? Or comprehensive Strategy? *Nurse Researcher*. 11(3):70-76.

Joseph-Williams N, Elwyn G, Edwards A. (2014) Knowledge is not power for patients: a systematic review and thematic synthesis of patient-reported barriers and facilitators to shared decision making. *Patient Education & Counselling* 94(3):291–309

Just, AC. (2005) Parent participation in care: bridging the gap in the pediatric intensive care unit. *Newborn and Infant Nursing Reviews*. 5(4): 179-187

Kahnenann, D. & Tversky, A. (1982) Prospect theory: an analysis of decision under risk. *Econemtrica.* 47:263-291

Kaiser, K. (2009) Protecting Respondent Confidentiality in Qualitative Research. *Qualitative Health Research*. 19(11): 1632–1641.

Kassam-Adams, N. & Newman, E. (2005) Child and parent reactions to participation in clinical research. *General Hospital Psychiatry*. 27:29-35.

Kastenbaum, R. (1969) *The Psychology of death*. (3rd edition). New York. Springer Publishing Group

Kinchelow, JL. (2001) Describing the Bricolage: Conceptualizing a New Rigor in Qualitative Research. *Qualitative Inquiry*. 7(6): 679-672

Kienle, G.S. & Kiene, H.K. (2011) Clinical judgement and the medical profession. *Journal of Evaluation in Clinical Practice*. 17(4):621-627.

King, M. (2004) From uncertainty as a challenge to law's programmes: The dilemma of parental disputes. *The Modern Law Review*. 63: 523 - 543.

King, N. (2004) Using Interviews in Qualitative Research. In Cassell, C. & Symon, G. *Essential Guide to Qualitative Methods in Organizational Research* P11-22

Kirsch, R. E., Balit, C.R., Carnevale, F. A., Latour, J. M., Larcher, V. (2018) Ethical, Cultural, Social, and Individual Considerations Prior to Transition to Limitation or Withdrawal of Life-Sustaining Therapies. *Pediatric Critical Care Medicine*: 19 (8S): S10-S18.

Knapp, C., Madden, M., Marcu, M., Wang, H., Curtis, C., Sloyer, P. & Shenkman, E. (2011) Information seeking behaviors of parents whose children have life-threatening illnesses. *Pediatric Blood & Cancer*. 56(5):805-811

Knoester, H., Bonner, MB., Boss, AP., (2008) Surviving pediatric intensive care: physical outcome after 3 months. *Intensive Care Medicine* 34(6):1076-1082

Knoester H, Grootenhuis MA, Bos AP (2007) Outcome of pediatric intensive care survivors. *European Journal Pediatrics* 166:1119–1128

Koch, T. (1999) An interpretive research process: revisiting phenomenological and hermeneutical approaches. *Nurse Researcher.* 6(3):20-34.

Konstantara, E., Vandrevala, T., Cox, A., Creagh-Brown, BC. & Ogden, J. (2016) Balancing professional tension and deciding upon the status of death: Making end-of-life decisions in intensive care units. *Health Psychology Open*. 1–9 DOI: 10.1177/2055102915622928 (Last accessed 24/08/2019)

Kopelman, LM. (2010) Using the best interests standard in treatment decisions for young children. In Miller, G. *Paediatric Bioethics*. Cambridge. Cambridge University Press. p22-37.

Kopelman, LM. (1997) The Best-Interests Standard as Threshold, Ideal, and Standard of Reasonableness. *Journal of Medicine and Philosophy.* 22 (3):271-289

Kuhse, H. & Singer, P. (1985) *Should the Baby Live? The Problems of Handicapped Babies*. Oxford University Press. Oxford.

Lachman, VD. (2010) Clinical ethics committees: organizational support for ethical practice. *Medical and Surgical Nursing*. 19:351-355

Lago, P.M., Piva, J., Kipper, D., Garcia, P.C., Pretto, C., Giongo, M., Branco, r. Bueno, F., Traiber, C., Aravjo, T., Wortmann, D., Liberato, G. & Soardi, D. (2004) Life support limitation at three paediatric intensive care units in southern Brazil. *Journal of Pediatrics* (Rio J). 81(2):111-117.

Lambert, V., Glacken, M. & McCarron, M (2011) Employing an ethnographic approach: key characteristics. *Nurse Researcher*.19(1):17-23.

Lantos, J. (2017) Intractable disagreements about futility. *Perspectives in Biology and Medicine*. Vol. 60: 390-399.

Lantos, J.D & Meadow, W.L. (2011) Costs and end of life care in the NICU: Lessons for the MICU? *Journal of Law, Medicine & Ethics*. 39(2)194-200

Larcher, V., Craig, F., Bhogal, K., Wilkinson, D., Brierley, J., on behalf of the Royal College of Paediatrics and Child Health (2015) Making decisions to limit treatment in life-limitingand life-threatening conditions in children: a framework for practice. *Archives of Diseases in Childhood* 100 (Suppl 2):s1–s23.

Larcher, V., Turnham, H., Brierley, J. (2018) Medical Innovation in a Children's Hospital: 'Diseases desperate grown by desperate appliance are relieved, or not at all'. *Bioethics*.32(1):36-42.

Latour, J., van Goudoever, JB., Schurman, BE., Albers, MJ., van Dam, AM., Dullart, E., van Heerde, M., Verlaat, CW., van Vught, EM. and Hazelzet, J. (2011) A qualitative study exploring the experiences of parents of children admitted to seven Dutch pediatric intensive care units. *Intensive Care Medicine.* 37(2):319-25

Latour J., van Goudoever, J. and Hazelzet, J. (2008) Parent satisfaction in the pediatric ICU. *Pediatric Clinics of North America.* 55: 779–790

Laurent, A., Bonnet, M., Capellier, G., Aslanian, P., and Herbert P. (2017) Emotional impact of end-of-life decisions on professional relationships in the ICU: An obstacle to Collegiality? *Critical Care Medicine*. 45: 2023-2030.

Lawton, J. (2001) Gaining and Maintaining Consent: Ethical Concerns Raised in a Study of Dying Patients. *Qualitative Health Research*. 11(5): 693-705

Lawton, J. (2000). *The dying process: Patients' experiences of palliative care.* London: Routledge.

Lee, Y.Y. & Lin, J.L. (2010) Do patient autonomy preferences matter? Linking patient-centred care to patient-physician relationships and health outcomes. *Social Science & Medicine*. 71: 1811-1818.

Lee, KJ., Tieves, K. & Scanlon, C. (2010) Alterations in End-of-Life Support in the Pediatric Intensive Care Unit. Pediatrics. 126(4)e859-864

Linney, M., Wain, RDW., Wilkinson, D., Fortune, PM., Barclay, S., Larcher, V., Fitzgerald, J. & Artell, E. (2019) Achieving consensus advice for paediatricians and other health professionals: on prevention, recognition and management of conflict in paediatric practice. *Archives of Disease in Childhood.*104:413-416.

Lingard, L., Espin, S., Evans, C. & Hawryluck, L. (2004) The rules of the game: interprofessional collaboration on the intensive care unit team. *Critical Care*. 8(6):R403-8.

Long, A.C., Spronk, P.E., and Sprung, C.L. (2016) Addressing uncertainty: what is the role of consensus in end-of-life care? *Intensive Care Medicine*. 42: 1043-1044.

Long, D., Forsyth, R., Iedema, R., and Carroll, K. (2006) The (im)possibilities of clinical democracy. *Health Sociology Review*. 15: 506-519.

Lotz, JD. Jox, RJ., Meurer, C., Borasio, GD. & Fuhrer, M. (2016) Medical indication regarding life-sustaining treatment for children: Focus groups with clinicians. *Palliative Medicine*, 30, 960-970.

Lützén K (1998) Subtle coercion in psychiatric practice. *Journal of Psychiatric and Mental Health Nursing*. 5(2):101-107

Lyons, B. (2012) Solidarity, children & research*. Bioethics*. 26(7): 369-375.

Madden, K., and Burns, J.P. (2017) Caring for long length of stay patients in the neonatal ICU and PICU: How do we ensure coherent decisions when the physicians are continuously rotating? *Pediatric Critical Care Medicine*. 18(9):907-908

Madrigal, V.N & Patterson, K.K. (2018) Supporting Family Decision-making for a Child Who Is Seriously Ill: Creating Synchrony and Connection. *Pediatrics*: 142 Supplement 3: s170-s176

Madrigal VN, Carroll KW, Hexem KR, Faerber JA, Morrison WE, Feudtner C. (2012) Parental decision-making preferences in the pediatric intensive care unit. *Critical Care Medicine*. 40(10):2876–2882

Mahon, PR. (2014) A critical ethnographic look at paediatric intensive care nurses and the determinants of nurses' job satisfaction. *Intensive and Critical Care Nursing*. 30(1):45-53

Manias, E. & Street, A. (2001) Rethinking ethnography: reconstructing nursing relationships. *Journal of Advanced Nursing*. 33(2):234-242

Manning, J., Neethi, P., Rennick., Colville, G., Curley, M. (2018) Conceptualizing Post Intensive Care Syndrome in Children—The PICS-p Framework. *Pediatric Critical Care Medicine*. 19 (4)298-300

Manning, J & Latour, J (2016) Family-Clinician Communication Within Critical Care Settings Unravelling the Complex and Valuing the Hidden. *Pediatric Critical Care Medicine*. 17(3):264-265.

Manning, J., Hemingway, P. & Redsell, S. (2013) Long-term psychosocial impact reported by childhood critical illness survivors: a systematic review. *Nursing in Critical Care* 19(3): 145-156

Marcus, KL., Henderson, CM. & Boss, RD. (2016) Chronic Critical Illness in Infants and Children: A Speculative Synthesis on Adapting ICU Care to Meet the Needs of Long-Stay Patients. *Pediatric Critical Care Medicine*. 17(8): 743-752

Mays, N. & Pope, C. (2000) Assessing quality in qualitative research. *British Medical Journal.* 320:50-52

McCabe, JL. & Holmes, D. (2009) Reflexivity, critical qualitative research and emancipation: A Foucauldian perspective. *Journal of Advanced Nursing* 65(7):1518-26.

McCallum, D.E., Byrne, P. & Bruera, E. (2000) How children die in hospital. *Journal of Pain Symptom Management*; 20:417-23.

McCrary, SV., Swanson, JW., Perkins, HS. & Winslade, WJ. (1994) Physicians' quantitative assessments of medical futility. *Journal of Clinical Ethics*. 5(2):100-5

McDougall, RJ. & Notini, L. (2013) Overriding parents’ medical decisions for theirchildren: a systematic review of normative literature. *Journal of Medical Ethics.* 40:448-452

McEvoy, P. (2001) Interviewing colleagues: addressing the issue of perspective, inquiry and representation. *Nurse Researcher*, 9(2): 49-59.

McGee, G., Spanogle, JP., Caplan, A. & Penny, D. (2002) Successes and Failures of Hospital Ethics Committees: A National Survey of Ethics Committee Chairs. *Cambridge Quarterly of Healthcare Ethics*. 11(1):87-93

McGraw, SA., Truog, RD., Solomon,. MZ., Cohen-Bearak, A., Sellers, DE. &. Meyer, EC. (2012) "I was able to still be her mom" Parenting at end of life in the PICU. *Pediatric Critical Care Medicine*. 13(6): e350–e356.

McHaffie, HE. (2001) *Crucial decisions at the beginning of life: Parents' experiences of treatment withdrawal from infants*. Oxford. Radcliffe Publishing.

McHaffie, H., Laing, I.A., Parker, M. & McMillan, J. (2001) Deciding for imperilled newborns: medical authority or parental autonomy? *Journal of Medical Ethics.* 27:104 – 109.

McKlindon D, Jacobson JA, Nathanson P, Walter, JK, Lantos, JD, Fuedtner, C. (2016) Ethics rounds: In the eye of a social media storm. *Pediatrics*. 138:e20161398

McLean, S. (2007) What and who are clinical ethics committees for? *Journal of Medical Ethics*.33:497–500.

McNeil, K., Mitchell, R. & Parker, V. (2012) Interprofessional Practice and Professional Identity Threat. *Health Sociology Review* 22(3):291-307

McPherson, G., Jefferson, R., Kissoon, N., Kwong, L. & R (2011) Toward the inclusion of parents on pediatric critical care unit rounds. *Pediatric Critical Care*. 12(6)e255-e261,

McPherson M, Sachdeva R and Jeferson L (2005) Development of a survey to measure parent satisfaction in a pediatric intensive care unit. *Critical Care Medicine* 6: 578–584.

Mental Capacity Act (2005) https://www.legislation.gov.uk/ukpga/2005/9/contents

Meert, KL., Keele, L., Morrison, W., Berg, RA., Dalton, H., Newth, JL., Harrison, R., Wessel, DL., Shanley, T, Carcillo, J. Clark, A., Holubokov, R., Jenkins, TL., Doctor, A., Dean, MJ. & Pollack, M. (2016) End-of-life practices among teriary care pediatric intensive care units in the US: a multicenter study*. Pediatric Critical Care Medicine* 16(7):e231-e238

Meert, K., Briller SH., Schim, SM., Thurston, C. & Kabe,l A. (2009) Examining the needs of bereaved parents in the pediatric intensive care unit: a qualitative study. Death Studies. 33(8):712-40.

Meert, KL., Eggly, S., Pollack, M., Anand, KJS., Zimmerman, J., Carcillo, J., Newth, CJL., Dean, JM., Wilson, DF., Nicholson, C., and the National Institute Of Child Health and Human Development Collaborative Pediatric Critical Care Research Network. (2008) Parents' perspectives on physician-parent communication near the time of a child's death in the pediatric intensive care unit. *Pediatric Critical Care Medicine*. 9(1): 2-7.

Meert, K.L., Thurston, C.S., Sarnick, A.P. (2000) End of life decision making and satisfaction with care: parental perspectives. *Pediatric Critical Medicine.* 1(2):179-185

Melia, KM. (2004) *Health Care Ethics: Lessons From Intensive Care.* London. SAGE Publications Ltd. Care Medicine; 1(2): 179-185.

Melia, KM. (2001) Ethical issues and the importance of consensus for the intensive care team. *Social Science & Medicine*. 53(6): 707-719

Meller, S. & Barclay, S. (2011) Mediation: an approach to intractable disputes between parents and paediatricians. *Archive of Diseases in Childhood*. 96(7):619-21.

Merk, L., and Merk, R. (2013) A parents' perspective on the pediatric intensive care unit. *Pediatric Clinics of North America*. 60: 773-780.

Merriam, S.B. (1998) *Qualitative Research and Case Study Applications in Education.* Jossey-Bass Publishers, San Francisco.

Meyer, EC., Sellers, DE., Browning, DM., et al. (2009) Difficult conversations: improving communication skills and relational abilities in health care. *Pediatric Critical Care Medicine.* 10: 352–359

Meyer, E.C., Ritholz, M.D., Burns, J.P. & Truog, R.D. (2006) Improving the quality of end of life care in the paediatric intensive care unit: parents' priorities and recommendations. *Pediatrics.* 117(3): 649-657.

