‘A qualitative exploration of neonatologists’ implicit biases towards extremely pre term infants’.

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Abstract

‘A qualitative exploration of neonatologists’ implicit biases towards extremely pre term infants’.

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Annie Janvier and her colleagues conducted research, which revealed an inconsistency in the application of the best interest principle for critically ill extremely preterm infants requiring resuscitation. Janvier and her colleagues carried out quantitative surveys, which used hypothetical clinical vignettes of critically ill incompetent patients of different ages in need of resuscitation. These surveys were conducted in nine countries and the findings were similar across; culturally different groups, physicians from a variety of specialties and in a non-medically educated population. The results of the surveys showed that the respondents were significantly more willing to respect the parents wishes for non resuscitation for the critically ill extremely preterm infant than for the critically ill two month old infant despite their initial judgment that resuscitation was both infant’s best interests and despite the fact that both infants had the same prognosis. This phenomenon, coined the ‘differential treatment’, demonstrates a different approach to resuscitation decision making for the extremely preterm infant, which is out of proportion to the prognosis. However, further work is needed to explore the reasons why clinicians responded differently to the extremely preterm infant clinical vignette compared with the other infant vignettes.

The aim of my research is to explore the clinical factors that influence the resuscitation decision-making process for critically ill infants of different ages. It also aims explore how neonatologists’ balance or weigh their clinical judgment of the infant’s best interest with the parental wishes. Finally, it aims to explore neonatologists’ reasons for the differential treatment of the critically ill extremely preterm infant compared with the critically ill two-month-old infant when both require resuscitation and have similar prognoses.

I conducted thirteen qualitative semi-structured interviews with English neonatologists. The interviews were divided into two parts: Participants were first asked to respond to three clinical vignettes similar to those used in Janvier’s surveys and secondly were asked open-ended questions based on concepts drawn from existing literature and designed to explore the underlying reasons for Janvier’s findings.

The results of this study confirmed and illuminated the differential treatment of critically ill extremely preterm infants, but also offered a deeper glimpse into how certain clinical factors as well as the parental wishes influenced the neonatologists' responses. In addition, my results revealed the neonatologists' reasons for the differential treatment of critically ill extremely preterm infants found in Janvier et al.'s surveys. Their reasons can be organized into four overarching themes which arose from the analysis of the interview data: The Influence of Personal Experiences and Previous Training, The Power of Emotions, The Fundamental Attitudes Towards Extremely Preterm Infants and The Responses to the Hypotheses From the Literature.

This project shows that resuscitation decision making for critically ill extremely preterm infants frequently involves complex behavioural decisional processes, which differ depending on an individual's experiences, emotions, perceptions and attitudes. These factors contribute to and explain the differential treatment of critically ill extremely preterm infants demonstrated in Janvier et al.'s studies.

Drawing on these findings, I conclude that the neonatal medical community, through open and honest dialogue, should come to a consensus about how to apply the best interest principle when making resuscitation decisions for extremely preterm infants as well as to determine whether the differential treatment of critically ill extremely preterm infants is ethically justifiable in the context of resuscitation. Finally, I provide recommendations for further research.

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To my wonderful family, Mom and Maryssa for your prayers, encouragement and endless support. You are everything to me and I am so blessed to have such a wonderful family.

Dedication

TO GOD BE THE GLORY

I dedicate this thesis to my God and my Lord for in Him I live and move and have my being. – Acts 17:28

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List of Abbreviations

NICU Neonatal intensive care unit
LST Life sustaining treatment
CIEPI Critically ill extremely preterm infant
CI2MOI Critically ill two-month-old infant
CITI Critically ill term infant
CINI Critically ill newborn infant
RCPCH The Royal College of Paediatrics and Child Health
BAPM The British Association of Perinatal Medicine
GMC The General Medical Council
UK United Kingdom
IVF Invitro fertilization
NHS National Health Service
SCU Special Care Unit
LNU Local Neonatal Unit
CN Consultant neonatologist
NT Neonatal trainee

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Chapter 1: Introduction

The first Neonatal Intensive Care Unit (NICU) was set up in 1965 by the Yale-New Haven Hospital in New Haven Connecticut. These units were dedicated for the care of critically ill preterm infants who otherwise would have died due to the immaturity of their lungs and other organs. Today, neonatal intensive care medicine allows for preterm infants born as small as 500 grams to survive. This is quite a significant change from 1950 where an infant born less than 1000 grams had close to a 90% mortality rate. (Center for Disease Control 2013)

As technology becomes more sophisticated the survival rates of these preterm infants increases. For example, the EPICURE 2 study compared the survival rates of infants between 22 and 26 weeks gestational age in 1995 and 2006. The study found that the probability of survival for a 24-week infant was 47% in 2006 compared with 35% in 1995. (EPICure 2 Perinatal Group 2008) More recent literature shows that the likelihood of survival for a 24-week extremely preterm infant is between 55-70% depending on where they are born. (N. B. Marlow, C. and Draper 2014) (Stoll 2010) There are very few medical specialties, which have seen such significant advances in survival over such a short time period. This is primarily due to rapid advances in technology.

Although neonatal intensive care medicine has improved the survival rate of extremely preterm infants, it does not come without a cost. Treatments have been known to produce side effects such as: cerebral palsy, chronic lung disease, hearing or vision loss and learning disabilities and behavioral problems. Such side effects can dramatically affect the quality of life of the child and his or her family for the rest of their lives. (N. Marlow 2004) Therefore, the physician has to weigh the benefit of resuscitating with the risks of the life sustaining treatment (LST) in order to decide whether or not it is in the infant's best interest to survive. Making judgments about best interests requires an analysis of a range of different factors such as: chance of survival, risk of resuscitation causing severe disability, amount of suffering endured, limitations to resources and parental wishes. The difficulty of these life or death decisions is further complicated by the uncertainty around predicting long term prognosis.

The nature of resuscitation decision making for critically ill infants is complex. These life or death decisions bring about many ethical questions, which require further exploration and analysis. One such question that has been discussed in literature is whether it is acceptable to treat critically ill extremely preterm infants differently than older critically ill infants when deciding whether or not to resuscitate. (Janvier et al. 2008c) The ethical theory and the clinical guidelines are unanimous in their support for treating all infants equally when deciding whether or not to resuscitate.

Beauchamp argued that "all equals should be treated equally and un-equals should be treated unequally" (Beauchamp 2009) Therefore, the ethical principle of justice implies that physicians treat all patients equally unless there is a morally relevant difference between them. (Mercurio 2009) The Nuffield Council on Bioethics' clinical guidelines also support the equal treatment of all patients: **"**In this respect, and independent of gestational age, we consider, for example, a child of six days, months or years to be worthy of equal consideration**.”** (Nuffield Council on Bioethics 2006) In addition, the Neonatal Resuscitation Program textbook, the standard guideline for resuscitation in North America, makes similar recommendations: “the ethical principles regarding the resuscitation of newborns should be no different from those followed in resuscitating an older child or adult.” (American Academy of Pediatrics 2011)

Research conducted by Annie Janvier and her colleagues revealed an inconsistency in how the best interest principle is applied for critically ill extremely preterm infants compared with critically ill two-month-old infants with a similar prognosis. (Janvier et al. 2008a) Janvier et al.’s surveys demonstrated that the clinicians were significantly more willing to respect the parents wishes for non resuscitation for the critically ill extremely preterm infant than for the critically ill two month old infant despite their initial judgment that resuscitation was in the patient’s best interests and despite the fact that both infants had the same prognosis. (Armstrong et al. 2011b; Hagen et al. 2012; Hansen 2013; Janvier et al. 2008b; Laventhal et al. 2011) This phenomenon, coined the ‘differential treatment’, demonstrates a different approach to resuscitation decision making for the extremely preterm infant, which is out of proportion to the prognosis. However, further work is needed to explore the reasons why clinicians responded differently to the extremely preterm infant clinical vignette compared with the other infant vignettes. (Janvier and Mercurio 2013)

It is not possible, from these surveys, to understand why physicians responded differently to the critically ill extremely preterm infant when deciding whether or not to resuscitate.

Therefore, this research project aims to conduct semi-structured qualitative interviews to answer the following research questions:

1. What clinical factors influence the resuscitation decision-making process for critically ill infants of different ages?

2. What are neonatologists' reasons that the parents' wishes for non-resuscitation should or should not be respected and how do they balance or weigh their clinical judgment of the infant's best interest with the parental wishes?

3. What are neonatologists' reasons for the differential treatment of a critically ill extremely preterm infant compared with a critically ill two-month-old infant when both require resuscitation and have similar prognoses?