Michelson, KN., Patel, R., Haber-Barker, N., Emanuel, L., and Frader, J. (2013) End-of-life care decisions in the pediatric intensive care unit: roles professionals play. *Pediatric Critical Care Medicine*.14(1):e34-e44

Michelson, KN., Emanuel, L., Brinkman, P., Clayman, M., & Frader, J (2011) Pediatric intensive care unit family conferences: One mode of communication for discussing end-of-life care decisions. *Pediatric Critical Care Medicine.* 12(6):e336-e343,

Michelson, KN., Koogler, T., Sullivan, C., Ortega, M., Hall, E. & Frader, J. (2009) Parental Views on Withdrawing Life-Sustaining Therapies in Critically Ill Children. *Archive of Pediatric and Adolescent Medicine*. 163(11):986-992

Michelson, KN., Koogler, TK., Skipton, K., Sullivan, C. & Frader, J. (2006) Parents' reactions to participating in interviews about end-of-life decision making. Journal of Palliative Care. 9(6):1329-1338

Miles, M. B. & Huberman, M. A. 1994. *Qualitative Data Analysis: An Expanded Sourcebook.* London, UK. SAGE Publications Ltd.

Miller-Smith, L., Wagner, AF. & Lantos, JD. (2019) Bioethics in the pediatric ICU*: Ethical dilemmas encountered in the care of the critically ill child*. Cham, Switzerland. Springer.

Moller, D. W. (1996). *Confronting death: Values, institutions, and human mortality.* Oxford. Oxford University Press.

Moller, D.W. 1990 *On Death Without Dignity: The Human Impact of Technological Dying*. Baywood, New York

Moratti, S (2009) The development of “medical futility”: towards a procedural approach based on the role of the medical profession. *Journal of Medical Ethics*. 35:369-372.

Morrison, W. & Madrigal, V. (2012) “My way or the highway” versus “Whatever the family wants”: intensivists reject both extremes*. Pediatric Critical Care Medicine*. 13 (5) 612–613

Morse, J.M. (2000) Determining sample size. *Qualitative Health Research.* 10(1): 3-5.

Mukherjee, K. (2010). A dual system model of preferences under risk. *Psychological Review*. 117(1), 243-255

Mulhall, A. (2003) In the field:notes on observation in qualitative research. *Journal of Advanced Nursing*. 41(3): 306-313.

Munthe, C., Sandman, L & Cuta, D. (2012) Person Centred Care and Shared Decision Making: Implications for Ethics, Public Health and Research. *Health Care Analysis* 20 (3):231–249

Murphy, E. & Dingwall, R. (2007) Informed consent, anticipatory regulation and ethnographic practice. *Social Sciences & Medicine*. 65(11): 2223-2234.

Murphy, E. and Dingwall, R. (2003). The ethics of ethnography. In P. Atkinson, A. Coffey, S. Delamont, J. Lofland and L. Lofland (Eds), *Handbook of Ethnography* (339–351). London. SAGE Publications Ltd.

Nadeau, K., Pinner, K., Murphy, K. & Belderson, KM. (2016) Perceptions of a primary nursing care model in a pediatric hematology/oncology unit. Journal of Pediatric Oncology Nursing. 34: 28– 34.

National Research Ethics Service (2011) *Does my project require review by a Research Ethics Committee?* London. NRES.

Needle, JS., Mularski, RA. & Nguyen, T. (2012) Influence of personal preferences for life-sustaining treatment on medical decision making among pediatric intensivists. *Critical Care Medicine.* 40(8):2464–2469

Needle, JS., O’Riordan, M., Smith, PG. (2009) Parental anxiety and medical comprehension within 24 hrs of a child’s admission to the pediatric intensive care unit. *Pediatric Critical Care Medicine*. 10:668–674.

Neuman, W.L. (2006) *Social Research Methods: Qualitative and Quantitative Approaches.* 6th Edition (International). London. Pearson Education Inc.

NHS Executive (1997) *A bridge to the future: nursing standards, education and workforce planning in paediatric intensive care. Report of the chief nursing officer's taskforce.* London. HMSO.

Nightingale, R., Sinha, MD., & Swallow, V. (2014) Using focused ethnography in paediatric settings to explore professionals' and parents' attitudes towards expertise in managing chronic kidney disease stage 3–5. *BMC Health Services Research* 14:403 doi.org/10.1186/1472-6963-14-403 (last accessed 21/07/2019)

Noyes, J. (1998) A critique of studies exploring the experiences and needs of parents of children admitted to paediatric intensive care units. *Journal of Advanced Nursing*. 28(1): 134–141

Nuffield Council on Bioethics (2019) *Disagreements in the care of critically ill children*. London. Nuffield Council on Bioethics.

Nuffield Council on Bioethics (2006) *Critical care decisions in fetal and neonatal medicine: ethical issues*. London. Nuffield Council on Bioethics.

Oberender, F. & Tibballs, J. (2011) Withdrawal of life-support in paediatric intensive care – a study of time intervals between discussion, decision and death. BMC *Pediatrics*: 11(39) http://www.biomedcentral.com/1471-2431/11/39 accessed 10 June 2012.

O'Connor, E., Winch, S., Lukin, W. &Parker, MH. (2011) Emergency medicine and futile care: Taking the road less travelled. *Emergency medicine Australasia*: EMA 23(5):640-3

October TW, Fisher KR, Feudtner C, & Hinds PS, (2014)The parent perspective: "Being a good parent" when making critical decisions in the PICU. *Pediatric Critical Care Medicine*. 15:291–298

Odeniyi, F., Nathanson, P.G., Schall, T.E., and Walter, J.K. (2017) Communication challenges of oncologists and intensivists caring for pediatric oncology patients: A qualitative study. *Journal of Pain and Symptom Management.* Vol. 54:909-15

Olcese, M.E. & Mack, J.W. (2012) The research participation experiences of parents of children with cancer who were asked about their child’s prognosis. *Journal of Palliative Medicine*. 15(3):269-273.

Orfali, K. (2004) Parental role in medical decision-making: fact or fiction? A comparative study of ethical dilemmas in French and American neonatal intensive care units. *Social Science & Medicine*. 58:2009-2022

Orfali, K., and Gordon, E. (2004) Autonomy gone awry: A cross-cultural study of parents’ experiences in neonatal intensive care units. *Theoretical Medicine*. 25: 329-365

O’Reilly, K (2012) *Ethnographic Methods*. Oxon. Routeledge.

Padgett, D. K. (2004). Coming of age: Theoretical thinking, social responsibility, and a global perspective in qualitative research. In Padgett, D. K. (Ed.). *The qualitative research experience* (pp. 297–315). Belmont, CA: Wadsworth/Thomson Learning.

Paradis, E., Reeves, S., Leslie, M., Aboumatar, H., Chesluk, B., Clark, P., Courtenay, M., Franck, L., Lamb, G., Lyndon, A., Mesman, J., Puntillo, K., Schmitt, M., van Soeren, M., Wachter, B., Zwarenstein, M., Gropper, M. & Kitto, S. (2014) Exploring the nature of interprofessional collaboration and family member involvement in an intensive care context. *Journal of Interprofessional Care*. 28(1):74-5

Parahoo, K. (2006) *Nursing Research: Principles, Process and Issues* Basingstoke. Palgrave Macmillan.

Park, ES. & Cho, IY. (2018) Shared decision-making in the paediatric field: a literature review and concept analysis. *Scandinavian Journal of Caring Sciences.* 32(2):478-489

Patton, MQ. (2002) *Qualitative Research & Evaluation Methods*. London, UK. SAGE Publications Ltd.

Pavia, TM. & Mason, MJ. (2012) Inclusion, exclusion and identity in the consumption of families living with childhood disability. *Consumption Markets and Culture* 15(1):87-115

Payne JW, Bettman JR. (2004) Walking with the scarecrow: the information-processing approach to decision research. In *Blackwell Handbook of Judgment and Decision Making*, ed. DJ Koehler, N Harvey, pp. 110–32. Malden, MA. London. Blackwell.

Pederson, R,. Arke, V. & Forde, R (2009) What is happening during case deliberations in clinical ethics committees? A pilot study. *Journal of Medical Ethics.* 35:147–152

Perakyla, A. (2006) in Heritage, J. & Maynard, D.W. Communication in medical care: Interaction between primary care physicians and patients. *Studies in International Social Linguistics Issue* 20: 214-247.

PICANet (2018) *Paediatric Intensive Care Audit Network Annual Report January 2015-December 2017*. Leeds: Universities of Leeds and Leicester.

PICANet (2015) *Paediatric Intensive Care Audit Network Annual Report January 2012-December 2014.* Leeds: Universities of Leeds and Leicester.

PICANet (2012) *Annual report of the paediatric intensive care audit network January 2009 – December 2011*. Leeds: Universities of Leeds and Leicester.

Pilnick, A. & Dingwall, R. (2011) On the remarkable persistence of asymmetry in doctor/patient interaction: A critical review. *Social Science & Medicine.* 72:1374-1382.

Plantin, L., and Daneback, K. (2009) Parenthood, information and support on the internet. A literature review of research on parents and professional online. *BMC Family Practice*. 10:34 doi:10.1186/1471-2296-10-34

Pollack, MM., Holubkov, R. Funai, T., Clark, A., Berger, JT et al (2014) Pediatric intensive care outcomes: development of new morbidities during pediatric critical care. *Pediatric Critical Care Medicine*. 15(9): 821–827.

Pope, C. & Mays, N. (1993) Opening the black box: an encounter in the corridors of health service research. *British Medical Journal*. 306:315-318.

Popejoy E, Pollock K, Almack K, Manning JC, Johnston B. (2017) Decision making and future planning for children with life-limiting conditions: a qualitative systematic review and thematic synthesis. *Child Care Health & Development*. 43(5):627–644

Pochard, F. Azoulay, E., Chevret, S., Visonneau, C. & Herve, C. (2001) Symptoms of anxiety and depression in family members of ICU patients: Ethical hypothesis regarding decision making capacity. *Critical Care Medicine*. 29, 1893-1897.

Power, KJ. (2012) *How are Ethical Problems Resolved in a Paediatric Intensive Care Unit?* Thesis submitted for Doctor of Philosophy, De Montfort University.

du Pré, P. & Brierley, J. (2018) Challenges in managing parental expectations in paediatric care. *British Journal of Haematology.*183(1):15-22

Quigley, M. (2008) Best interests and the power of the medical profession, and the power of the judiciary. *Health Care Analysis.* 16(3):233-239

Quill, T.E. & Brody, H. (1996) Physician recommendations and patient autonomy*. Annals Internal Medicine*. 125(9): 763-769.

Radley, A. (2002) *Worlds of Illness: Biographical and Cultural Perspectives on Health and Disease*. London. Routledge

Ramnarayan, P., Craig, F., Petros, A. and Pierce, C. (2007) Characteristics of deaths occurring in hospitalised children: changing trends. *Journal of Medical Ethics*. 33:255-260.

Randolph, AG., Zollo, MB., Egger, MJ., Guyatt, GH., Nelson, RM. & Stidham, GL. (1999) eVariability in Physician Opinion on Limiting

Pediatric Life Support. *Pediatrics.* 103(4)e46 DOI: 10.1542/peds.103.4.e46 (last accessed 24/08/2019)

Rashid, M., Caine, V. & Goez, H (2015) The Encounters and Challenges of Ethnography as a Methodology in Health Research. International *Journal of Qualitative Methods*. 1-16 doi: 10.1177/160940691562142 (last accessed 24/08/2019)

Re A (Medical Treatment: Male Sterilisation) [2000] 1 FLR 549, (2000) 1 FCR 193

Re: Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67.

Re: An NHS Trust v MB and Others [2006] EWHC 507 (Fam)

Re: B [A Minor] [Wardship: Medical Treatment] [1981] 1 W.L.R. 1421

Re: Alder Hey Children's NHS Foundation Trust v Evans [2018] EWCA Civ 805; [2018] 4 WLUK 188

Re: Bolam v Friern Hospital Management Committee [1957] 1 WLR 582

Re E (A Child) [2018] EWCA Civ 550; [2018] 3 WLUK 120

Re: Evans v Alder Hey Children's NHS Foundation Trust [2018] 3 WLUK 483

Re: Evans v Alder Hey Children's NHS Foundation Trust [2018] EWCA Civ 984; [2018] 4 WLUK 432

Re: Evans v the United Kingdom UKSC 18770/18

Re: Gard v United Kingdom (Admissibility) (39793/17) [2017] 6 WLUK 575; [2017] 2 F.L.R. 773; (2017) 157 B.M.L.R. 59; (2017) 65 E.H.R.R. SE9

Re: Great Ormond Street Hospital for Children NHS Foundation Trust v Yates [2017] EWCA Civ 410; [2018] 4 W.L.R. 5; [2018] 1 All E.R. 569

Re Charlie Gard (Permission to appeal) Supreme Court Hearing, 19 June 2017 https://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html.

Re: J (A minor) (Wardship: Medical Treatment) [1991] Fam. 33; [1991] 2 W.L.R. 140; [1990] 3 All E.R. 930

Re: J (A Minor) (Child in Care: Medical Treatment), Re [1993] Fam. 15; [1992] 3 W.L.R. 507; [1992] 4 All E.R. 614

Re: L (A Child) (Medical Treatment: Benefit) Re [2004] EWHC 2713 (Fam); [2005] 1 F.L.R. 491.

Re: Montgomery v Lanarkshire Health Board (General Medical Council intervening) [2015] UKSC 11.

Re: OT [2009] EWHC 633 (Fam)

Re: Portsmouth NHS Trust v Wyatt [2005] EWCA Civ 1181: [2005] 1 W.L.R. 3995

Re: R v Cambridge HA ex parte B [1995] 1 WLR 898, 1 F.L.R. 1055, 2 All E.R. 129

Re: T (A Minor) (Medical Treatment) [1997] 1 ALL ER 906.

Re: Wilsher v Essex Area Health Authority [1988] AC 1074

Reed, J. & Proctor, S. (1995) Practitioner research in health care: The inside story. London. Chapman & Hall.

Rennick, J.E., Childerhose, J.E. (2015) Redefining Success in the PICU: New Patient Populations Shift Targets of Care. *Pediatrics.* 135 (2): e289-e291; DOI: 10.1542/peds.2014-2174 (last accessed 29/06/2019)

Richards, T. (2014) When doctors and patients disagree. *British Medical Journal*. 349:g5567 doi: 10.1136/bmj.g5567

Richards, CA., Starks, H., O’Connor, MR., Bourget, E., Lindhorst, T., Hays, R. & Doorenbos, (2018a) When and Why Do Neonatal and Pediatric Critical Care Physicians Consult Palliative Care? *American Journal of Hospice & Palliative Medicine*. 35(6) 840-846

Richards, CA., Starks, H., O’Connor, MR., Bourget, E., Hays, R. & Doorenbos, (2018b) Physicians Perceptions of Shared Decision-Making in Neonatal and Pediatric Critical Care. *American Journal of Hospice & Palliative Medicine.* 35(4):669-676

Ritchie, J., Spencer, L. & O’Connor, W. (2003) Carrying out qualitative analysis in Ritchie, J & Lewis, J *Qualitative Research Practice: A Guide for Social Science Students and researchers*. p 219-262. London. SAGE Publications. Ltd.

Robert, G. Permstien, DM. & Curley, MA. (2009) Experiencing the paediatric intensive care unit: Perspective form parents of children with severe antecedent disabilities. *Critical Care Medicine*. 37(6): 2064-2070.

Roden, J. (2005) The involvement of parents and nurses in the care of acutely-ill children in a non-specialist paediatric setting. *Journal of Child Health Care.* 9(3) 222–240

Roper, J.M. & Shapira, J. (2000) *Ethnography in Nursing Research.* London. Sage Publications Inc.

Roscigno, C.I., Savage, T.A., Kavanaugh, K., Moro, T.T., Kilpatrick, S.J., Strassner, H.T., Grobman, W.A. & Kimura, R.E. (2012) Divergent views of hope influencing communications between parents and hospital providers. *Qualitative Health Research*. 22(9): 1232-1246.

Royal College of Paediatrics and Child Health (2004) *Withholding or withdrawing life sustaining medical treatment in children: A framework for Practice*. London. RCPCH.

Roth, A. Rapoport, A. Widger, K. Friedman, J. (2017) General paediatric inpatient deaths over a 15-year period. *Paediatrics & Child Health*. 22(1):80–83 doi:10.1093/pch/pxx005 (last accessed 29/06/2019)

Royal College of Paediatrics and Child Health (2012) *Facing the Future: standards for paediatric care*. London. RCPCH

Royal College of Paediatrics and Child Health (2004) *Withholding or withdrawing life sustaining medical treatment in children: A framework for Practice.* London. RCPCH.

Royal College of Paediatrics and Child Health (1997) *Withholding or withdrawing life sustaining medical treatment in children: A framework for Practice.* London. RCPCH.

Rubin, MA. & Truog, RD. (2017) What to Do When There Aren't Enough Beds in the PICU. AMA *Journal of Ethics* 19(2:157-163

Ryan, J. & Sysko, J. (2007) The contingency of patient preferences for involvement in health decision making. *Health Care Management Review.* 32, 30-36.

Ryan, M. (2000) Micro-political strategies and their implications for participative decision making. *International Journal of Value-Based Management.* 13: 79-88.

Sackett, DL., Rosenberg, WMC., Muir Gray, JA., Haynes, RB & Richardson, WS (1996) Evidence based medicine: what it is and what it isn't*. British Medical Journal*. 312:71

Saldaña, J. (2009) *The Coding Manual for Qualitative Researchers.* London, UK. SAGE Publications Ltd.

Salhani, D. & Coulter, I. (2009) The politics of interprofessional working and the struggle for professional autonomy in nursing*. Social Sciences and Medicine.* 68(7):1221-1228

Sandman, L. & Munthe, C. (2010) Shared Decision Making, Paternalism and Patient Choice. *Health Care Analysis*. 18(1):60–84

Sands, R., Manning, J.C., Vyas, H. & Rashid, A. (2009) Characteristics of death in a paediatric intensive care: a 10 year study. *British Association of Critical Care Nurses, Nursing in Critical Care*; 14(5): 235-240.

Savage, J (2006) Ethnographic evidence: The value of applied ethnography in healthcare. *Journal of Research in Nursing*. 11(5): 383-393

Savage, J (2000) Ethnography and healthcare. *British Medical Journal*. 321:1400-1402.

Schneiderman, L.J. (2011) Defining medical futility and improving Care. *Bioethical Inquiry* 8:123-131.

Schniederman, L.J. & Capron, A.M. (2000) How can hospital futility policies contribute to establishing standards of practice? *Cambridge Quarterly Quarterly of Healthcare Ethics*. 9(4):524-531

Schneiderman, LJ., Jecker, NS. and Jonsen, AR. (1990) Medical futility: its meaning and ethical implications. *Annals of Internal Medicine* 112(12):949-954

Scott, D.A., Valery, P.C., Boyle, F.M. & Bain, C.J. (2002) Does research into sensitive areas do harm? Experiences of research participation after a child's diagnosis with Ewing's sarcoma. *Medical Journal of Australia*. 177(9): 507-51

Seymour, JE. (2007) Ethnography. In: Addington-Hall, J.M., Bruera, E., Higginson, I. and Payne, S.A. (eds) *Research Methods in Palliative Care*. Oxford: Oxford University Press.

Seymour, JE. (2001) *Critical moments: death and dying in intensive care*. Buckingham. Open University Press.

Seymour, JE. (1999) Revisiting medicalisation and natural death*. Social Sciences and Medicine*. 5(2):691-704

Seymour, J.E. 1997 (Unpublished PhD thesis) *Caring for Critically Ill People: A Study of Death and Dying in Intensive Care*. The University of Sheffield, Sheffield.

Shapiro, M., Donohue, P.K., Kudchadkar, S.R., Hutton, N., and Boss, R.D. (2017) Professional responsibility, consensus, and conflict: A survey of physician decisions for the chronically critically ill in neonatal and pediatric intensive care units. *Pediatric Critical Care Medicine*. 18(9):e415-422

Sharkey, S. & Larsen, J. (2005) Ethnographic exploration: Participation and meaning in everyday life. In Holloway, I. (Editor) *Qualitative research in health care*. P169-190. Maidenhead. Open University Press.

Shaw, C., Stokoe, E., Gallagher, K., Aladangady, N., and Marlow, N. (2016) Parental involvement in neonatal critical care decision-making. *Sociology of health and Illness*. 38(8):1217-1242.

Shaw, D. & Elger, B (2013) Evidence-Based Persuasion: An Ethical Imperative. *JAMA*. 309(16):1689-90

Shudy, M., de Almeida, ML., Ly, S., Landon, C., Groft, S., Jenkins, TL. & Nicholson, CE. (2006) Impact of Pediatric Critical Illness and Injury on Families: A Systematic Literature Review. *Pediatrics.* 118 Supplement 3

Simpson, B. (2011) Ethical moments: future directions for ethical review and ethnography. *Journal of Royal Anthropological Institute*. 17(2)377-393

Silverman, D (2014) *Interpreting Qualitative Data*. 5th Edition. London. SAGE Publications Ltd.

Silverman, D (2010) *Doing Qualitative Research*. 3rd Edition. London. SAGE Publications Ltd.

Silverman (2000) Doing Qualitative Research: A practical handbook. 2nd Edition. London. SAGE Publications Ltd Sinkovics, R.R. & Alfoldi, E. (2012) Progressive focussing and trustworthiness in qualitative research: The enabling role of computer-assisted qualitative data analysis software (CAQDAS). *Management International Review*. 52(6): 817-845 (DOI;10.1007/s11575-012-0140-5).

Sinkovics, R.R. & Alfoldi, E. (2012) Facilitating the interaction between theory and data in qualitative research using CAQDAS in *Qualitative organisational research: Core methods and current challenges*, Symon,

G. & Cassell, C (Eds). London. Sage Publications. 109-131 http://www.manchester.ac.uk/escholar/uk-ac-man-scw:1595960.

Skolol, D (2013) “First do no harm” revisited. *British Medical Journal*. 347:f6426doi: https://doi.org/10.1136/bmj.f6426

Soman, D. (2004) Framing, loss aversion and mental accounting, in Koehler D.J. and Harvey N. (eds), *Blackwell Handbook of Judgement and Decision Making*. Malden. Blackwell Publishing.

Slowther, AM., McClimans, L. & Price, C. (2012) Development of clinical ethics services in the UK: a national survey. *Journal of Medical Ethics.* 38:210214.

Sorenson, R. & Iedema, R. (2008) Redefining accountability in health care: managing the plurality of medical interests. *Health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine.* 12(1):87-106

Sorenson, R. & Iedema, R. (2008) Advocacy at end-of-life: Research design: An ethnographic study of an ICU *International Journal of Nursing Studies*. 44(8):1343-1353

Smith, L. & Coleman, V. (2010) *Child and family centred healthcare: Concept, theory and practice*. 2nd Edition. Basingstoke. Palgrave Macmillan.

Stake, R. E. (2006). *Multiple case study analysis*. New York: The Guilford Press

Stake, R.E. (1995) *The Art of Case Study Research*. London. SAGE Publications Ltd.

Stark, Z., Hynson, J. & Forrester, M. (2008) Discussing withholding and withdrawing of life-sustaining medical treatment in paediatric inpatients: Audit of current practice. *Journal of Paediatrics and Child Health*. 44 (7-8): 399-403

Starks, H. & Trinidad, S. B. (2007) Choose your method: A comparison of phenomenology, discourse analysis and grounded theory. *Qualitative Health Research*. 17(10): 1372-1380.

Stanovich, KE. & West, RF (2000) Individual Differences in Reasoning: Implications for the Rationality Debate. *Behavioral and Brain Sciences* 23(5):645-726

Stewart, C (2011) Futility Determination as a process: Problems with medical sovereignty, legal issues and the strengths and weaknesses of the procedural approach. *Bioethical Inquiry* 8: 155-163.

Stevens, M., Lord, A., Proctor, MT., Nagy, S. & O'Riordan, E (2010) Research with Vulnerable Families Caring for Children With Life-Limiting Conditions. *Qualitative Health Research*. 20:496-505

Stivers, T. (2005) Non-antibiotic treatment recommendations: Delivery formats and implications for parent resistance, *Social Science & Medicine.* 60(5):949–64.

Stocker, M., Pilgrim, S.B., Burmester, M., Allen, M.L., and Gijselaers, W.H. (2016) Interprofessional team management in pediatric critical care: some challenges and possible solutions. *Journal of Multidisciplinary Healthcare*. 9: 47-58.

Street, K., Ashcroft, R., Henderson, J. & Campbell, AV.(2000) The decision making process regarding the withdrawal or withholding of potential life-saving treatments in a children's hospital. *Journal of Medical Ethics*. 26:346–352

Streubert-Speziale, HJ. & Carpenter, DR. (2011) *Qualitative research in nursing: advancing the humanistic imperative.* Philadelphia. Lippincott Williams

Strong, PM. & Dingwall, R (1979) *The Ceremonial Order of the Clinic: Parents, Doctors and Medical Bureaucracies*. London. Routledge.

Studdert, D.M., Mello, M.M., Burns, J.P., Puopolo, A.L., Galper, B.Z., Truog, R.D., and Brennan, T.A. (2003a) Conflict in the care of patients with prolonged stay in ICU: types, sources, and predictors. *Intensive Care Medicine*. 29: 1489-1497.

Studdert, D.M., Burns, J.P., Mello, M.M. et al (2003b) Nature of Conflict in the care of pediatric intensive care patients with prolonged stay. *Pediatrics.*112: 553-558.

Swenson, S.I., Buell, S., Zettler, P., White, M., Ruston, D.C. & Lo, B. (2004) Patient centered communication: do patients really prefer it? *Journal of General Internal Medicine*. 19 1069-1079.

Taneja, G.S., Brenner, R.A., Klinger, R., Trumble, A.C., Qian, C. & Klebanoff, M. (2007) Participation of next of kin in research following sudden, unexpected death of a child. *Archives Pediatric Adolescent Medicine.* 161(5): 453-456.

TenHave, EC. & Nap, RE. (2014) Mutual agreement between providers in intensive care medicine on patient care after interdisciplinary rounds. *Journal of Intensive Care Medicine*. 29(5):292-7

Thomas, F. & Azoulay, E (2010) Conflicts and communication gaps in the intensive care unit. *Current Opinion in Critical Care*. 16(6): 654–665

Thompson, A. (2016) Hippocrates and the smart phone: The evolving parent and doctor relationship. *Journal of Paediatrics and Child Health*. 52:366-369

Thorne, S. (2000) Data analysis in qualitative research. *Evidence Based Nursing Notebook.* doi.org/10.1136/ebn.3.3.68 (last accessed 24/08/19)

Thornton, T. (2009) Clinical judgement and individual patients: Invited Commentary on … In Defence of Professional Judgement. *Advances in Psychiatric Treatment.* 15 (5): 328-331

Timmermans, S. (2005) Death brokering: constructing culturally appropriate deaths. *Sociology of Health and Illness*. 27(7): 993-1013

Timmermans, S. (1998) Resuscitation technology in the emergency department: towards a dignified death. *Sociology of Health and Illness*. 20(2):144-167

Tofolli, L. & Rudge, T (2006) Organizational predicaments: Ethical conditions for nursing research. *Journal of Advanced Nursing*. 56(6): 600-606.

Tolich, M. (2004) Internal confidentiality: When confidentiality assurances fail relational informants. *Qualitative Sociology*. 27(1):101-106

Tversky, D. & Kahneman, A. (1992) Advances in prospect theory: Cumulative representation of uncertainty. *Journal of Risk and Uncertainty*. 5 (4): 297–323

United Kingdom Human Rights Act 1998 https://www.legislation.gov.uk/ukpga/1998/42/contents

United Nations (1989). *Convention on the rights of the child.* Geneva: United Nations.

Veatch, R.M. (2005) "Terri Schiavo, Son Hudson, And ‘Nonbeneficial’ Medical Treatments." *Health Affairs* (2005): 976-79.

Verhagen AA, Dorscheidt JH, Engels B, Hubben JH, Sauer PJ. (2009) End-of-life decisions in Dutch Neonatal Intensive Care Units. *Archives Pediatric and Adolescent Medicine*. 163: 895–901

Vemuri, G. & Playfor, S.D. (2005) Futility and inappropriate care in paediatric intensive care: a cross sectional survey. *Pediatric Anesthesia* 16(3):309-313

Vidich, A. J., & Lyman, S. M. (2000). Qualitative methods: Their history in sociology and anthropology. In N. K. Denzin, & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 37-84). Thousand Oaks, California. Sage.

Wainstein, BK., Sterling-Levis, k., Baker, SA., Taitz, J & Brydon, M (20060 Use of the Internet by parents of paediatric patients*. Journal of Paediatrics and Child Health.* 42(9):528-532

Walford, G. (2005). Research ethical guidelines and anonymity. *International Journal of Research & Method in Education*. 28, 83–93.

Waters, LA. (2008) An ethnography of a children's renal unit: experiences of children and young people with long-term renal illness. *Journal of Clinical Nursing*. 17(23):3103-3114.

Welie, JVM. & Welie, SPK. (2001) Patient decision making competence: Outlines of a conceptual analysis. *Medicine, Health Care and Philosophy* 4:127–138

Wellesley, H. & Jenkins, I.A. (2009) Withholding and withdrawing life sustaining treatment in children. Paediatric Anaesthesia. 19:972-978.

Weiss EM, Xie D, Cook N, Coughlin K, Joffe S. (2018) Characteristics associated with preferences for parent-centered decision making in neonatal intensive care. JAMA *Pediatrics*. 172(5):461–468austin

Weiss EM, Barg FK, Cook N, Black E, Joffe S. (2016) Parental decision-making preferences in neonatal intensive care. *Journal of Pediatrics.* 179:36–41.e3

Weiss, J., Zoffman, V. & Ergood, I. (2015) Enhancing person-centred communication in NICU: a comparative thematic analysis. *Nursing in Critical Care.* 20(6):287-298

Whitney, SN. (2003) A new model of medical decisions: exploring the limits of shared decision making. *Medical Decision Making*. 23:275–80.

Wightman, A., Largent, e., Del Beccaro, M., Lantos, JD (2014) Who Should Get the Last PICU Bed? *Pediatrics*. 133(5):907-912

Wilkinson, D. (2017) Restoring balance to "best interests" disputes in children. British Medical Journal. *British Medical Journal*.358:j3666 doi.org/10.1136/bmj.j3666 (last accessed 24/08/19)

Wilkinson, D., Truog, R. and Savulescu, J. (2016) In favour of dissensus: why we should agree to disagree about end-of-life decisions. *Bioethics.* 30: 109-118.

Wilkinson, D. & Truog, R. (2013) The luck of the draw: physician-related variability in end-of-life decision-making in intensive care. *Intensive Care Medicine*. 39:1128–1132

Wilkinson, DJC. & Savulescu, J. (2011) Knowing when to stop: futility in the intensive care unit. *Current Opinion in Anaesthesiolgy*. 24(2): 160–165.

Winters, J. & Balou, K. (2004) The idea of Nursing Science. *Journal of Advanced Nursing.* Vol.45 No. 5: 533-535.

Wirtz. V., Cribb, A. & Barber, N. (2006) Patient-doctor decision-makingabout treatment within the consultation—a critical analysis of models. *Social Science Medicine*. 62:116–24.

Wocial, LD. (2000) Life support decisions involving imperiled infants. *Journal of Perinatal and Neonatal Nursing*. 14: 73– 86.