The next section, Chapter 2, provides a summary of the key literature and guidelines surrounding the differential treatment of critically ill extremely preterm infants in the context of resuscitation decision making. Chapter 3 describes the methodology used to answers the three central research questions of this project. Chapter 4 and Chapter 5 describes the results of the semi-structured interviews and Chapter 6 discusses these results in light of the literature and clinical guidelines as well as makes conclusions and recommendations for future research.

Chapter 2: Literature Review

2.1 Introduction

Neonatal medicine has made great progress in the past forty years and enabled more infants to survive despite prematurity, severe health conditions and congenital abnormalities. However, these advances have resulted in complex ethical issues, which require difficult decisions to be made regarding the resuscitation and initiation of life-sustaining treatment (LST). This chapter presents a review of the literature relevant to the ethical aspects of resuscitation decision making in the Neonatal Intensive Care Unit (NICU). Given the large amount of literature on this topic, this literature review focuses on the aspects of the literature relevant to resuscitation decision making for critically ill newborn infants and the differential treatment of critically ill extremely preterm infants. I begin with a broad overview of the ethical guidance on resuscitation decision making for critically ill newborn infants (2.2) because it is important to understand the main ethical issues that arise when making resuscitation decisions for critically ill newborn infants. Within this context, I present a review of the literature on the use of the best interest principle in resuscitation decisions for critically ill newborn infants as well as a review of the literature about differing views on the role of parental authority in determining best interests (2.3). Next, I review the literature relating to the practical application of the best interest principle and the inconsistencies in the way it is applied for critically ill newborn infants (2.4). In the last section I review the literature relating to the possible hypotheses for the inconsistency or differential treatment of critically ill newborn infants, particularly critically ill extremely preterm infants (2.5). I conclude with a summary of the knowledge gaps in the literature and a statement on the rationale for this research project (2.6).

2.2 Resuscitation Decision Making for Critically Ill Newborn Infants – Ethical Guidelines in the UK

When a newborn infant is critically ill, a decision must be made about whether or not to resuscitate in order to save his or her life. Resuscitation involves the use of life sustaining treatment (LST), which replaces or supports ailing bodily functions until the infant is able to regulate these functions without support. Some examples of LST for critically ill newborn infants include: temperature regulation (an incubator), opening the airway, inserting a breathing tube (intubating) into the trachea (windpipe) and connecting it to a manual ventilator (breathing machine), chest compressions and/or medications to speed up the pumping of the heart. (Resuscitation Council 2010)

Resuscitation decision making in the Neonatal Intensive Care Unit (NICU) is medically and ethically complex and therefore, a group of guidelines was produced in the United Kingdom (UK), which provided practical help for professionals involved in the care of critically ill newborn infants. The Nuffield Council on Bioethics Working Party (Working Party) published a report in 2006 entitled *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues*. (Nuffield Council on Bioethics 2006) which provided extensive guidance about the ethical, social and legal issues that arise in neonatal intensive care medicine. The Royal College of Paediatrics and Child Health (RCPCH) (Royal College of Paediatrics and Child Health 2004) also published a framework for making decisions about withholding or withdrawing life sustaining treatment in critically ill infants and children. Other relevant guidelines were produced by both the British Association of Perinatal Medicine (BAPM) (British Association of Perinatal Medicine 2008) and the General Medical Council (GMC) (General Medical Council 2002). The GMC document provided a structured decision making model for a case if the patient lacks capacity to decide for themselves.

This section provides a brief overview of the guidelines specifically focusing on the ethical issues surrounding resuscitation decisions for critically ill newborn infants. In practice, it is difficult to apply a set of rules or checklists to all cases because each case can have divergent factors and nuances that come into play. The decision of whether or not to resuscitate a critically ill newborn infant requires a consideration of a range of different factors such as: gestational age, survival rate, likelihood of future disability, suffering, best interest principle, resource limitations and parental wishes. Therefore, the Working Party outlined a guiding framework for making resuscitation decisions which center on determining the best interests of the infant.

Best Interests

The principle of best interest was codified in the United Nations Convention on the Rights of the Child (United Nations 20 November 1989) and serves as an important guideline for both medical practitioners and others involved in the care of children. Best interest is an ethical principle, which was defined by the Working Party as “factors that affect a person’s quality of life.” (Nuffield Council on Bioethics 2006). The principle of best interest is used to guide decisions that are made on behalf of a person who lacks capacity. Specifically in the newborn population, the best interest principle is very important as all newborns ultimately lack capacity and therefore require others to make decisions on their behalf.

All of the ethical guidelines discussed the fact that the best interest of the child must be the central consideration when making decisions regarding life-sustaining treatment. (Royal College of Paediatrics and Child Health 2004) (British Association of Perinatal Medicine 2008) (Nuffield Council on Bioethics 2006) Therefore, the physician has to consider whether the benefit of resuscitating outweighs the burdens of LST in order to determine what is in the child's best interest. Both the GMC and the Working Party outlined some factors, which the healthcare team should take into account. It is apparent that these criteria are not exhaustive and cannot be applied rigidly in every case but should be used as a framework for guiding decision making. The Working Party stated:

> "When a decision must be made whether or not to institute or to withhold further treatment from a baby after birth, the following questions should be considered: The degree of pain, suffering and mental distress that treatment is likely to inflict, or is inflicting, on the child. The likely future benefits the child might get from treatment. Will the child be able to survive independently of life support, be capable of establishing relationships with other people and be able to experience pleasure of any kind? The extent to which treatment is likely to effect a significant prolongation of a child's life (as opposed to simply prolonging the dying process). The level of support likely to be available to assist in long-term care for the child. The views and feelings of the parents as to the interests of the child." (Nuffield Council on Bioethics 2006)

Partnership of Care

The United Nations Convention on the Rights of a Child stated that the best interests should be a “primary consideration” but do not trump the interests of other parties involved. (United Nations 20 November 1989) Similarly, the Working Party set out that those who make the decisions in respect of the child must carefully consider the interests of all those who may be affected. (Nuffield Council on Bioethics 2006) For this reason, the Working Party, The RCPCH and the BAPM emphasized the importance of a “partnership of care” between parents and the healthcare team to ensure that: the decision is in the child’s best interest, that all parties involved have their perspectives acknowledged and that each person’s competencies have been considered appropriately in the decision making process. (Royal College of Paediatrics and Child Health 2004) (British Association of Perinatal Medicine 2008) (Nuffield Council on Bioethics 2006)

There is a consensus among the guidelines that parents have both a moral and statutory right to make decisions in their child’s best interest. Nevertheless, the Working Party made it clear that parents should not make decisions as if they owned the child or “were merely extensions of their own person.” (Nuffield Council on Bioethics 2006) The team of healthcare professionals should actively participate in the decision making process and voice what they think would be in the child’s best interests. However the Working Party stated that “their command of medical knowledge does not make them able to predict the future health of the baby with complete accuracy or give them any special moral authority with regard to the decision of his or her best interests.” (Nuffield Council on Bioethics 2006) This slightly contradicted the position of both the GMC and RCPCH which emphasized that the physician leading the decision making process ultimately carries the moral responsibility for the decision made and is responsible for the chosen course of action. (Royal College of Paediatrics and Child Health 2004) (General Medical Council 2002)

2.3 Best Interests and Parental Authority – Review of the Literature

The best interest principle is central in the ethical guidelines, the law and in clinical ethics texts as the guiding principle that should be used in making decisions for incompetent patients. (Salter 2012) Buchanan and Brock defined best interest as “a principle that expresses a positive obligation, a duty to do what best promotes someone’s interests or is most conducive to his or her good.” (Buchanan and Brock 1989) There are many interpretations of the meaning of best interest principle. However, before exploring these other interpretations, it is important to consider what the concept of interests means.

Micah Hester’s analysis of the concept of interests showed that there are three interpretations of the term. The first interpretation referred to *taking* an interest in something or “that which we actively pursue.” (Hester 2007) For example, I am interested in classical music. We also use it when someone *has* an interest in something because it affects the individual’s pursuits. For example, I am interested in the stock market because I invest in 3-D printers. In other words, we *have* an interest in something when we can benefit or be harmed by it. Lastly, we might speak of something *being* in our interest. When something *is* in our interest it means it matters to our well-being even if we are unaware of or unconcerned with it. For example, it is in my interest to continue breathing.