Wolcott, H.F. (1994) *Transforming Qualitative Data: Description, Analysis & Interpretation*. London. Sage Publications Ltd.

Wolfinger, NH. (2002) On writing fieldnotes: collection strategies and background expectancies. *Qualitative Research*. 2(1): 85-93

Wong, N. & King, T. (2008) The Cultural Construction of Risk Understandings through Illness Narratives. *Journal of Consumer Research.* 34(5): 579–594,

Woods, S. (2008) Best interests: puzzles and plausible solutions at the end of life. *Health Care Analysis*. 16(3): 279-287.

Wu, J. Springett, A,. Morris, J. (2013) Survival of trisomy 18 (Edwards syndrome) and trisomy 13 (Patau Syndrome) in England and Wales: 2004–2011. *American Journal of Medical Genetics* 161(10):2512-2518

Yardi, S., Caldwell P., Barnes, E., Scott, K. (2018) Determining parents' patterns of behaviour when searching for online information on their child's health. *Journal of Paediatrics and Child Health*. 54:1246–1254

Yin, R.K (2009) Case Study Research: Design and Methods. 4th Edition. London. SAGE Publications Ltd.

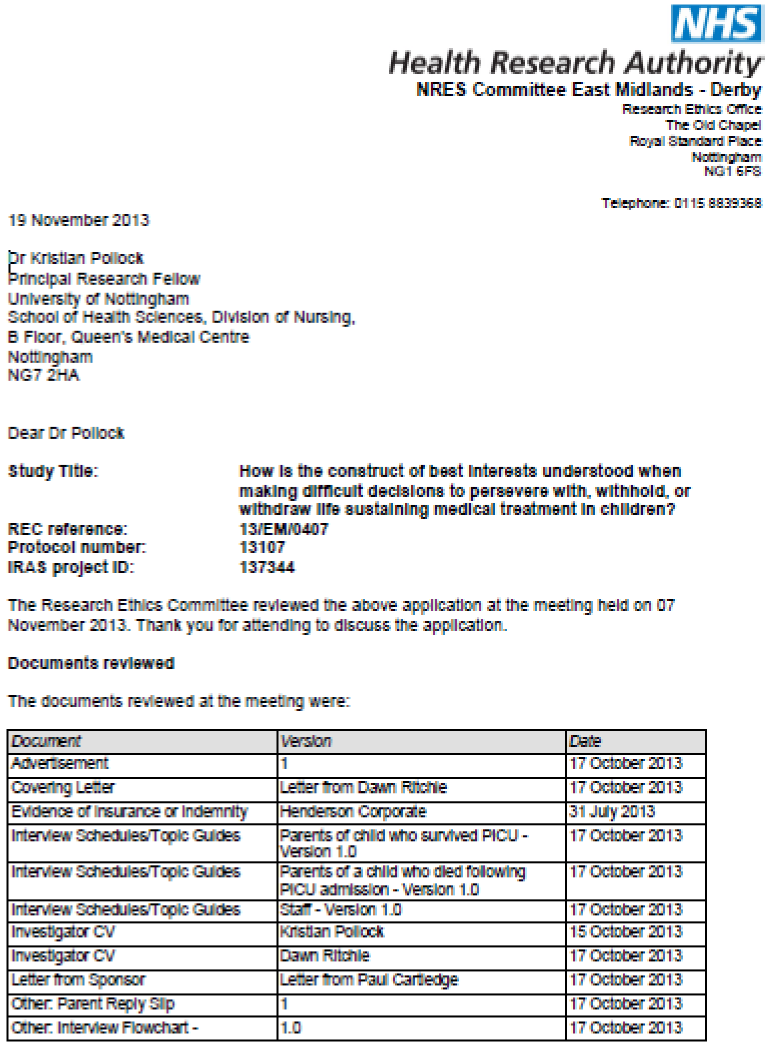
Yorke, D. (2011) Parents' memories of having a child die in the PICU. The World of Critical Care Nursing. 8:97–102.

Zamperetti, N., Bellamo, R. & Ronco, C. (2003) Defining death in non-heart beating organ donors. Journal of Medical Ethics 29(3): 182-185.

Appendices

Appendix 1: Ethics approvals

November 2013



NHS
Health Research Authority
NRES Committee East Midlands - Derby
Research Ethics Office
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839368

19 November 2013

Dr Kristian Pollock
Principal Research Fellow
University of Nottingham
School of Health Sciences, Division of Nursing,
B Floor, Queen's Medical Centre
Nottingham
NG7 2HA

Dear Dr Pollock

Study Title:	**How is the construct of best interests understood when making difficult decisions to persevere with, withhold, or withdraw life sustaining medical treatment in children?**
REC reference:	**13/EM/0407**
Protocol number:	**13107**
IRAS project ID:	**137344**

The Research Ethics Committee reviewed the above application at the meeting held on 07 November 2013. Thank you for attending to discuss the application.

Documents reviewed

The documents reviewed at the meeting were:

Document	*Version*	*Date*
Advertisement	1	17 October 2013
Covering Letter	Letter from Dawn Ritchie	17 October 2013
Evidence of insurance or indemnity	Henderson Corporate	31 July 2013
Interview Schedules/Topic Guides	Parents of child who survived PICU - Version 1.0	17 October 2013
Interview Schedules/Topic Guides	Parents of a child who died following PICU admission - Version 1.0	17 October 2013
Interview Schedules/Topic Guides	Staff - Version 1.0	17 October 2013
Investigator CV	Kristian Pollock	15 October 2013
Investigator CV	Dawn Ritchie	17 October 2013
Letter from Sponsor	Letter from Paul Cartledge	17 October 2013
Other: Parent Reply Slip	1	17 October 2013
Other: Interview Flowchart -	1.0	17 October 2013

Observation		
Other: Interview Flowchart - Interviews	1.0	17 October 2013
Participant Consent Form: Parent - Observation	1.0	17 October 2013
Participant Consent Form: Parent - Interview	1.0	17 October 2013
Participant Consent Form: Staff	1.0	17 October 2013
Participant Information Sheet: Parent	1.0	17 October 2013
Participant Information Sheet: Staff	1.0	17 October 2013
Participant Information Sheet: Information Pamphlet	1	17 October 2013
Protocol	1.0	17 October 2013
REC application	137344/515304/1/264	17 October 2013
Referees or other scientific critique report	Email from Lindsay McLoughlin	18 October 2013
Referees or other scientific critique report	Email from Harish Vyas	07 August 2013
Referees or other scientific critique report	Letter from Sue Mager	07 August 2013

Provisional opinion

The Chair asked you whether the use of a poster to advertise the study in PICU might result in parents of children who are not expected to die expressing an interest in the study but being rejected, which may lead to the identification of children who are likely to die but whose families have not been given their prognosis. You advised that you have consulted with the clinical team at PICU and also with Research and Innovation at the Trust, who have both advised you to use a poster to ensure you are being explicit and obvious regarding the study taking place on the ward, and to ensure families and staff are aware why the observations are being conducted within the unit. You also advised the Committee that families whose children are inpatients in PICU are ordinarily aware of the seriousness of their condition.

The Chair asked you to ensure consent is taken from staff during the observation phase of the study, which would also ensure good coordination when planning staff and families being present on the unit at the same time. You advised that you chose to use the "opt out" method after consulting with the PICU staff and the Research and Innovation Department at the Trust. The reasoning behind this was that most staff are aware that research participation is very common in the Trust and staff are more familiar with the "opt out" format. Staff are being briefed about the study for 1-2 months at the start of it and this will allow you to attend the PICU and meet with all staff who will be encouraged to ask any questions and ensure they are fully aware of the study.

The Chair asked you if you have considered other members of the Trust staff attending the unit to perform routine tasks, such as Radiographers, and how they would be observed as part of the study without consent. You advised that the unit is a semi-public environment and the use of the poster will ensure staff and the public are aware that the observations are likely to be taking place whilst they are on the unit. You also confirmed that they will only be observing the interactions between the family and the immediate clinical care team within PICU.

The Chair asked you if you have deliberately avoided including any mention of religious beliefs on the PIS. You confirmed that you had considered including this but as the UK does not have an especially high number of practicing Christians; any mention of religious beliefs during the observation and interview phases will be recorded as part of the study.

The Chair asked you how you would deal with any disclosure during the observation phase of the study. You advised that all staff within the trust have a professional obligation to report any suspicion of poor practice. The Chair agreed with this but advised that for complete transparency, you should include details of this in the PIS.

The Chair asked you to clarify the process of retrospective consent for the observation phase. You confirmed that as the average length of stay on the PICU has dropped to around 2 ½ days the initial arrival of the child is often extremely intense so it is not considered appropriate to take consent at this stage. Retrospective consent is therefore taken once the observations have been completed and it is the parent's right to refuse their consent at this stage. If consent is refused, you confirmed that you will withdraw any information gathered during the observations.

The Chair queried whether the transcription service is confidential. You confirmed that all members of the transcription service have signed a confidentiality agreement.

The Committee is unable to give an ethical opinion on the basis of the information and documentation received so far. Before confirming its opinion, the Committee requests that you provide the further information set out below.

Authority to consider your response and to confirm the Committee's final opinion has been delegated to the Chair.

Further information or clarification required

1. The Committee would like you to check the contact details for NHS Direct Complaints Service, to ensure that this is correct information.
2. The Committee would like you to create a Consent Form for staff to opt in to the observation phase of the study.
3. The Committee would like you to include details in the PIS of what steps would be taken if there was a disclosure during the observation phase.
4. The Committee would like clarification in the PIS on who "authorised persons" are.

If you would find it helpful to discuss any of the matters raised above or seek further clarification from a member of the Committee, you are welcome to contact Tracy Leavesley, REC Manager on NRESCommittee.EastMidlands-Derby@nhs.net

When submitting your response to the Committee, please send revised documentation where appropriate underlining or otherwise highlighting the changes you have made and giving revised version numbers and dates.

If the committee has asked for clarification or changes to any answers given in the application form, please do not submit a revised copy of the application form; these can be addressed in a covering letter to the REC.

The Committee will confirm the final ethical opinion within a maximum of 60 days from the date of initial receipt of the application, excluding the time taken by you to respond fully to the above points. A response should be submitted by no later than 19 December 2013.

Membership of the Committee

The members of the Committee who were present at the meeting are listed on the attached sheet.

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

13/EM/0407	**Please quote this number on all correspondence**

Yours sincerely

Mr Peter Korczak (Chair)

Email: NRESCommittee.EastMidlands-Derby@nhs.net

Enclosures:	*List of names and professions of members who were present at the meeting and those who submitted written comments.*
Copy to:	*Mr Paul Cartledge, Nottingham University* *Dr Tim Dumbleton, Nottingham University Hospitals NHS Trust*

NRES Committee East Midlands - Derby

Attendance at Committee meeting on 07 November 2013

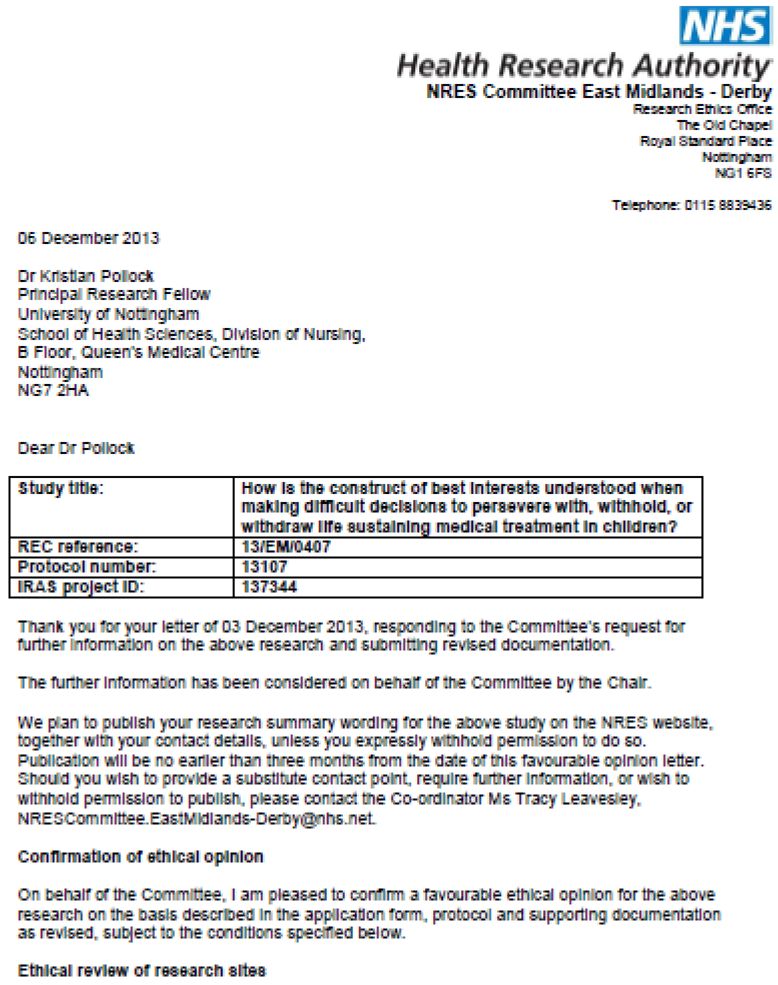
Committee Members:

Name	*Profession*	*Present*	*Notes*
Dr Charles Beck	Lecturer & Honorary Specialty Registrar in Public Health	No	
Mr Peter Fox	Principal Pharmacist	No	
Mr David Grenz	Lay Member	Yes	
Dr Brian Hands	General Practitioner	Yes	
Dr David Henson	Principal Clinical Biochemist	Yes	
Mr Phil Hopkinson	Retired Mental Health Act Manager	Yes	
Mr Peter Korczak (Chair)	Consultant Maxillo-facial Surgeon	Yes	
Mrs Janet Mallett	Lay Member	Yes	
Dr Helen Sammons (Vice Chair)	Associate Professor in Child Health	No	
Dr Penny Smith	Lay Member	Yes	
Dr Nicholas Taub	Research Fellow in Medical Statistics	Yes	
Mr Michael Wakeman	Consultant Pharmacist	Yes	
Mrs Anne Walker	Lay Member	Yes	

Also in attendance:

Name	*Position (or reason for attending)*
Mr Paul Hamilton	Ethics Officer
Dr Nicola James	Observer
Ms Tracy Leavesley	REC Manager

December 2013



NHS
Health Research Authority
NRES Committee East Midlands - Derby
Research Ethics Office
The Old Chapel
Royal Standard Place
Nottingham
NG1 6FS

Telephone: 0115 8839436

06 December 2013

Dr Kristian Pollock
Principal Research Fellow
University of Nottingham
School of Health Sciences, Division of Nursing,
B Floor, Queen's Medical Centre
Nottingham
NG7 2HA

Dear Dr Pollock

Study title:	**How is the construct of best interests understood when making difficult decisions to persevere with, withhold, or withdraw life sustaining medical treatment in children?**
REC reference:	**13/EM/0407**
Protocol number:	**13107**
IRAS project ID:	**137344**

Thank you for your letter of 03 December 2013, responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the NRES website, together with your contact details, unless you expressly withhold permission to do so. Publication will be no earlier than three months from the date of this favourable opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to withhold permission to publish, please contact the Co-ordinator Ms Tracy Leavesley, NRESCommittee.EastMidlands-Derby@nhs.net.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Ethical review of research sites

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of approvals from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Advertisement	1	17 October 2013
Covering Letter	Letter from Dawn Ritchie	17 October 2013
Evidence of insurance or indemnity	Henderson Corporate	31 July 2013
Interview Schedules/Topic Guides	Parents of child who survived PICU - Version 1.0	17 October 2013
Interview Schedules/Topic Guides	Parents of a child who died following PICU admission - Version 1.0	17 October 2013
Interview Schedules/Topic Guides	Staff - Version 1.0	17 October 2013
Investigator CV	Kristian Pollock	15 October 2013
Investigator CV	Dawn Ritchie	17 October 2013
Letter from Sponsor	Letter from Paul Cartledge	17 October 2013
Other: Parent Reply Slip	1	17 October 2013
Other: Interview Flowchart - Observation	1.0	17 October 2013
Other: Interview Flowchart - Interviews	1.0	17 October 2013
Participant Consent Form: Parent - Observation	1.0	17 October 2013
Participant Consent Form: Parent - Interview	1.0	17 October 2013
Participant Consent Form: Staff	1.0	17 October 2013
Participant Consent Form: Staff (Observation)	1.1	28 November 2013
Participant Information Sheet: Staff	1.0	17 October 2013
Participant Information Sheet: Information Pamphlet	1	17 October 2013
Participant Information Sheet: Staff	1.1	28 November 2013
Participant Information Sheet: Parents	1.1	28 November 2013
Protocol	1.0	17 October 2013
REC application	137344/515304/1/264	17 October 2013
Referees or other scientific critique report	Email from Lindsay McLoughlin	18 October 2013
Referees or other scientific critique report	Email from Harish Vyas	07 August 2013
Referees or other scientific critique report	Letter from Sue Mager	07 August 2013
Response to Request for Further Information	Letter from Dawn Ritchie	03 December 2013

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document *"After ethical review – guidance for researchers"* gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

13/EM/0407 **Please quote this number on all correspondence**

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

With the Committee's best wishes for the success of this project.