The difference between the interests of a critically ill newborn infant and the interests of other incompetent patients is that, unlike adults, we cannot attempt to extrapolate from their previous actions, stated values or shared experiences what their interests may be. Usually when an adult is unable to make a decision due to lack of competence, the decision making authority is transferred to a surrogate decision maker who is required to make decisions based on the adult's past beliefs and desires. (Buchanan and Brock 1989) This substitutive judgment is not applicable in the case of critically ill newborn infants because they have no history as a "thinking being." (Janvier and Lantos 2011) Hester argued that they are "of such an age and intellect that their personality is unformed, their interests are unavailable—that is, their very selves have yet to be determined." (Hester 2007) Therefore, it is presumed that parents will act as the surrogate decision makers for their children and will make decisions based on the best interest principle. (Mercurio 2006)

As Buchanan discussed, the best interest principle is generally assessed by determining competing interests i.e. weighing the "net benefit" and subtracting the "net burdens" of a proposed course of action. (Buchanan and Brock 1989) This model of the best interest standard is individualistic in that the interests of the infant are given priority over all other interests. (Salter 2012) In the context of resuscitation, this translates to examining survival and outcome (disability, future quality of life) of a proposed intervention. Therefore, as the chance of survival decreases, the benefits also decrease. (Armstrong et al. 2011b) The proposed benefits of resuscitation for critically ill newborn infants include: “the chance of survival, and all the benefits or pleasures (physical and emotional), continued living might bring” and the burdens include “the pain of resuscitation and the NICU course, and the ongoing pain (physical and emotional) that continued living might bring to the child.” (Mercurio 2006)

Armstrong argued that the weighing of benefits and burdens requires providers take into account quality of life judgments however, these judgments are essentially subjective (Armstrong et al. 2011b) Therefore, healthcare providers and parents frequently have different views on a good quality of life. (Janvier and Mercurio 2013) A study by Burkenhorst et al. showed that the general public and medical staff judge the quality of life lower than the individuals with the medical impairment themselves. (Brunkhorst et al. 2014) However, policy and guidelines recognized that critically ill newborn infant’s welfare or quality of life is directly linked with the parents’ ability to provide care: “There is no doubt that the interests of a baby are bound up with those of his or her parents, in that the degree of care that parents can devote to their child can make a very substantial difference to the quality of life that he or she can expect to enjoy.” (Nuffield Council on Bioethics 2006)

For critically ill extremely preterm infants born at the threshold of viability, these quality of life judgments are further complicated by uncertainties around the long-term prognosis and the future quality of life of the child. (Albersheim et al. 2010) (Weir 2011) Thus, it is considered ethically acceptable that, given the uncertainty, parents’ wishes regarding whether or not to resuscitate should always be honored, unless there is evidence that the parents do not represent the best interests of their infant. (Seri and Evans 2008) The guidelines in the UK also recommended that parents' wishes be given precedence for critically ill extremely preterm infants born between 23 and 25 weeks gestational age because of the uncertainty around prognosis. (Nuffield Council on Bioethics 2006) The American Academy of Pediatrics guidelines are guidelines that stated: "When early death is very likely and survival would be accompanied by high risk of unacceptably severe morbidity, intensive care is not indicated. When survival is likely and risk of severe morbidity is low, intensive care is indicated. For cases that seem to fall between these two categories, parental desires should determine the treatment."(American Academy of Pediatrics 2011) If physicians judge that the surrogate threatens the infant's best interests, then the parents' decision is usually overridden. (McDougal and Notini 2014)

Nevertheless, others argue that the best interest principle is not ideal in determining when to override the parental wishes. (Beckstrom and Woodrum 2011) Laine Ross and Douglas Diekema have proposed two alternative approaches to the best interest standard namely; constrained parental autonomy and the harm principle. Constrained parental autonomy, unlike the individualistic and restricted relational models, does not necessarily give preference to the interests of the critically ill newborn infant and poses fewer limits on the degree to which the parents' interests are incorporated. Ross argued that beyond a minimum threshold of care for the critically ill newborn infant, parents should be free to make decisions that "accommodate intra-familial trade-offs." (Ross 1998) Ross changed the term from the promotion of *best interests* to the promotion of *basic interests*. Diekema's model of the harm principle also allowed for flexibility in giving preference to parental interests when making resuscitation decisions for critically ill newborn infants. The harm principle focuses on identifying a threshold for state intervention by "identifying the level of harm to be tolerated in parental decisions." (Diekema 2004) Thus he argued that parental decisions that do not significantly go beyond this threshold of serious harm as compared to other decisions should be tolerated.

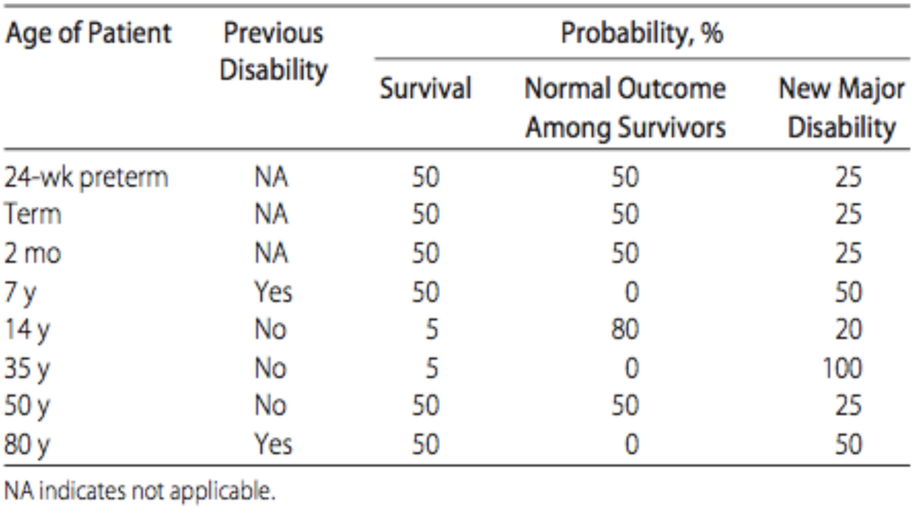
This section demonstrated that there are a range of applications of the best interest principle. However, moving from the abstract concept of best interest to a practical application of that principle in individual cases is not always simple. (Weir 2011) There are many complex factors such as age, work experience, sex, religious background, fear of litigation and personal prejudices that may skew physicians' judgments of best interests. (Bellieni 2009) Loretta Kopelman argued "a test of moral judgment is that one is willing to generalize ones decision to everyone similarly situated." (Kopelman 2007b) However, Janvier et al.'s surveys demonstrate that this may not be the case for critically ill extremely preterm infants requiring resuscitation.

2.4 Differential Treatment

Annie Janvier and her colleagues conducted extensive research, which highlighted an inconsistency in the way the best interest principle is applied for critically ill extremely preterm requiring resuscitation. This research was conducted in nine countries and the findings were similar across; culturally different groups, physicians from a variety of specialties and in a non-medically educated population. (Janvier and Lantos 2011)

Most of the research was in the form of quantitative surveys, which described a group of critically ill incompetent patients in need of resuscitation with a potential for neurologic sequelae if they survived. (Armstrong et al. 2011a; Hagen et al. 2012; Janvier et al. 2008a; Janvier et al. 2008d; Janvier et al. 2008b; Laventhal et al. 2011) All patients arrived in the emergency department of a tertiary hospital and family members/parents were not immediately available for consultation. The patients were different ages and their outcomes were explicitly described. (See Table 1)

Table 1 Probability of Outcomes for Each of the 8 Clinical Vignettes



Age of Patient	Previous Disability	Probability, %		
		Survival	Normal Outcome Among Survivors	New Major Disability
24-wk preterm	NA	50	50	25
Term	NA	50	50	25
2 mo	NA	50	50	25
7 y	Yes	50	0	50
14 y	No	5	80	20
35 y	No	5	0	100
50 y	No	50	50	25
80 y	Yes	50	0	50

NA indicates not applicable.

The patients included: a newly delivered 24 week critically ill extremely preterm infant (CIEPI), a critically ill newborn infant just born at term with a known brain malformation (CITI), a critically ill 2-month-old infant with bacterial meningitis (CI2MOI), a critically ill 50-year-old patient with severe trauma, including head injury, resulting from a car accident, a critically ill 7-year-old patient with multiple disabilities and new head trauma, a critically ill 80-year-old patient with substantial disability from dementia and a new stroke, a critically ill 14-year-old patient with acute myeloid leukemia with central nervous system involvement, and a critically ill 35-year-old patient with brain cancer.

The patients were presented from oldest to youngest, and the following questions were asked to respondents: (1) Would you resuscitate this patient? (2) If the parents/family asked you not to resuscitate would you respect their wishes? (3) Do you think resuscitation is in the patient's best interest (4) If the patient were your own child/family member would you wish for active treatment? (Hagen et al. 2012)

The results of the surveys showed that the respondents were significantly more willing to respect the parents wishes for non resuscitation for the critically ill extremely preterm infant than for the critically ill two month old infant despite their initial judgment that resuscitation was in the patient's best interests and despite the fact that both infants had the same prognosis. (Armstrong et al. 2011a; Hagen et al. 2012; Janvier et al. 2008a; Janvier et al. 2008d; Janvier et al. 2008b; Laventhal et al. 2011) This phenomenon, coined the 'differential treatment', demonstrated a different approach to resuscitation decision making for the extremely preterm infant, which was out of proportion to the prognosis. (Janvier et al. 2007)

Table 2 below is a summary of the main questions, methods, target population and areas for further exploration of Janvier et al.'s surveys from the literature:

Table 2 Summary of Surveys from the Literature

Research	*Focus of Research*	*Method Used*	*Target Interviewees*	*Questions for further exploration*
Armstrong et al 2010 Ireland	Application of the best interest principle for the resuscitation of critically ill patients across	Questionnaire using clinical vignettes	*Consultants Physicians* *Trainee Physicians* (Neonatology, Obstetrics, Pediatrics)	Exploring reasons why caregivers apply best interest principle differently for

	a range of ages		*Medical Students* (fourth year)	extremely preterm infants compared with other patients
Janvier et al 2007 Quebec	Attitudes of caregivers towards the resuscitation of a 24 week preterm infant	Questionnaire using clinical vignettes	*Trainee physicians* (obstetrics, pediatrics) *Nurses* (perinatal and neonatal)	Exploring reasons why caregivers unwillingness to resuscitate preterm infants is out of proportion to their prognosis.
Janvier et al 2008 Quebec	Determination if newborns are dealt with according to different standards with regard to resuscitation	Questionnaire using clinical vignettes	*Students* (law, anthropology, medicine, bioethics) *Consultant Physicians* (family medicine, obstetrics, neonatology, emergency) *Trainee physicians* (obstetrics, pediatrics, family medicine)	Further exploration of the underlying reasons for the systematic devaluation of extremely preterm infants.
Hagen et al 2012 Norway	Attitudes of physicians regarding life saving interventions in pediatric life or death situations	Questionnaire using clinical vignettes	*Consultant Pediatricians*	Exploration of physicians inherent values which influence ethically challenging life & death decisions
Laventhal et al 2011 United States	Application of best interests and surrogate autonomy across critically ill patients ranging from extremely preterm to extremely elderly.	Questionnaire using clinical vignettes	*Consultant Neonatologists* (comparison) *Consultant Obstetricians*	Exploring the clinical factors, the weighing of the parents interests and the reasons for differential treatment of the populations.

The analysis of these surveys shed light on the fact that the best interest principle is applied differently for critically ill patients of different ages and that the willingness to resuscitate may not be solely related to survival rates or long-term outcome. (Armstrong et al. 2011; Hagen et al. 2012; Janvier et al. 2008a; Janvier et al. 2008d; Janvier et al. 2008b; Laventhal et al. 2011) Interestingly, respondents did not seem to adhere to the best interest standard in the cases of the CITI and the CIEPI. (Laventhal et al. 2011) (Hagen et al. 2012) However, the inconsistent application of the best interest principle was most marked for the CIEPI which illustrated; "a consistently negative approach to the very preterm infant, which is out of proportion to the prognosis." (Janvier et al. 2008d) Janvier explained that this "differential treatment" of the CIEPI was probably not related to medical factors because physicians and students had almost identical answers. (Janvier et al. 2008a) Moreover, the fact that the assessment of whether resuscitation was in the best interests of the CITI and the CIEPI was "out of proportion to their prognosis" suggested that the relative value placed on the life of the CIEPI, was less than expected by objective medical data.(Armstrong et al. 2011b; Hagen et al. 2012; Janvier et al. 2008a; Janvier et al. 2008b) For this reason, I will focus my discussion in relation to CIEPIs.

In addition to these surveys, the clinical guidelines and policy statements also supported Janvier's conclusions that the lives of CIEPIs are systematically devalued because the guidelines "have been tailored around completed weeks of gestational age." (Dupont-Thibodeau 2014) For example, the Working Party recommended that before 23 weeks gestation, resuscitation should not be performed but infants older than 25 weeks gestational age should always be resuscitated. In between 23 and 25 weeks gestational age they recommended offering full resuscitation unless the parents and clinicians agree it is not in the infant's best interest. (Nuffield Council on Bioethics 2006).

There do not appear to be any professional bodies or official policies that suggest an age limit for resuscitation of critically ill patients except in the case CIEPIs. (Janvier and Lantos 2011) Age is considered as one of a number of factors to be incorporated into the resuscitation decision-making process. (Janvier et al. 2007) (Janvier 2013) Furthermore, there is no other patient group in which a 50% chance of survival and a 50% chance normal outcome would justify non-resuscitation on the basis of age alone. (Janvier et al. 2008a) Janvier argued that because the guidelines set gestational age-based thresholds for limiting resuscitation, they reflect an implicit endorsement of using a different ethical standard for CIEPIs than for critically ill older infants, children and adults.

Patrick Jones disagreed with Janvier's claim, on the basis that using gestational age does not reflect a systematic devaluation but instead provides helpful information for families and practitioners as they make difficult decisions for a critically ill infant. (Jones 2008) He argued that "gestational age is being used to describe an expected set of comorbidities found with a certain level of prematurity; it is like stating that a patient has Group B streptococcal meningitis or a certain type of cancer."

Similarly, Dominic Wilkinson challenged Janvier and Dupont-Thibodeau's claims that gestational aged based guidelines "reflect a form of prejudice against premature infants." (D. Wilkinson 2012) Wilkinson recognized that gestational aged based guidelines can be considered arbitrary however, "the mere fact that a cutoff point is arbitrary does not mean it is illegitimate." (D. Wilkinson 2012) He used examples of other thresholds used in medicine such as those for cardiac transplantation, IVF and publicly funded medications to support his claim. However, he concluded that "In both groups, age is appropriate to consider with other factors, and moderate forms of ageism may be justified. Indeed, age should be taken into account in prognosis and decisions about treatment wherever it can be shown to have independent predictive power." (D. Wilkinson 2012)

John Lantos in his paper *Justifiable and Unjustifiable Ageism* disagreed with Wilkinson's justification for moderate gestational ageism. (Lantos 2012) Lantos conceded that it is appropriate to consider gestational age in association with outcome when making resuscitation decisions for extremely preterm infants. However, he argued that "premature babies with a reasonable prognosis for survival are denied LST more readily than older children with a similar (or worse) prognosis" was inappropriate and represented a discrimination based on gestational age. (Lantos 2012) Lantos acknowledged Wilkinson's claim that parents should be given the choice between resuscitation and palliative care when outcomes are sufficiently ambiguous or uncertain. However, he argued that should be the case for term infants, older children and adults, not just for CIEPIs . He concluded that the key question we should be asking is: "Would we allow non-treatment of a 2 year old child with the same prognosis?" If not, then respecting parents' wishes for non-resuscitation in the CIEPI but not respecting them in the case of the CI2MOI, infant represents unjustifiable gestational ageism and should be condemned. (Lantos 2012)

It is now worth considering some other hypotheses for the differential treatment of the CIEPI in the context of resuscitation. (Janvier and Mercurio 2013) (Hagen et al. 2012)

2.5 Eight Hypotheses for the Differential Treatment

The research done by Janvier et al. spurred a significant amount of ethical literature on the possible explanations for differential treatment of the CIEPI compared with CI2MOI. Herein follows eight hypotheses for the differential treatment from the literature review.

1. Not Persons

Janvier hypothesized that the pattern of responses in her survey could be explained "by a combination of an evaluation of reduced personhood for the term, preterm and elderly demented patients." (Janvier et al. 2008b) Several authors suggested that newborns do not have the same moral status as older infants, because they lack personhood. Peter Singer, whose view is the most widely cited in the literature argued that both newborn infants and fetuses are not persons and do not come into existence until sometime after their birth. (P. Singer and Kuhse 1985) He emphasized the importance of distinguishing the difference between a human being and a person because the two terms are often used synonymously. He defined a human being as relating to a biological species but he defined a person as “a type of being whose existence has a particular value and importance” (P. Singer and Kuhse 1985) and as “a thinking intelligent being, that has reason and reflection, and can consider itself as itself, the same thinking thing, in different times and places.” (P. Singer 1993) Singer argued that a newborn becomes a person “sometime in late infancy” and until that point there is a radical discontinuity between the newborn and the person he or she may grow into. (P. Singer 1993) Therefore, according to Singer, since CIEPIs are not rational and do not have a concept of self, they are not persons and thus do not have moral claims to life.