Yours sincerely

pp C Halliwell

Mr Peter Korczak (Chair)

Email:NRESCommittee.EastMidlands-Derby@nhs.net

Enclosures: "After ethical review – guidance for researchers"

Copy to: *Mr Paul Cartledge*
Dr Tim Dumbleton, Nottingham University Hospitals NHS Trust

Appendix 2: Information leaflet

Confidentiality

All information given to the researchers during the Primacy Study will be kept strictly confidential, and only the researchers will have access to the notes and tapes. It will be used exclusively for research purposes. Every care will be taken so that no-one can be identified from anything written in any reporting of the findings.

Who is the main study researcher?

The study is being conducted by Dawn Ritchie, a qualified Children's Intensive Care Nurse with many years experience in caring for very sick children and their families. Dawn is a research student at the University of Nottingham carrying out this research into decision making as part of her doctoral studies.

The PRIMACY project Final Version1 17 October 2013

Further information and contact details.

If you are interested in taking part in this study, or would like more information about this research project please contact:

Dawn Ritchie
PhD Student
School of Health Sciences
University of Nottingham
B Floor, Queen's Medical Centre
Nottingham, NG7 2HA

Phone: 0115 823980

Email: dawn.ritchie@nottingham.ac.uk

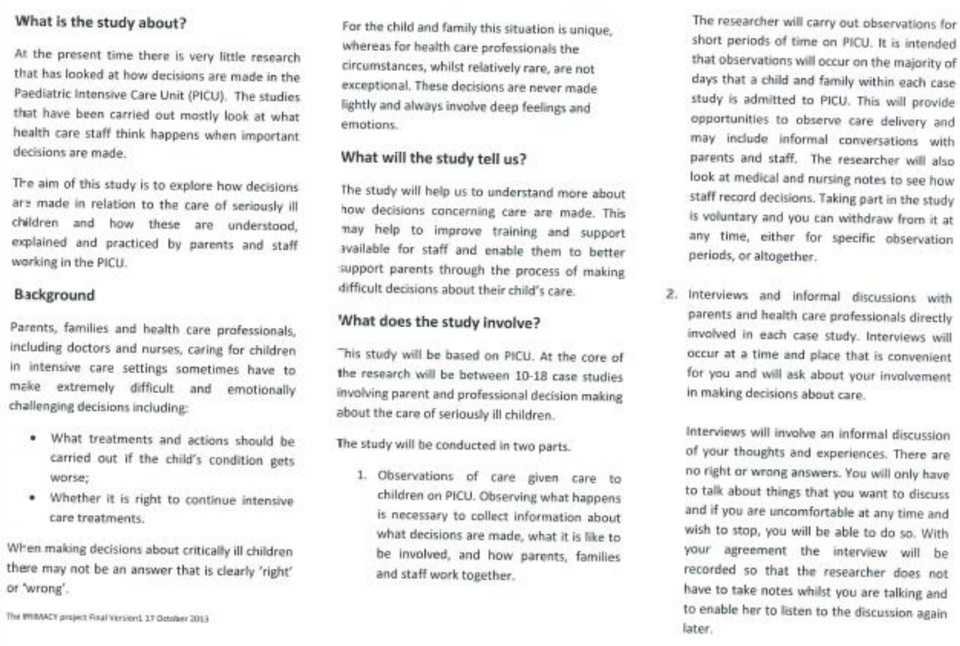
The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

The Primacy Project:

Making Difficult Decisions in the Paediatric Intensive Care Unit

(PICU)

[redacted]



What is the study about?

At the present time there is very little research that has looked at how decisions are made in the Paediatric Intensive Care Unit (PICU). The studies that have been carried out mostly look at what health care staff think happens when important decisions are made.

The aim of this study is to explore how decisions are made in relation to the care of seriously ill children and how these are understood, explained and practiced by parents and staff working in the PICU.

Background

Parents, families and health care professionals, including doctors and nurses, caring for children in intensive care settings sometimes have to make extremely difficult and emotionally challenging decisions including:

- What treatments and actions should be carried out if the child's condition gets worse;
- Whether it is right to continue intensive care treatments.

When making decisions about critically ill children there may not be an answer that is clearly 'right' or 'wrong'.

The PRIMACY project Final Version1 17 October 2013

For the child and family this situation is unique, whereas for health care professionals the circumstances, whilst relatively rare, are not exceptional. These decisions are never made lightly and always involve deep feelings and emotions.

What will the study tell us?

The study will help us to understand more about how decisions concerning care are made. This may help to improve training and support available for staff and enable them to better support parents through the process of making difficult decisions about their child's care.

What does the study involve?

This study will be based on PICU. At the core of the research will be between 10-18 case studies involving parent and professional decision making about the care of seriously ill children.

The study will be conducted in two parts.

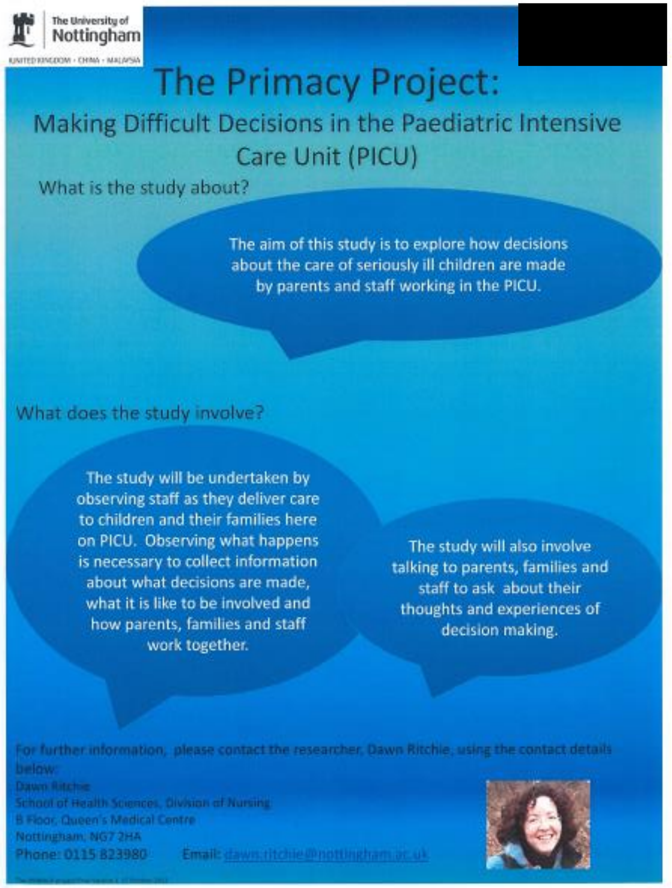
1. Observations of care given care to children on PICU. Observing what happens is necessary to collect information about what decisions are made, what it is like to be involved, and how parents, families and staff work together.

   The researcher will carry out observations for short periods of time on PICU. It is intended that observations will occur on the majority of days that a child and family within each case study is admitted to PICU. This will provide opportunities to observe care delivery and may include informal conversations with parents and staff. The researcher will also look at medical and nursing notes to see how staff record decisions. Taking part in the study is voluntary and you can withdraw from it at any time, either for specific observation periods, or altogether.

2. Interviews and informal discussions with parents and health care professionals directly involved in each case study. Interviews will occur at a time and place that is convenient for you and will ask about your involvement in making decisions about care.

   Interviews will involve an informal discussion of your thoughts and experiences. There are no right or wrong answers. You will only have to talk about things that you want to discuss and if you are uncomfortable at any time and wish to stop, you will be able to do so. With your agreement the interview will be recorded so that the researcher does not have to take notes whilst you are talking and to enable her to listen to the discussion again later.

Appendix 3: Information poster



[redacted]

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

The Primacy Project:

Making Difficult Decisions in the Paediatric Intensive Care Unit (PICU)

What is the study about?

The aim of this study is to explore how decisions about the care of seriously ill children are made by parents and staff working in the PICU.

What does the study involve?

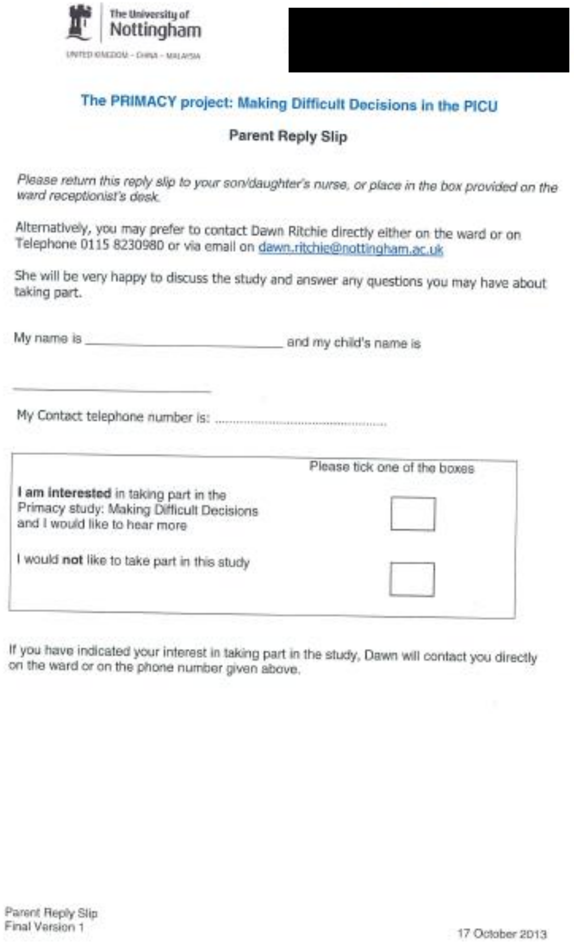
The study will be undertaken by observing staff as they deliver care to children and their families here on PICU. Observing what happens is necessary to collect information about what decisions are made, what it is like to be involved and how parents, families and staff work together.

The study will also involve talking to parents, families and staff to ask about their thoughts and experiences of decision making.

For further information, please contact the researcher, Dawn Ritchie, using the contact details below:

Dawn Ritchie
School of Health Sciences, Division of Nursing
B Floor, Queen's Medical Centre
Nottingham, NG7 2HA
Phone: 0115 823980 Email: dawn.ritchie@nottingham.ac.uk

Appendix 4: Parent reply slip



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

The PRIMACY project: Making Difficult Decisions in the PICU

Parent Reply Slip

Please return this reply slip to your son/daughter's nurse, or place in the box provided on the ward receptionist's desk.

Alternatively, you may prefer to contact Dawn Ritchie directly either on the ward or on Telephone 0115 8230980 or via email on dawn.ritchie@nottingham.ac.uk

She will be very happy to discuss the study and answer any questions you may have about taking part.

My name is ______________________ and my child's name is

____

My Contact telephone number is: ....

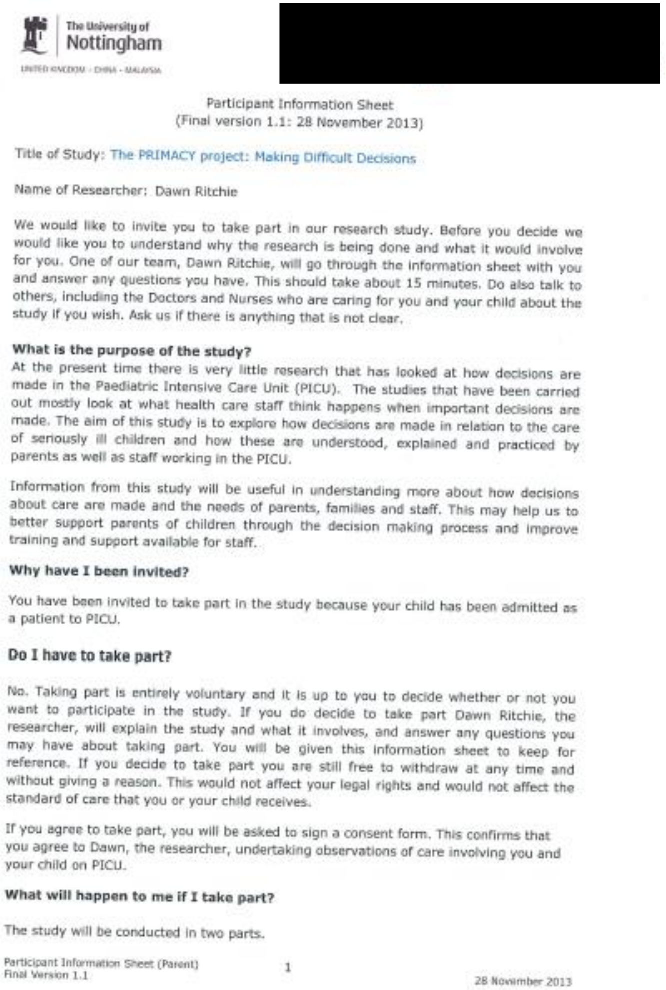
	Please tick one of the boxes
I am interested in taking part in the Primacy study: Making Difficult Decisions and I would like to hear more	☐
I would **not** like to take part in this study	☐

If you have indicated your interest in taking part in the study, Dawn will contact you directly on the ward or on the phone number given above.

Parent Reply Slip
Final Version 1

17 October 2013

Appendix 5: Parent information sheet



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

Participant Information Sheet
(Final version 1.1: 28 November 2013)

Title of Study: The PRIMACY project: Making Difficult Decisions

Name of Researcher: Dawn Ritchie

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team, Dawn Ritchie, will go through the information sheet with you and answer any questions you have. This should take about 15 minutes. Do also talk to others, including the Doctors and Nurses who are caring for you and your child about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?
At the present time there is very little research that has looked at how decisions are made in the Paediatric Intensive Care Unit (PICU). The studies that have been carried out mostly look at what health care staff think happens when important decisions are made. The aim of this study is to explore how decisions are made in relation to the care of seriously ill children and how these are understood, explained and practiced by parents as well as staff working in the PICU.