2. Weaker or No Interest In Continuing Life

In Singer’s view, all moral claims are derived from the principle of equal consideration of interests, which requires that “the comparable interests of all sentient beings be given equal weight in our moral deliberations.” (Warren 1997) The premise of his argument centered on the fact that *all* and *only* persons have interests and is based on a desire-based definition of interests. (Harris 1989) Therefore, it is necessary for individuals to have a desire for something for it to be in their interest. In order to desire something, an individual must have a self-conscious awareness of the future and the capacity to experience suffering and enjoyments. Therefore, according to Singer, because CIEPIs are not persons and do not have the capacity for self-conscious awareness of the future, they cannot have desires or interests in continuing life.

In the book *The Ethics of Killing* Jeff McMahan argued that, unlike Singer, infants have an interest in continuing life but it is not as strong as that of an older child or an adult. He argued that a persons' interest in continuing her life depends on two factors: the amount of wellbeing that will be added to her life if she continues to live and how much this amount of wellbeing matters to her. Each individual's interests are "time relative" because they change in strength over time and are dependent on how much an individual is psychologically linked or invested to their future life. (McMahan 2002) This in turn explains our intuitions that the death of a newborn is worse than the death of an older child because a newborns interest in continuing life is not that same as that of an older child due to the fact that the older child is more psychologically invested in or connected to his or her future life than the newborn. However, this begs the question how do we weigh the strength of a CIEPI and a CI2MOI's interests who have very similar if not the same psychological links with their future life?

Dominic Wilkinson engaged with the time relative interests account in his book however he highlighted its limitations by comparing the interests of a newborn infant and a near term fetus. He argued that "there are relevant differences between the fetus and newborn that would potentially warrant different treatment." (Kaposy 2007) One difference he noted was that there is an explosive phase of synaptic development, which occurs mostly in the period immediately following birth as the newborn responds and adapts to her changing environment. (Bourgeois 2001) However, these arguments didn't explain the relevant differences between CIEPIs and CI2MOIs who have both gone through the "explosive phase of synaptic development" post birth. (D. Wilkinson 2013)

3. Confusion Surrounding Moral Status

Another reason for the differential treatment of the CIEPI compared with the CI2MOI could be due to the fact that terminations of pregnancy are performed after fetal viability in some countries, which caused questions about the moral status of CIEPI. Janvier argued that “the disjunction between the moral status of the fetus in utero and the baby ex utero creates cognitive dissonance that may be resolved by either elevating the status of the fetus or denigrating that of the newborn.” (Janvier et al. 2007) The disjunction between the transition in development from fetus to infant was also highlighted in a paper by Clare Williams titled; ‘Conflicting perceptions of the fetus: person, patient, ‘nobody’, commodity?’ Williams found that health practitioners had contrasting and conflicting perceptions of the fetus due to innovations in reproductive and neonatal medicine. (Williams et al. 2001) William’s follow up research interviewed medical practitioners who work with pregnant women and fetuses in contrasting settings. William’s findings highlighted how the growing recognition of fetal pain and fetal patienthood was shifting the way practitioners perceive the fetus. William’s also concluded that the “growing recognition of the sophisticated abilities of even very premature babies” could extend to fetuses and therefore elevate their moral status. (Williams 2005) Against this, Janvier argued that her results showed “that decisions regarding life and death for newborns, especially premature infants may still be in the realm of reproductive choice and essentially considered a family decision suggesting that life is perhaps still optional.” (Janvier et al. 2008b) The main reason for this is because of the rapid change from a fetus in utero to a neonate ex utero who is suddenly granted the same rights as every other citizen: the change “may be so rapid that the caregivers are unable to relate to this enormous increase in the infant’s moral status.” (Janvier et al. 2007) (Janvier et al. 2008c)

4. Protective Grief Mechanisms

Some of the literature referred to the cultural, social and anthropological factors, which affects how both physicians and parents perceive critically ill newborn infants. Until recently in the Western world, most parents experienced the death of a newborn or an infant, often several times. Janvier explained that “the commonness of infant death lead to protective cultural and emotional mechanisms in the form of philosophic differentiation of the newborn from older people.” (Janvier et al. 2007) These mechanisms contributed to the devaluation of CIEPIs in order to avoid continual grief over their deaths. (Janvier et al. 2008a) (Janvier et al. 2008b)

Another difference that emerged in the literature was the fact that CIEPIs lack the interpersonal attachments that older infants and children have. (Janvier and Mercurio 2013) The attachment that both physicians and parents feel toward CIEPIs may be different because they haven’t developed a personality of their own and because they haven’t gone home and thus may spend all of their life in the NICU and then die there. (Dupont-Thibodeau et al. 2014) Armstrong argued that more moral value is placed on the CI2MOI because the parents have developed stronger attachments compared with the CIEPI who was just born.(Armstrong et al. 2011b)

In a similar vein, Lainie Ross endorsed the differential treatment of CIEPIs on the basis that they have not yet acquired “social membership in a community.” She argued that older infants and children “have a lived biography that intertwines them with their parents and other members of society giving them moral claims to life.” (Ross and Frader 2013) Ross discussed how the concept of a lived biography explains the differential treatment of the CIEPI in relation to the CI2MOI because “we value the born child more than the fetus, just as we value the child with a biography more than a newly born.” (Ross and Frader 2013)

5. *Medical Harm of Intensive Care*

Another hypothesis for the differential treatment of critically ill extremely preterm infants has to do with the harm of intensive care before death. Infants who are born at 24 weeks gestational age are likely to have a longer and more difficult hospital course with many requiring prolonged mechanical ventilation and almost one half requiring surgery for a patient ductus arteriosus. (D. Wilkinson 2012) This hypothesis for the differential treatment of CIEPIs is supported by Morrison who argued that “respondents may have been more willing to accept a family’s request for no resuscitation for a premature infant because of the months spent in an ICU on a ventilator that would be required to have a chance of intact survival.” (Morrison 2008) Physicians perceive a difference in the harm of intensive care for CIEPIs who die after many months of suffering in the NICU than for CI2MOIs who are likely to spend less time in the ICU because they will be transferred to the ward for the remainder of their admission. (Dupont-Thibodeau et al. 2014) (Janvier and Mercurio 2013)

6. Different Healthcare Systems

Another possible explanation offered for the differential treatment of CIEPIs is related to the differences among how various health care systems operate. For example, in Canada, the responses of Canadian physicians might be influenced by their system of universal access and fixed national health care expenses, which "may impart a perceived obligation to consider allocation of limited health care resources in medical decision making." (Laventhal et al. 2011) However, when the same surveys were repeated in Norway, a country with a similar healthcare system to Canada, the resources and expense to society were ranked last among the arguments for all patients. (Hagen et al. 2012) Furthermore, when compared with the surveys done in the United States, results showed that physicians decisions about the initiation of expensive resource intensive interventions with complex risk/benefit profiles in the 2 countries do not seem to differ." (Laventhal et al. 2011).

7. The Perception of Saving versus Creating

Another reason for the differential treatment between the CIEPI and the CI2MOI is the physician's perception of saving versus creating. Janvier hypothesized that physicians "perceive that we have rescued or saved patients who present to the hospital beyond the immediate newborn period, with or without residual disability, but that we have 'created' the critically ill extremely preterm infant who survived with significant disability." (Janvier and Mercurio 2013) This hypothesis is supported by a survey of medical students, which showed that they were more likely to resuscitate a previously disabled child than a previously healthy child even though the survival and prognosis were equal between the two. (Zhong et al. 2011) Morrison hypothesized that "this view could arise because attitudes about premature infants among the general public and physicians in fields other than neonatology has not kept pace with the rapidly improving outcomes in this population." (Morrison 2008)

8. Negative Perceptions of Prognosis

The last hypothesis for the differential treatment of CIEPIs is that physicians may form negative assumptions about the prognoses for the CIEPI based on their prior personal experiences with CIEPIs who had poor long term outcomes. (Morrison 2008) (Hagen et al. 2012) This was reflected in the response of medical students who appear to have a more vitalistic approach to resuscitation compared with the physicians. (Armstrong et al. 2011b) Another possible explanation is that the clinical vignettes were not taken at face value and thus the information about survival and outcome was "filtered through preformed ideas and pre-existing knowledge." (Hansen 2013) (Janvier et al. 2008d) The hypothesis that personal and clinical experiences affect the perception of the outcome was supported by a study which showed that nurses working in a mostly surgical NICU were much more negative about CIEPIs both in the estimates of their outcome and their willingness to intervene. This was because these nurses were likely to have had experiences mainly with CIEPIs who had complications or poor outcomes. Furthermore, the disease process could have also interfered, as healthcare workers may not consider prematurity as the same kind of disease because it is not reversible. (Janvier and Mercurio

2013) Thus, when seeing the word premature perhaps the respondent did not read further and assumed a bad outcome for the CIEPI.

2.6 Conclusion

It is apparent from this literature review that the nature of resuscitation decision making for critically ill extremely preterm infants is complex. As my literature review indicated, the surveys conducted by Janvier et al. showed that physicians endorsed the differential treatment of CIEPIs because their responses show they were significantly more willing to respect the parents' wishes for non resuscitation for the CIEPI than for the CI2MOI despite their initial judgment that resuscitation was in the patient's best interests and despite the fact that both infants had the same prognosis. The results of Janvier et al.'s surveys stimulated numerous possible explanations or hypotheses for the differential treatment of the CIEPI however, Janvier acknowledged that "additional research is needed to explore the underlying reasoning for these responses" (Janvier et al. 2008a; Janvier et al. 2008b) Therefore, further work is needed to explore the reasons for the physician's responses in Janvier et al.'s surveys in order to understand why they endorsed the differential treatment of CIEPIs.

Against this background, the aim of this project is to explore, through semi-structured interviews, English neonatologists' reasons for the responses given in Janvier et al.'s surveys. Therefore, I will address the following research questions:

1. What clinical factors influence the resuscitation decision-making process for critically ill infants of different ages?

2. What are neonatologists' reasons that the parents' wishes for non-resuscitation should or should not be respected and how do they balance or weigh their clinical judgment of the infant's best interest with the parental wishes?

3. What are neonatologists' reasons for the differential treatment of a critically ill extremely preterm infant compared with a critically ill two month old infant when both require resuscitation and have similar prognoses?

In the next Chapter, I describe and discuss the methodology and research methods used to address these research questions.

Chapter 3: Research Design

3.1 Introduction

This research built on previous surveys carried out by Janvier et al., which showed that physicians were significantly more willing to respect the parents wishes for non resuscitation for the CIEPI than for the CI2MOI despite their initial judgment that resuscitation was in the patient's best interests and despite the fact that both infants had the same prognosis. Janvier's results demonstrated a differential treatment of CIEPIs because respondents perceived resuscitation as being more optional and less morally obligatory for the CIEPI compared with the CI2MOI. Janvier and her colleagues concluded that there was a need for qualitative studies, which explore clinician's reasons for the differential treatment of CIEPI in the context of resuscitation. Therefore, I conducted thirteen semi-structured qualitative interviews with English neonatologists, which explored the clinical factors that influence the resuscitation decision-making process for CIEPI, CITI and CI2MOI. It also explored the reasons why the parents' wishes for non-resuscitation should or should not be respected as well as how the neonatologists weighed the parental wishes with their clinical judgment in order to decide whether or not to resuscitate against the parents wishes. Finally, it explored the reasons for the differential treatment of the CIEPI compared with the CI2MOI when both require resuscitation and have similar prognoses.

3.2 Research Setting and Context

The research was conducted in four National Health Service (NHS) Trust sites in England. The trusts are divisions within the NHS, which generally serve a geographical area or a specialized function. There are 180 Neonatal Units, which are organized into 23 formal geographical networks in England.

The neonatal services within these networks provide care for all babies less than 44 weeks that require ongoing medical care and these services are provided in a variety of settings depending on the interventions required for the baby. Within each network the neonatal units are organized into three categories, which include: Special Care Unit (SCU), Local Neonatal Unit (LNU) and Neonatal Intensive Care Unit (NICU).

The main differences between the three categories are based both on the gestational age of the infant and the severity of their illness. Therefore, I focused on NICUs because they provide services for births anticipated after 22+6 weeks gestational age whereas LNUs only have the capacity to provide services for singleton births anticipated after 26+6 weeks gestational age. NICUs provide care for infants who are the most unwell and are likely to require any form of mechanical respiratory support that is either invasive (e.g. endotracheal intubation) or non-invasive (e.g. continuous positive airway pressure, bi-level positive airway pressure or nasal high flow) and parenteral nutrition. Furthermore, the British Association of Perinatal Medicine recommendations require that a NICU deliver a minimum of 100 extremely preterm infants per year. Therefore, it is guaranteed that physicians working in a NICU will have had recent experience making resuscitation decisions for critically ill 24-week gestation infants.

I chose the London, Thames Valley and Wessex Networks because they were the closest networks, which have NICUs. I choose four Trusts in these networks however I will not specify the names of the Trusts in order to ensure that the anonymity of participants is protected.

3.3 Methodology and Research Methods

All seven of the studies that examined the differential treatment of CIEPIs used surveys. While these surveys highlighted the fact that CIEPIs were treated differently than older infants with regard to resuscitation they have not adequately explored underlying reasons for the differential treatment of CIEPI. Furthermore, surveys are limited in their ability to understand the considered moral judgments and intuitions of individuals in practice. (Dunn et al. 2012; Sheehan and Dunn 2013)

Ethically sensitive areas, such as resuscitation decision making for critically ill infants, requires an empirical approach in order to acquire knowledge by means of direct or indirect observation or experience. Empirical research can be divided into two categories: quantitative and qualitative. Quantitative and qualitative methods “have different strengths and logics and are often best used to address different kinds of questions and goals.” (Maxwell 2013) Qualitative research seeks to understand how events, actions and meanings are shaped by the unique circumstances in which these occur. (Maxwell 2013) It also emphasizes the importance of understanding the process by which events and actions take place. In other words, the focus is less on the outcomes and more on the process, which lead to the outcomes. On the other hand, quantitative research is more focused on the outcomes and less on identifying the processes. (Patton 1990) Another strength of qualitative research is its inherent openness and flexibility to modify the design and focus of the research, which allows for the exploration of unanticipated phenomena, influences and relationships whereas quantitative research generally adheres to the rules of statistical hypothesis testing of not altering the research plan after the data collection has begun. (Maxwell 2013)

The main reason I chose to conduct semi-structured interviews was because they are extremely useful for examining the complexities of clinical decision-making. (Pope 1995) Furthermore, qualitative research answers questions that quantitative research cannot such as; "questions about individuals' motivations, perceptions, expectations and meaning." (Gilchrist and Engel 1995) In order to explore, in depth, the neonatologists' perspectives on resuscitation decision making for critically ill infants as well as their reasons for differential treatment of CIEPIs, I decided to use a qualitative interpretive approach, which focused on understanding meaning:

> "Understanding the meaning, for participants in the study, of the events, situations, experiences, and actions they are involved with or engage in. I am using 'meaning' here in a broad sense, including cognition, affect, intentions and anything else that can be encompassed in what qualitative researchers often refer to as the 'participant's perspective.' This perspective is not simply their account of these events and actions, to be assessed in terms of truth or falsity; it is part of

> the reality you are trying to understand. In a qualitative study you are interested not only in the physical events and behavior that are taking place but also in how the participants in your study make sense of these and how their understanding influences their behavior." (Maxwell 2013)

3.4 The Research Process

Although the nature of neonatology is quite similar across different countries, the structure and practicalities can vary. Therefore, before starting my research, I arranged a meeting with two consultant neonatologists in England in order to discuss my research ideas as well as to ask them about the differences between neonatology in England and Canada where I had practiced. These meetings also allowed me to take suggestions about ways to further strengthen my project so that it was appropriate and applicable to the English setting.

Selection of physicians for the interviews

The potential interviewees were purposively selected in order to construct a sample of maximum variation in age, sex, location and clinical experience. Two categories of physicians were targeted: 1. consultant neonatologists who were working in a NICU in England; 2. neonatal grid trainees who were working in a NICU in England. Initial contact details of physicians were sought through the European Neonatal Ethics Conference (Southampton NHS Trust, May 1, 2014) in order to select physicians who had a special interest in neonatal ethics to ensure interviewees would have good knowledge of the subject area.