Information from this study will be useful in understanding more about how decisions about care are made and the needs of parents, families and staff. This may help us to better support parents of children through the decision making process and improve training and support available for staff.

Why have I been invited?

You have been invited to take part in the study because your child has been admitted as a patient to PICU.

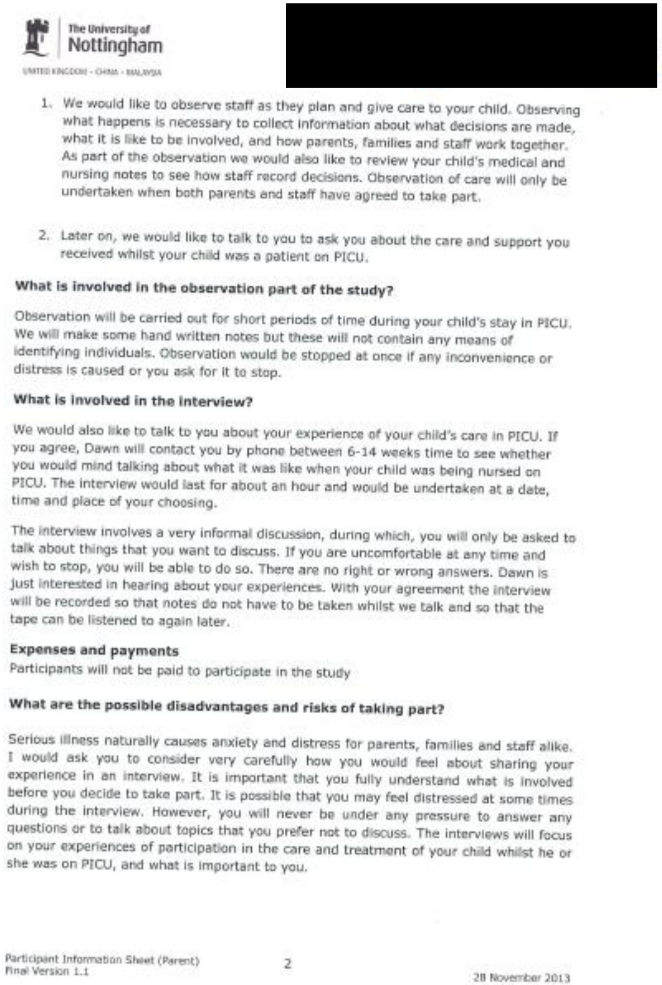
Do I have to take part?

No. Taking part is entirely voluntary and it is up to you to decide whether or not you want to participate in the study. If you do decide to take part Dawn Ritchie, the researcher, will explain the study and what it involves, and answer any questions you may have about taking part. You will be given this information sheet to keep for reference. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights and would not affect the standard of care that you or your child receives.

If you agree to take part, you will be asked to sign a consent form. This confirms that you agree to Dawn, the researcher, undertaking observations of care involving you and your child on PICU.

What will happen to me if I take part?

The study will be conducted in two parts.



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

1. We would like to observe staff as they plan and give care to your child. Observing what happens is necessary to collect information about what decisions are made, what it is like to be involved, and how parents, families and staff work together. As part of the observation we would also like to review your child's medical and nursing notes to see how staff record decisions. Observation of care will only be undertaken when both parents and staff have agreed to take part.

2. Later on, we would like to talk to you to ask you about the care and support you received whilst your child was a patient on PICU.

What is involved in the observation part of the study?

Observation will be carried out for short periods of time during your child's stay in PICU. We will make some hand written notes but these will not contain any means of identifying individuals. Observation would be stopped at once if any inconvenience or distress is caused or you ask for it to stop.

What is involved in the interview?

We would also like to talk to you about your experience of your child's care in PICU. If you agree, Dawn will contact you by phone between 6-14 weeks time to see whether you would mind talking about what it was like when your child was being nursed on PICU. The interview would last for about an hour and would be undertaken at a date, time and place of your choosing.

The interview involves a very informal discussion, during which, you will only be asked to talk about things that you want to discuss. If you are uncomfortable at any time and wish to stop, you will be able to do so. There are no right or wrong answers. Dawn is just interested in hearing about your experiences. With your agreement the interview will be recorded so that notes do not have to be taken whilst we talk and so that the tape can be listened to again later.

Expenses and payments
Participants will not be paid to participate in the study

What are the possible disadvantages and risks of taking part?

Serious illness naturally causes anxiety and distress for parents, families and staff alike. I would ask you to consider very carefully how you would feel about sharing your experience in an interview. It is important that you fully understand what is involved before you decide to take part. It is possible that you may feel distressed at some times during the interview. However, you will never be under any pressure to answer any questions or to talk about topics that you prefer not to discuss. The interviews will focus on your experiences of participation in the care and treatment of your child whilst he or she was on PICU, and what is important to you.

[redacted]

What are the possible benefits of taking part?

We cannot promise the study will help you directly, but the information we get from this study may contribute to a greater understanding of how decisions are made in the treatment of seriously ill children on the PICU, and how parents and staff may work together to secure the best interests of children cared for on these units.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet.

You can discuss your concerns and seek advice form the Patient Advice Liaison Service (PALS) at QMC: Freephone 0800183 0204 or via mobile phone on 0115 924 9924 ext 65412 or 62301

If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints through NHS Direct on 0845 4647 or at

http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, the research study team who are organising the research will look at your data collected for the study. In order to check that the study is being carried out correctly research data may be reviewed by authorised individuals from the University of Nottingham Research Governance department, the Research Ethics Committee and Nottingham University Hospitals Research & Innovation department. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information which is collected about you during the course of the research will be kept **strictly confidential**, stored in a secure and locked office, and on a password protected database. Any information about you which leaves the hospital will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (name and contact details) will be kept for one year after the end of the study so that we are able to contact you about the findings of the study and possible follow up studies (unless you advise us that you do not wish to be contacted).

All other data (research data) will be kept securely for 7 years. After this time the data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality. Only members of the research team will have access to your personal data.

[redacted]

The only circumstances in which confidentiality might be broken would arise if you disclosed something which we feel puts you or anyone else at risk. In this case we would discuss with you the necessity of reporting this to the appropriate persons or services.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason, and without your legal rights being affected. If you withdraw then the information collected so far cannot be erased and this information may still be used in the project analysis.

What will happen to the results of the research study?

The findings from the study will form part of Dawn Ritchie's PhD dissertation and will also be used for professional publications in nursing/medical journals and conference presentations. Everyone who takes part in the study will be offered a summary of the results.

Who is organising and funding the research?

This research is being organised by the University of Nottingham and is being self funded by the investigator, Dawn Ritchie. Dawn is a qualified Children's Intensive Care Nurse with many years experience in caring for very sick children and their families. She is now a research student at the University of Nottingham and as part of her doctoral studies is carrying out this research into decision-making.

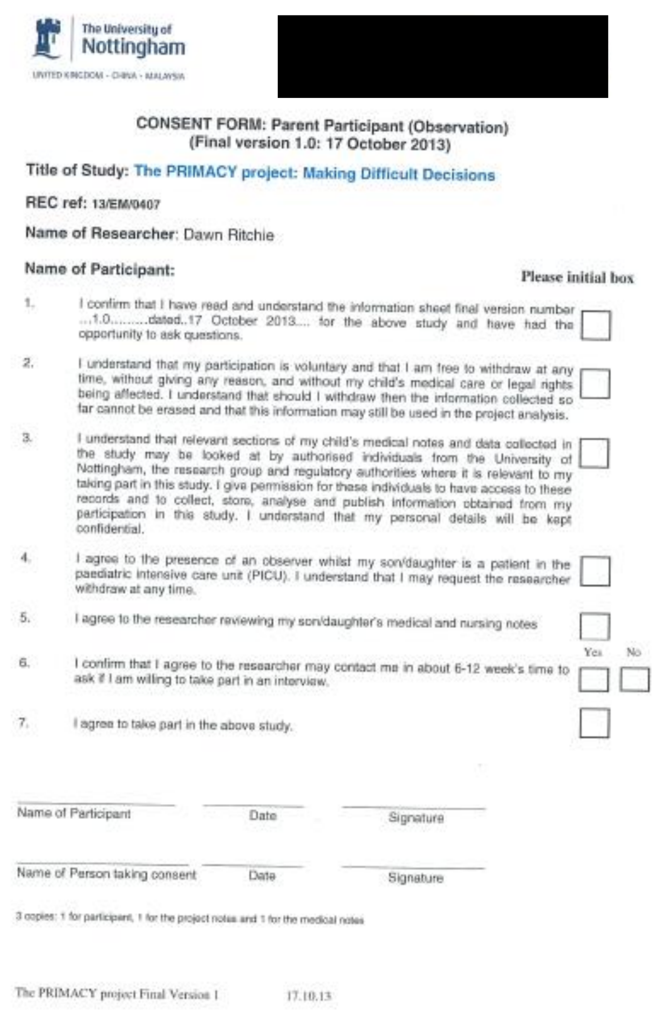
Who has reviewed the study?

All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by Derby Research Ethics Committee.

If you have any questions or would like further information please contact:

Dawn Ritchie (Researcher)	**Dr Kristian Pollock (Chief Investigator)**
Tel 0115 82 30980	**Tel 0115 82 31211**
E-mail **dawn.ritchie@nottingham.ac.uk**	**E-mail** **kristian.pollock@nottingham.ac.uk**

Appendix 6: Parent consent for observation



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

CONSENT FORM: Parent Participant (Observation)
(Final version 1.0: 17 October 2013)

Title of Study: **The PRIMACY project: Making Difficult Decisions**

REC ref: 13/EM/0407

Name of Researcher: Dawn Ritchie

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet final version number ...1.0.........dated..17 October 2013.... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my child's medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my child's medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I agree to the presence of an observer whilst my son/daughter is a patient in the paediatric intensive care unit (PICU). I understand that I may request the researcher withdraw at any time. ☐
5. I agree to the researcher reviewing my son/daughter's medical and nursing notes ☐
6. I confirm that I agree to the researcher may contact me in about 6-12 week's time to ask if I am willing to take part in an interview. Yes ☐ No ☐
7. I agree to take part in the above study. ☐

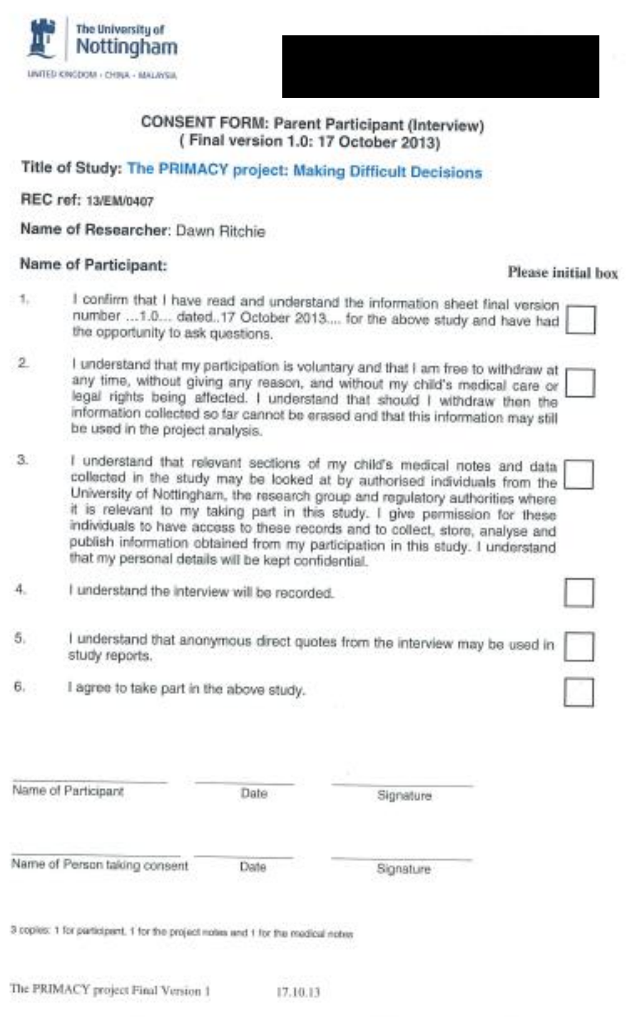
Name of Participant ____ Date ____ Signature ____

Name of Person taking consent ____ Date ____ Signature ____

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

The PRIMACY project Final Version 1 17.10.13

Appendix 7: Parent consent for interview



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

CONSENT FORM: Parent Participant (Interview)
(Final version 1.0: 17 October 2013)

Title of Study: **The PRIMACY project: Making Difficult Decisions**

REC ref: 13/EM/0407

Name of Researcher: Dawn Ritchie

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet final version number ...1.0... dated..17 October 2013.... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my child's medical care or legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my child's medical notes and data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand the interview will be recorded. ☐
5. I understand that anonymous direct quotes from the interview may be used in study reports. ☐
6. I agree to take part in the above study. ☐

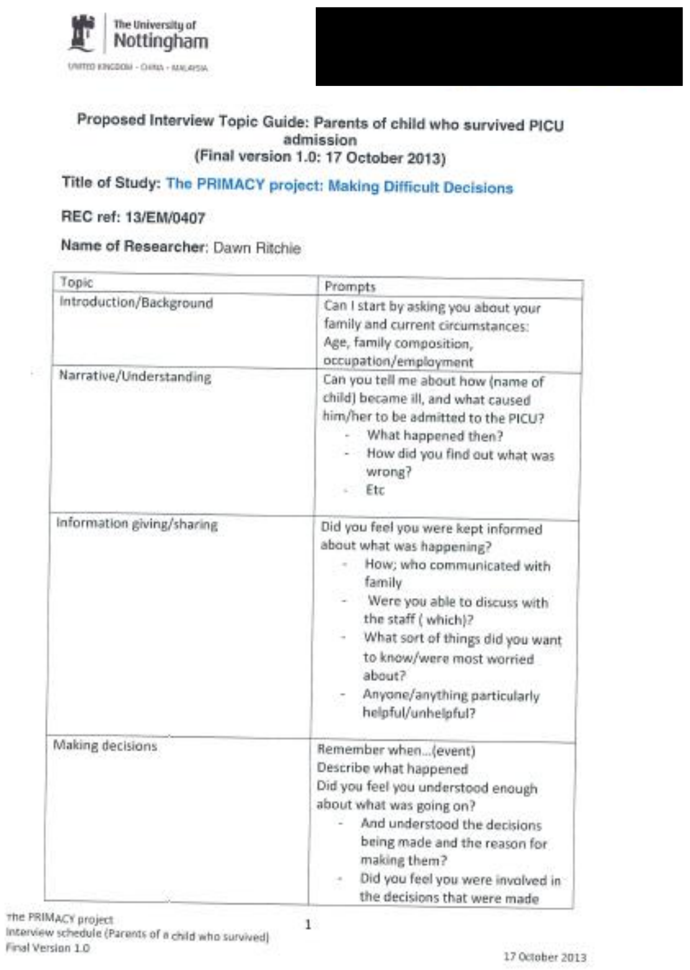
Name of Participant ____ Date ____ Signature ____

Name of Person taking consent ____ Date ____ Signature ____

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

The PRIMACY project Final Version 1 17.10.13

Appendix 8: Parent interview schedule for child who survived admission to PICU



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

Proposed Interview Topic Guide: Parents of child who survived PICU admission
(Final version 1.0: 17 October 2013)