1. *Consultant Neonatologists (10):* Consultant neonatologists who work in a NICU are one of the few cohorts of physicians who take care of CIEPIs on a daily basis. Consultant is the highest post attainable in Neonatology and it requires four years of training in general Pediatrics as well as a further four to six years of training in neonatal intensive care medicine. Therefore, consultant neonatologists are the most senior experts in their field and have more clinical experience with CIEPIs than any other subset of physicians. Consultant neonatologists have also had clinical experience taking care of a range of critically ill infants, not only CIEPIs. Therefore, they were the most likely to be familiar with all three of the clinical vignettes. Furthermore, consultant neonatologists have practical insights about the key ethical issues and challenges surrounding resuscitation because they are responsible for making these decisions as part of their everyday practice.

2. *Neonatal Grid Trainees (3):* Neonatal grid trainees are physicians who have completed their training in Paediatrics and have decided to sub-specialize in neonatology. Their training lasts four to six years and will eventually lead to a post as a consultant neonatologist. Neonatal grid trainees also have experience taking care of CIEPI however not to the same extent at consultants. They are still in the process of learning how to make resuscitation decisions for CIEPI. Therefore, they were included in order to ensure a diversity of experience level while still ensuring they had expertise.

Method

Semi- Structured Interviews: The semi-structured interviews were carried out in order to explore the underlying reasons for the differential treatment of CIEPIs in the context of resuscitation. Guided by the objectives of this research, a two-part semi-structured interview schedule was developed based on concepts from the literature (see Appendix 3). The interview schedule was piloted with my supervisor as well as a consultant neonatologist in order to refine it and ensure that it was medically accurate.

The first part of the interview included three clinical vignettes based on the vignettes used in Janvier's surveys. However, more clinical information was added and only the infant vignettes were used (see Appendix 3 for the clinical vignettes) and permission was obtained from Dr. Janvier in order to use her vignettes as the basis for my interviews. The vignettes that I used were designed by myself and were reviewed by a neonatologist in order to ensure their medical accuracy. The order in which the vignettes were given was randomized prior to the interview in order to minimize bias. Each vignette was designed to control for prognosis, sex, level of disability and ethnicity in order to eliminate any selection bias. The three questions asked after each vignette were worded exactly the same and the interviewer used a script so as to ensure the wording was not altered. The purpose of the vignettes was not to re-illustrate Janvier's results but rather, to take interviewees through a thought experiment which helped them understand the context of her results and conclusions.

The second part of the interview consisted of open-ended questions, which were designed based on concepts drawn from existing literature to explore the neonatologist's reasons for Janvier's results and conclusions. The open-ended questions also explored other related themes found in the literature review however the actual interviews and discussions were responsive and sometimes ranged beyond these. As is typical of qualitative research, the guide was used flexibly, in order to allow the flow of the interview to be guided by the responses of the interviewees although at the end it was ensured that most of the questions in the guide were discussed.

Data Collection

I conducted 13 semi-structured face-to-face interviews, between June 2014 and January 2015, with consultant neonatologists and neonatal grid trainees from four NHS Trusts in South East England. The sample size was determined through theoretical saturation. Ten of the neonatologists were consultants of which five were male and five were female. Three of the neonatologists were trainees of which two were female and one was male. Two neonatologists had over twenty years experience, six neonatologists had 10-20 years experience and five neonatologists had less than ten years experience working in neonatology.

The interviews lasted between 40 and 70 minutes and were audio recorded and transcribed verbatim. In order to comply with ethical guidelines we insured that participation was voluntary, that participants could withdraw at any time, and that confidentiality was protected (see Appendix 2). All responses were anonymised and particular care was taken not to reveal potentially identifying details of hospitals, practices or clinicians. I travelled to each NHS Trust and conducted the interviews in quiet rooms in the NICU. Participants were asked demographic questions at the end of the interview, which included: age, years in neonatology, training and ethnicity.

An interview guide was used and was refined during the course of the study in light of ongoing data analysis. The interviews examined the following broad themes: (1) Weight of parental interests when making resuscitation decisions for critically ill infants, (2) Differential treatment of CIEPI with regards to resuscitation decision making, (3) Moral status of CIEPIs compared with CI2MOIs, (4) The strength of a newborn infant's interest in continuing life and (5) the guidelines and laws surrounding resuscitation decision making for critically ill infants.

3.5 Data Management and Analysis

The data analysis was an iterative process throughout the course of data collection. I familiarized myself with the data by transcribing some of the interviews myself which allowed me to start to identify recurring ideas and patterns that emerged. After the first seven interviews were completed, I conducted a preliminary exploratory analysis using the in-vivo coding method which is recommended for beginner qualitative researchers because it helps identify "what is significant to the participant and may help to crystallize and condense meanings." (Charmaz 2006) Therefore, I coded the initial set of interviews using the in-vivo coding method, which helped me to become familiar with the data and attune myself to certain words or phrases used by the interviewees. In-vivo coding initially involves coding every line of data, which can provide metaphors for rich category, theme and concept development. However, using the in-vivo method as the sole coding method can limit the ability to transcend to more conceptual and theoretical level of analysis and insight by the over fracturing the data. Therefore, I also used systematic coding which involved reading all of the interviews consecutively and labeling paragraphs of interview extracts with words and phrases that captured the meaning of the data. I then combined the codes from the initial phase and the second phase into a list of emergent codes and possible themes. At this point, I met with my supervisors to get their input on the appropriateness of my codes and to identify possible codes or patterns I had missed. This preliminary data analysis allowed me to create a framework for future data analysis and was very helpful for refining some of the questions in my interview guide.

Data Analysis

Ten of the thirteen interviews were transcribed by a trained transcriber who was recommended by my supervisors. I verified all of the interviews by listening to the audio files. I filled in any gaps and made corrections on the transcripts.

Once the second set of interviews were completed and transcribed, I read all of the transcripts thoroughly line by line and axially coded them. The codes were constantly grouped, regrouped and compared in order to reduce the number of initial codes developed in the preliminary analysis. One of the ultimate goals of axial coding was to sort and re-label codes into conceptual categories so that the “codes are sharpened to achieve their best fit.” (Saldina 2013) Therefore, an iterative process was used to create a hierarchical list of codes, which were further collated into various categories.

The thematic analysis involved a conceptual interpretation of the data set in order to “bring meaning and identity to a recurrent [patterned] experience and its variant manifestations” (Saldina 2013) During my analysis I paid particular attention to the reasons for differential treatment which were highlighted in the literature as well as being open to new themes arising from the data set. After the initial thematic analysis, I generated a codebook, which was circulated to my supervisors together with a sample of interview transcripts. My supervisors independently reviewed them and gave suggestions for revision and further analysis. At this point, I deleted codes and themes I found incidental or inappropriate and subsumed some themes under broader themes in order to try to achieve “meaning condensation”. (Rubin and Rubin 2012) The final codebook was reviewed with my supervisors and then used to code the entire data set. Reflective memos about some of the interesting issues that were arising from that data were written during the coding process. This helped to highlight and identify variation in perspective across the neonatologists.

3.6 Ethical Considerations

Ethics Approval

This research project was reviewed and approved by the following ethics committees (see Appendix1): The Oxford University Clinical Trials and Research Governance, Central

University Research Ethics Committee (Ref: MSD-IDREC-C1-2014-029), Oxford University NHS Trust (Ref: 377/PID 1-752). This study was also conducted in accordance with the principles of the Declaration of Helsinki.

According to the requirements of each local ethics committee, the neonatologists were approached after initial contact with the medical director of each NICU. Each physician was provided with an information sheet about the study, a letter of invitation and a letter of support from my supervisor, Professor Michael Parker (see Appendix 2). The information sheet outlined in detail the purpose of the research, why the research is important, the details about the interview process, the possible benefits/disadvantages of taking part and my personal contact details. Once the physician agreed to be interviewed, written consent was obtained prior to the interview as well as permission to audio record the interviews. None of the physicians declined to have their interview recorded.

Confidentiality

To ensure the confidentiality of all physicians, the research audio files were anonymously coded before they were sent for transcription. Transcripts were password protected and all personal identifiers were removed. In the presentation of the data, verbatim quotes have been anonymised and assigned with a generic identifier. CN represented a consultant neonatologist and NT represented a neonatal grid trainee. It was apparent that consultant neonatologists and neonatal trainees who participated formed part of a small potentially identifiable group. For this reason the consultant neonatologists and neonatal trainees were provided with the opportunity to review the transcripts.

Contact details and interview transcripts of the participants were kept in a secure password protected file with access limited to myself. The data storage described above is in accordance with the advice of the University department data protection adviser to ensure compliance with the Data Protection Act 1998. When the data is destroyed, the computer files will be disposed of in accordance with the University secure erasure of data policy and any paper records will be treated as confidential waste.