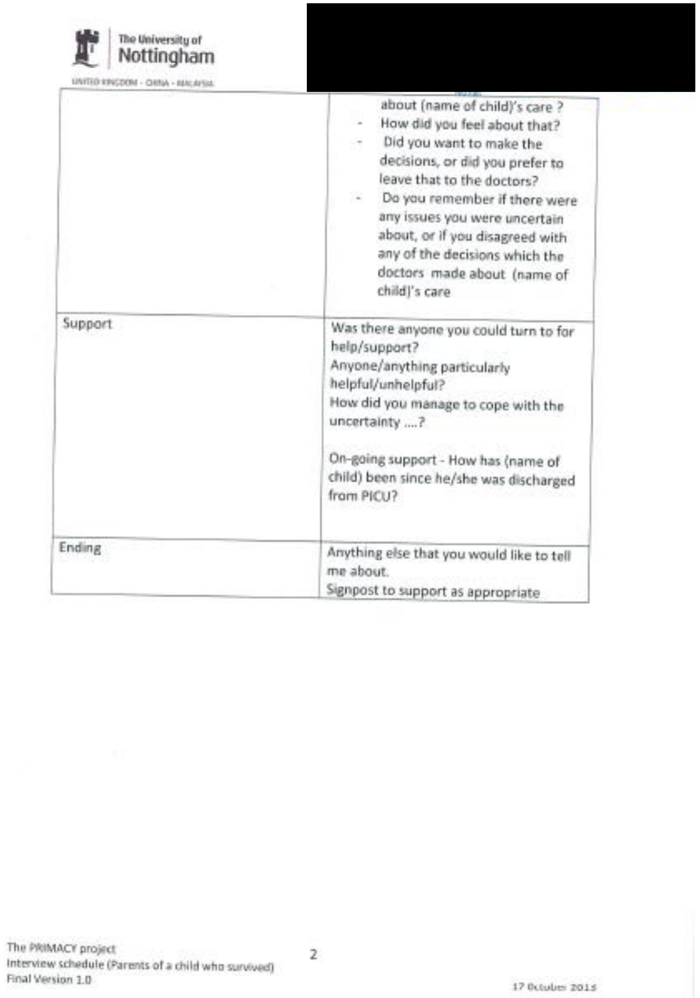
Title of Study: The PRIMACY project: Making Difficult Decisions

REC ref: 13/EM/0407

Name of Researcher: Dawn Ritchie

Topic	Prompts
Introduction/Background	Can I start by asking you about your family and current circumstances: Age, family composition, occupation/employment
Narrative/Understanding	Can you tell me about how (name of child) became ill, and what caused him/her to be admitted to the PICU? - What happened then? - How did you find out what was wrong? - Etc
Information giving/sharing	Did you feel you were kept informed about what was happening? - How; who communicated with family - Were you able to discuss with the staff (which)? - What sort of things did you want to know/were most worried about? - Anyone/anything particularly helpful/unhelpful?
Making decisions	Remember when...(event) Describe what happened Did you feel you understood enough about what was going on? - And understood the decisions being made and the reason for making them? - Did you feel you were involved in the decisions that were made

The PRIMACY project
Interview schedule (Parents of a child who survived)
Final Version 1.0
1
17 October 2013



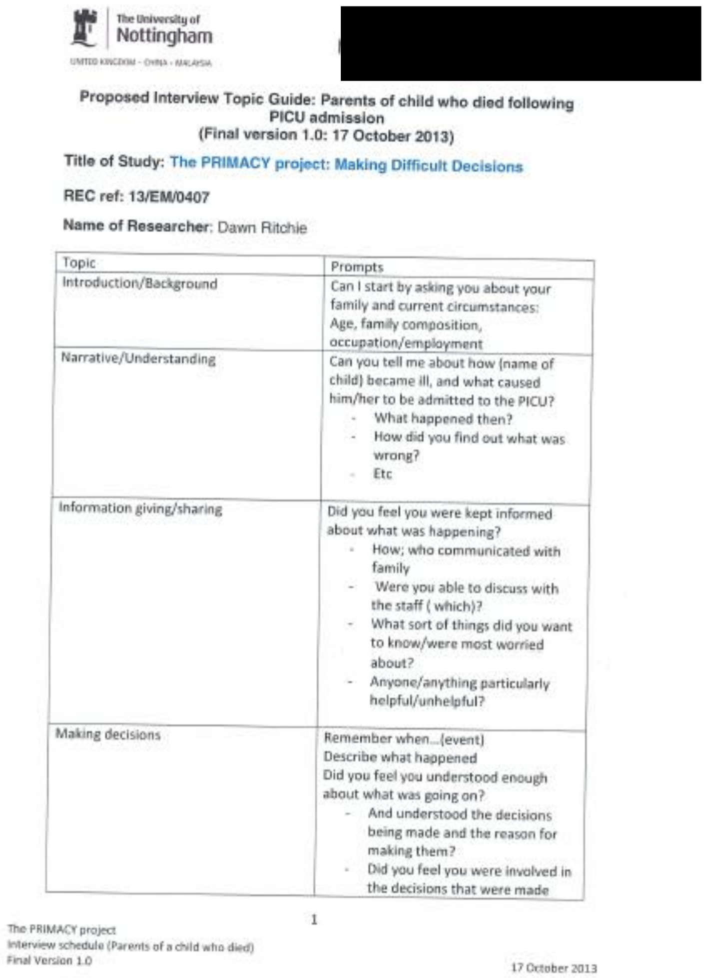
The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

	about (name of child)'s care ? - How did you feel about that? - Did you want to make the decisions, or did you prefer to leave that to the doctors? - Do you remember if there were any issues you were uncertain about, or if you disagreed with any of the decisions which the doctors made about (name of child)'s care
Support	Was there anyone you could turn to for help/support? Anyone/anything particularly helpful/unhelpful? How did you manage to cope with the uncertainty ....? On-going support - How has (name of child) been since he/she was discharged from PICU?
Ending	Anything else that you would like to tell me about. Signpost to support as appropriate

The PRIMACY project
Interview schedule (Parents of a child who survived)
Final Version 1.0
2
17 October 2013

Appendix 9: Parent interview schedule for child who died following admission to PICU



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

Proposed Interview Topic Guide: Parents of child who died following PICU admission
(Final version 1.0: 17 October 2013)

Title of Study: **The PRIMACY project: Making Difficult Decisions**

REC ref: 13/EM/0407

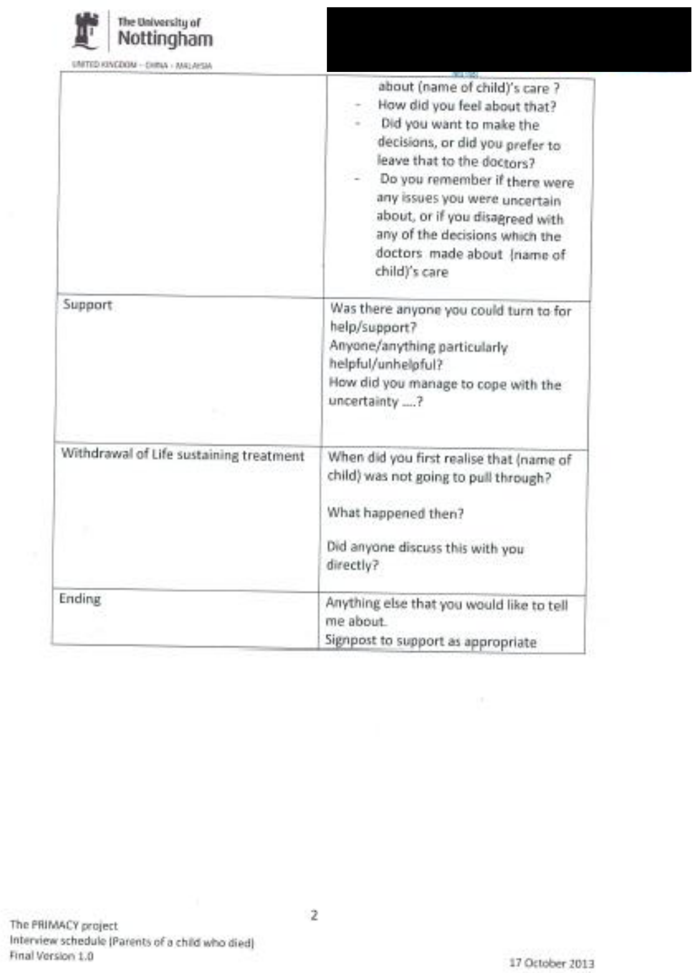
Name of Researcher: Dawn Ritchie

Topic	Prompts
Introduction/Background	Can I start by asking you about your family and current circumstances: Age, family composition, occupation/employment
Narrative/Understanding	Can you tell me about how (name of child) became ill, and what caused him/her to be admitted to the PICU? - What happened then? - How did you find out what was wrong? - Etc
Information giving/sharing	Did you feel you were kept informed about what was happening? - How; who communicated with family - Were you able to discuss with the staff (which)? - What sort of things did you want to know/were most worried about? - Anyone/anything particularly helpful/unhelpful?
Making decisions	Remember when...(event) Describe what happened Did you feel you understood enough about what was going on? - And understood the decisions being made and the reason for making them? - Did you feel you were involved in the decisions that were made

1

The PRIMACY project
Interview schedule (Parents of a child who died)
Final Version 1.0

17 October 2013



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

	about (name of child)'s care ? - How did you feel about that? - Did you want to make the decisions, or did you prefer to leave that to the doctors? - Do you remember if there were any issues you were uncertain about, or if you disagreed with any of the decisions which the doctors made about (name of child)'s care
Support	Was there anyone you could turn to for help/support? Anyone/anything particularly helpful/unhelpful? How did you manage to cope with the uncertainty ....?
Withdrawal of Life sustaining treatment	When did you first realise that (name of child) was not going to pull through? What happened then? Did anyone discuss this with you directly?
Ending	Anything else that you would like to tell me about. Signpost to support as appropriate

2

The PRIMACY project
Interview schedule (Parents of a child who died)
Final Version 1.0

17 October 2013

Appendix 10: Staff participant information sheet

[redacted]

Staff Participant Information Sheet
(Final version 1.1: 28 November 2013)

Title of Study: The PRIMACY project: Making Difficult Decisions

Name of Researcher: Dawn Ritchie

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team, Dawn Ritchie, will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

At the present time there is very little research that has looked at how difficult treatment decisions are made in the Paediatric Intensive Care Unit (PICU). Previous studies have mostly looked at what health care staff think happen when important decisions are made. The aim of this study is to explore how decisions are made in relation to the care of seriously ill children and how these are understood, explained and practiced by parents and staff working in the PICU. The focus of the study will be on observations of care and interventions given to selected children from shortly after admission to PICU and throughout their stay on the unit.

Information from this study will be useful in understanding more about how difficult decisions about care are made and the needs of parents, families and staff. This may help us to better support parents of children through the decision making process and improve training and support available for staff.

Why have I been invited?

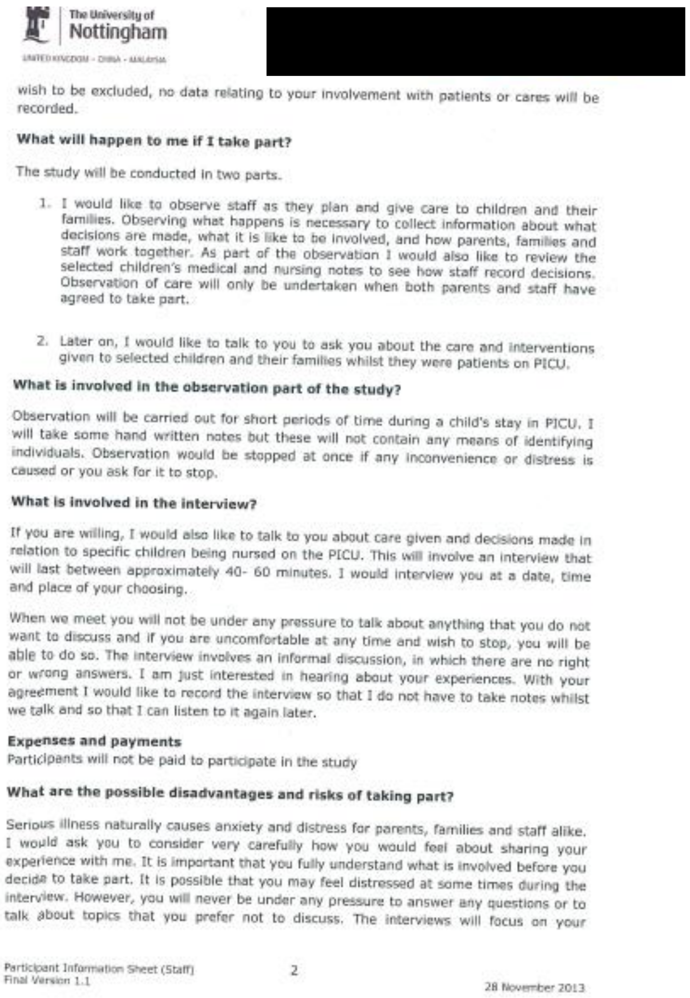
The PICU has been selected as the case study site because it provides regional services to a multi-cultural population. You have been invited to take part in the study because you work as part of the PICU team providing care to children and their families.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. Taking part is entirely voluntary and it is up to you to decide whether or not you want to participate in the study. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

There has been ongoing discussion with senior clinical medical and nursing staff during the planning and design of the study. Their support and permission has been obtained together with permission for the PICU to be the study site for observations of care. You may be involved during the observations of care and interventions given to selected children and families. However you are free to opt out of the study or specific observations at any time, without giving a reason. An opt-out slip is attached. If you do

Participant Information Sheet (Staff) 1
Final Version 1.1 28 November 2013



[redacted]

wish to be excluded, no data relating to your involvement with patients or cares will be recorded.

What will happen to me if I take part?

The study will be conducted in two parts.

1. I would like to observe staff as they plan and give care to children and their families. Observing what happens is necessary to collect information about what decisions are made, what it is like to be involved, and how parents, families and staff work together. As part of the observation I would also like to review the selected children's medical and nursing notes to see how staff record decisions. Observation of care will only be undertaken when both parents and staff have agreed to take part.

2. Later on, I would like to talk to you to ask you about the care and interventions given to selected children and their families whilst they were patients on PICU.

What is involved in the observation part of the study?

Observation will be carried out for short periods of time during a child's stay in PICU. I will take some hand written notes but these will not contain any means of identifying individuals. Observation would be stopped at once if any inconvenience or distress is caused or you ask for it to stop.

What is involved in the interview?

If you are willing, I would also like to talk to you about care given and decisions made in relation to specific children being nursed on the PICU. This will involve an interview that will last between approximately 40- 60 minutes. I would interview you at a date, time and place of your choosing.

When we meet you will not be under any pressure to talk about anything that you do not want to discuss and if you are uncomfortable at any time and wish to stop, you will be able to do so. The interview involves an informal discussion, in which there are no right or wrong answers. I am just interested in hearing about your experiences. With your agreement I would like to record the interview so that I do not have to take notes whilst we talk and so that I can listen to it again later.

Expenses and payments
Participants will not be paid to participate in the study

What are the possible disadvantages and risks of taking part?

Serious illness naturally causes anxiety and distress for parents, families and staff alike. I would ask you to consider very carefully how you would feel about sharing your experience with me. It is important that you fully understand what is involved before you decide to take part. It is possible that you may feel distressed at some times during the interview. However, you will never be under any pressure to answer any questions or to talk about topics that you prefer not to discuss. The interviews will focus on your

Participant Information Sheet (Staff) 2
Final Version 1.1 28 November 2013

[redacted]

experiences of participation in the care and treatment of critically ill children and what is important to you. You can stop an interview, or withdraw from the study at any time

What are the possible benefits of taking part?

We cannot promise the study will help you directly but the information we get from this study may contribute to a greater understanding of how decisions are made in the treatment of seriously ill children on the PICU, and how parents and staff may work together to secure the best interests of children cared for on these units.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researchers who will do their best to answer your questions. The researchers contact details are given at the end of this information sheet.

You can discuss your concerns and seek advice from Dr Patrick Davies, (Consultant Paediatric Intensivist / PICU Clinical Lead or Ms Sue Major (PICU Ward Manager)

If you remain unhappy and wish to complain formally, you can do this by contacting NHS Complaints through NHS Direct on 0845 4647 or at
http://www.nhs.uk/choiceintheNHS/Rightsandpledges/complaints/Pages/NHScomplaints.aspx

Will my taking part in the study be kept confidential?

We will follow ethical and legal practice and all information about you will be handled in confidence. If you join the study, the research study team who are organising the research will look at your data collected for the study. In order to check that the study is being carried out correctly research data may be reviewed by authorised individuals from the University of Nottingham Research Governance department, the Research Ethics Committee and Nottingham University Hospitals Research & Innovation department. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information, which is collected about you during the course of the research, will be kept **strictly confidential**, stored in a secure and locked office, and on a password-protected database. Any information about you, which leaves the hospital, will have your name and address removed (anonymised) and a unique code will be used so that you cannot be recognised from it.

Your personal data (name and current PICU role) will be kept for 12 months after the end of the study so that we are able to contact you about the findings of the study and possible follow up studies (unless you advise us that you do not wish to be contacted).

All other data (research data) will be kept securely for 7 years. After this time the data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality. Only members of the research team will have access to your personal data.

[redacted]

Staff Participant Information Sheet
(Final version 1.1: 28 November 2013)

Title of Study: The PRIMACY project: Making Difficult Decisions

Name of Researcher: Dawn Ritchie

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. One of our team, Dawn Ritchie, will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

At the present time there is very little research that has looked at how difficult treatment decisions are made in the Paediatric Intensive Care Unit (PICU). Previous studies have mostly looked at what health care staff think happen when important decisions are made. The aim of this study is to explore how decisions are made in relation to the care of seriously ill children and how these are understood, explained and practiced by parents and staff working in the PICU. The focus of the study will be on observations of care and interventions given to selected children from shortly after admission to PICU and throughout their stay on the unit.

Information from this study will be useful in understanding more about how difficult decisions about care are made and the needs of parents, families and staff. This may help us to better support parents of children through the decision making process and improve training and support available for staff.

Why have I been invited?

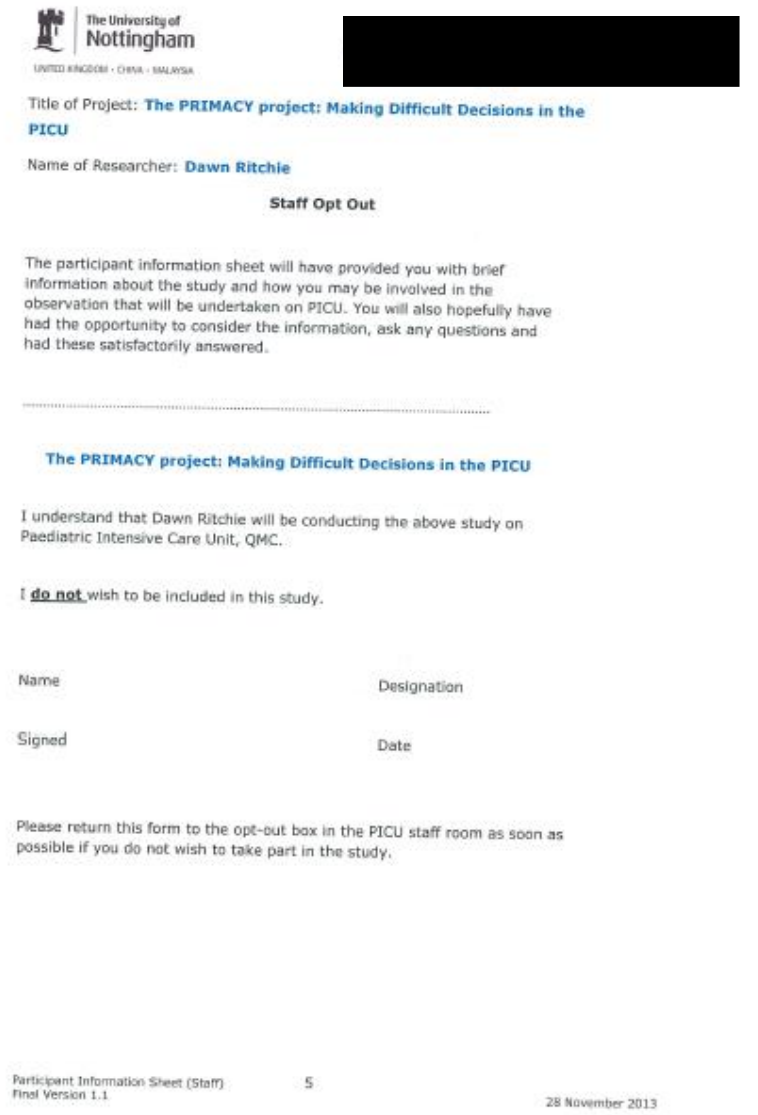
The PICU has been selected as the case study site because it provides regional services to a multi-cultural population. You have been invited to take part in the study because you work as part of the PICU team providing care to children and their families.

Do I have to take part?

No. It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep. Taking part is entirely voluntary and it is up to you to decide whether or not you want to participate in the study. If you decide to take part you are still free to withdraw at any time and without giving a reason. This would not affect your legal rights.

There has been ongoing discussion with senior clinical medical and nursing staff during the planning and design of the study. Their support and permission has been obtained together with permission for the PICU to be the study site for observations of care. You may be involved during the observations of care and interventions given to selected children and families. However you are free to opt out of the study or specific observations at any time, without giving a reason. An opt-out slip is attached. If you do

Appendix 11: Staff opt-out from



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

Title of Project: **The PRIMACY project: Making Difficult Decisions in the PICU**

Name of Researcher: **Dawn Ritchie**

Staff Opt Out

The participant information sheet will have provided you with brief information about the study and how you may be involved in the observation that will be undertaken on PICU. You will also hopefully have had the opportunity to consider the information, ask any questions and had these satisfactorily answered.

....

The PRIMACY project: Making Difficult Decisions in the PICU

I understand that Dawn Ritchie will be conducting the above study on Paediatric Intensive Care Unit, QMC.

I **do not** wish to be included in this study.

Name Designation

Signed Date

Please return this form to the opt-out box in the PICU staff room as soon as possible if you do not wish to take part in the study.

Participant Information Sheet (Staff) 5
Final Version 1.1 28 November 2013

Appendix 12: Staff consent for observation

The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

CONSENT FORM: Staff Participant (Observation)
(Final version 1.1: 28 November 2013)

Title of Study: The PRIMACY project: Making Difficult Decisions

REC ref: 13/EM/0407

Name of Researcher: Dawn Ritchie

Name of Participant:

Please initial box

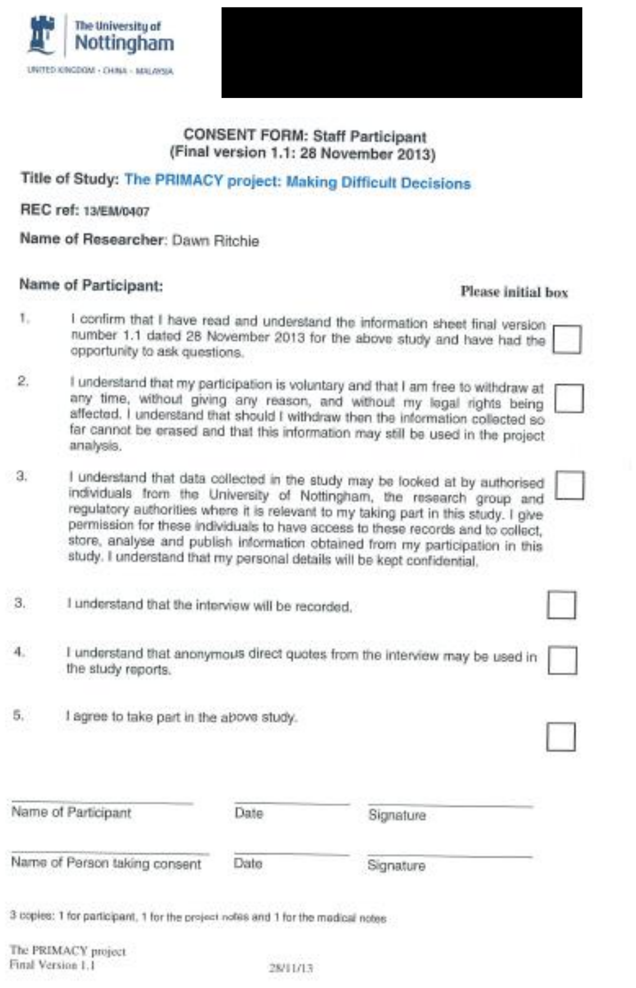
1. I confirm that I have read and understand the information sheet final version number ...1..1.........dated..28 November 2013.... for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I agree to the presence of a researcher who will be undertaking observations in the paediatric intensive care unit (PICU) of care given to children and their families who have been recruited to the study. I understand that I may request the researcher to withdraw at any time. ☐
5. I agree to take part in the above study. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

3 copies: 1 for participant and 1 for the project notes 1

The PRIMACY project Final Version 1.1 28.11.2013

Appendix 12: Staff consent for interview



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

CONSENT FORM: Staff Participant
(Final version 1.1: 28 November 2013)

Title of Study: The PRIMACY project: Making Difficult Decisions

REC ref: 13/EM/0407

Name of Researcher: Dawn Ritchie

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet final version number 1.1 dated 28 November 2013 for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
3. I understand that the interview will be recorded. ☐
4. I understand that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I agree to take part in the above study. ☐

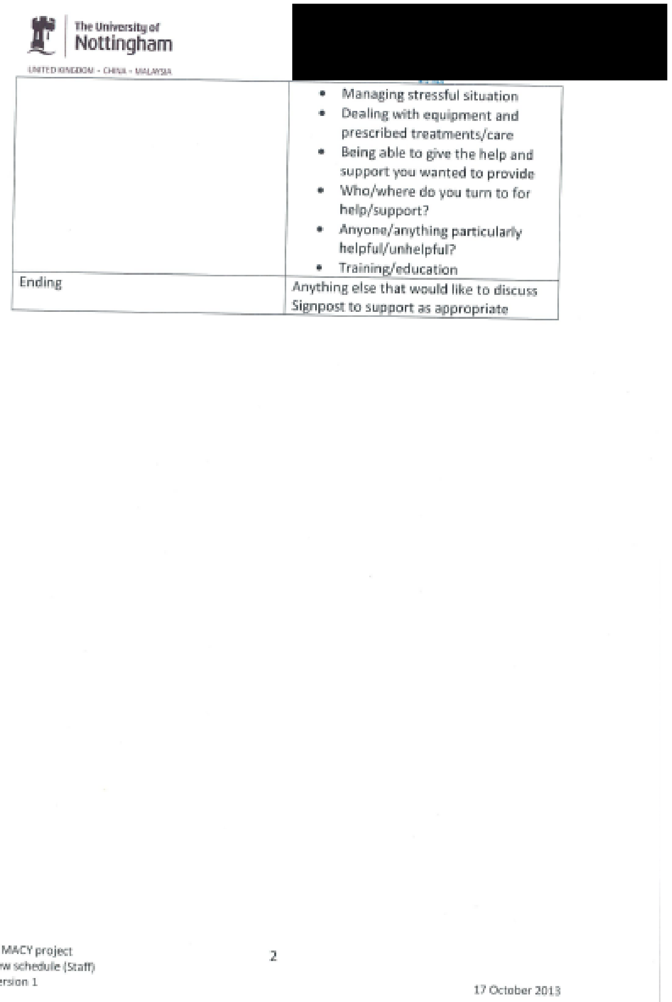
Name of Participant ________ Date ________ Signature ________

Name of Person taking consent ________ Date ________ Signature ________

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

The PRIMACY project
Final Version 1.1 28/11/13

Appendix 13: Staff interview guide



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

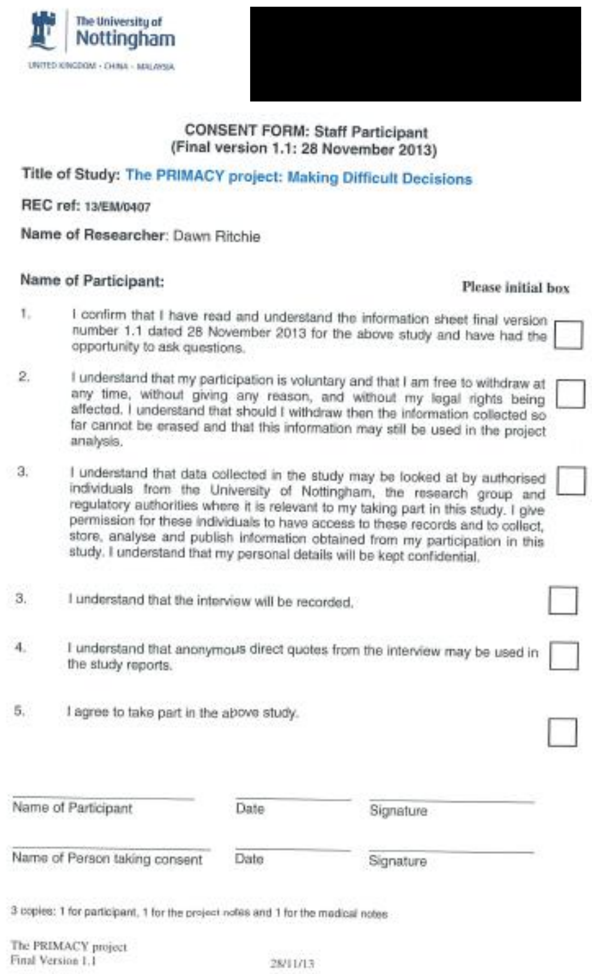
[redacted]

	• Managing stressful situation • Dealing with equipment and prescribed treatments/care • Being able to give the help and support you wanted to provide • Who/where do you turn to for help/support? • Anyone/anything particularly helpful/unhelpful? • Training/education
Ending	Anything else that would like to discuss Signpost to support as appropriate

The PRIMACY project
Interview schedule (Staff)
Final Version 1

2

17 October 2013



The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

[redacted]

CONSENT FORM: Staff Participant
(Final version 1.1: 28 November 2013)

Title of Study: **The PRIMACY project: Making Difficult Decisions**

REC ref: 13/EM/0407

Name of Researcher: Dawn Ritchie

Name of Participant:

Please initial box

1. I confirm that I have read and understand the information sheet final version number 1.1 dated 28 November 2013 for the above study and have had the opportunity to ask questions. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, and without my legal rights being affected. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐

3. I understand that data collected in the study may be looked at by authorised individuals from the University of Nottingham, the research group and regulatory authorities where it is relevant to my taking part in this study. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐

3. I understand that the interview will be recorded. ☐

4. I understand that anonymous direct quotes from the interview may be used in the study reports. ☐

5. I agree to take part in the above study. ☐

Name of Participant ____ Date ____ Signature ____

Name of Person taking consent ____ Date ____ Signature ____

3 copies: 1 for participant, 1 for the project notes and 1 for the medical notes

The PRIMACY project
Final Version 1.1

28/11/13