Reflexivity: Acknowledging my role and some methodological challenges

Reflexivity was a way to reflect on my role in the research process and to acknowledge the impact it had on my results and it also enhanced the rigor of my qualitative research. I have spent time working in the NICU during my Paediatrics residency at London Children's Hospital in Ontario and I have had personal experiences with the ethical issues I explored in this research, which made complete objectivity unachievable during the research process. However, feedback and discussions with my supervisors during the research process ensured that the actual experiences and perspectives of the neonatologists were reflected in the analysis and interpretation of the interview data.

My previous experiences and knowledge of the context can also be seen as a strength to the research process. A key strength was my understanding the context of resuscitation decisions because it allowed me to probe further during my interviews and to present the neonatologists with alternative views. Furthermore, my medical knowledge helped me to understand the nuances of the neonatologists' responses and also helped me to establish rapport with them during the interviews in order to gain their trust.

A limitation of this research was the fact that the interviews only represented the views of neonatologists from a small geographical radius. Thus, the findings cannot be generalized to represent the views of English neonatologists. Furthermore, the small sample of trainee neonatologists meant that I was not able to make comparisons between the responses of trainees and consultants. It is also important to note that the neonatologists' responses to the vignettes may not necessarily translate into their actions in practice. Finally, the vignettes were designed using current data to ensure their medical accuracy and were reviewed by a consultant neonatologist to ensure they were realistic however it was impossible to include all of the complexities and nuances that characterize a clinical case in practice. Therefore, some neonatologists may have felt that parts of the hypothetical clinical vignettes were unrealistic or different to their experiences of similar cases in practice. However, there were two benefits to giving the neonatologists the clinical vignettes; the first was that it allowed for a more in depth exploration of how they think through these very difficult decisions and the second was that it helped them to understand the context of Janvier's results and conclusions. Using this approach helped me to gain a deeper understanding of the intuitions of the neonatologists and of the essential component parts of the resuscitation decision-making process for critically ill infants across a range of ages. I was also able to explore the context specific factors, which influence the behavior and attitudes of those making resuscitation decisions for critically ill infants on a daily basis. Lastly, it has allowed me to develop explanations for the differential treatment of CIEPIs in the context of resuscitation. (Miles and Huberman 2002)

Another strength of this research was the fact that I designed and carried out qualitative semi-structured interviews in order to explore this very complex phenomenon, namely the differential treatment of CIEPIs. Over the course of 8 months, I spent approximately 16 hours interviewing neonatologists in England and asked each neonatologist over 20 questions about the differential treatment of CIEPIs. The interview transcripts were over 300 hundred pages in length which were condensed to the 50 quotes included in my results chapters. The data from these interviews provided some very rich insights about how these neonatologists think, including their values, perceptions and their unique perspectives about the differential treatment of CIEPIs.

Chapter 4: Factors Which Characterize The Context of Resuscitation Decision Making for Critically Ill Infants

4.1 Introduction

This chapter aims to provide an overview of how the neonatologists responded when they were given the three infant clinical vignettes similar to those used in Annie Janvier et al.'s surveys. After each clinical vignette, the neonatologists were asked whether they thought the consultant in the vignette should resuscitate, intubate and admit the critically ill infant to the ICU. The neonatologists were unanimous (13/13) and answered yes in all three of the vignettes (the CIEPI, the CITI and the CI2MOI) however it is important to note that the parents were not present and therefore the neonatologists' initial answers were based solely on their clinical judgment. In the next part of the scenario, the parents arrived and after hearing all of the information they refused to give consent for resuscitation because they feared the consequences of having a severely disabled child (see Appendix 3).

I have provided a graph (see Figure 1 below), which, illustrates the number of the neonatologists who would resuscitate in the absence of the parents wishes compared with the number of neonatologists who would still resuscitate even when the parents refused to consent to resuscitation. Those neonatologists who respected the parents' wishes for non-resuscitation in the case of the CIEPI but not in the case of the CI2MOI were endorsing the differential treatment described in Janvier et al.'s surveys. Approximately 60% (8/13) neonatologists endorsed the differential treatment of the CIEPI and approximately 30%

(3/10) neonatologists endorsed the differential treatment of the CITI. No neonatologists endorsed the differential treatment of the CI2MOI as all of them opted to resuscitate against the parents wishes. Due to the nature of qualitative research, it is important to note that the neonatologists' response rates cannot be generalized. However, their responses to the clinical vignettes provided an interesting comparison with other studies as well as provided a starting point for a more in depth analysis of their responses.

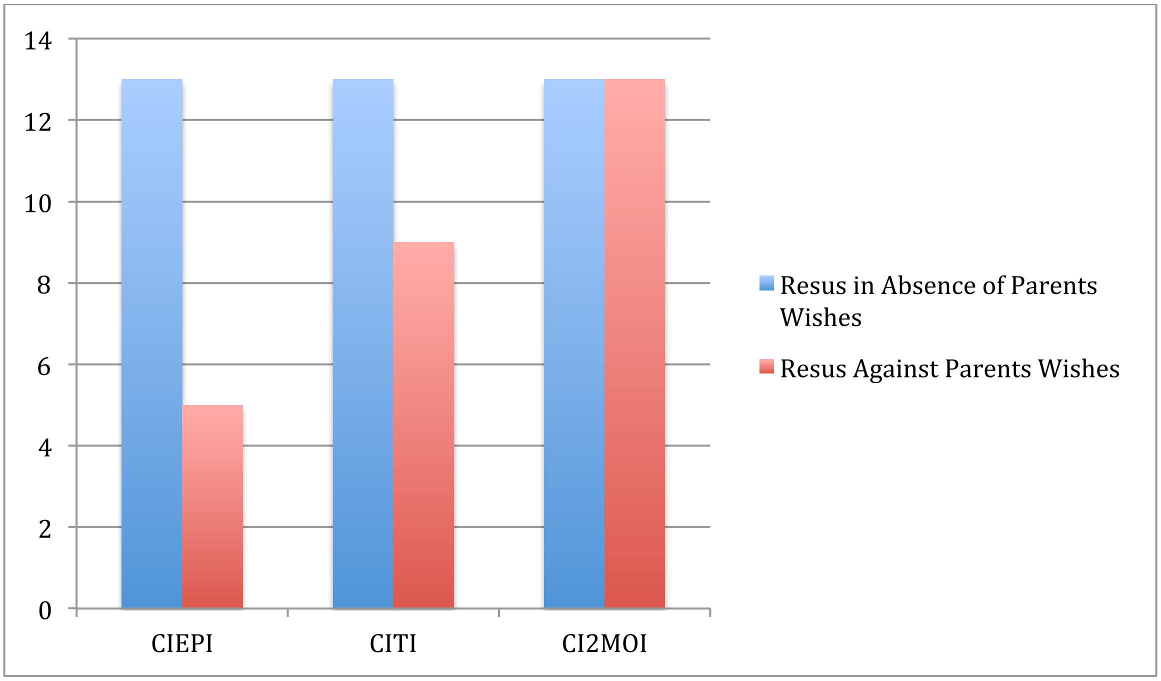


Figure 1 Responses of the neonatologists to the clinical vignettes

The main aim of this chapter is to describe the clinical factors, which influenced the neonatologists' decision to resuscitate before the parents wishes were made known as well as to explore how the neonatologists weighed the parental wishes with their clinical judgment in order to decide whether or not to resuscitate against the parents wishes.

The first half of this chapter describes two themes that arose from the first part of the interviews: General Clinical Factors and Specific Clinical Factors. There were two main general clinical factors, *Uncertainty* and *Buying More Time*, which were cited by the neonatologists across all three clinical vignettes (the CIEPI, the CITI and the CI2MOI). These general clinical factors will be described in detail in section 4.2. There were also a number of clinical factors that the neonatologists mentioned that were specific to each vignette (see Table 3) and which are described in detail in section 4.3.

Table 3 Summarizing Specific Clinical Factors

	CIEPI	**CITI**	**CI2MOI**
Factors	Initial Clinical Presentation	Uncommon Diagnosis/Lack of Expertise	Reversible /Treatable Illness
	Harm of Intensive Care	Harm of Intensive Care	Acuity

The second half of this chapter describes the neonatologists' responses after the wishes of the parents were made apparent and describes how the parents' wishes influenced the resuscitation decision-making process as well as describes how the neonatologists weighed their clinical judgment with the parental wishes when deciding whether or not to resuscitate against the parents wishes.

Interview Key:

CN: Consultant Neonatologist

NT: Neonatal Trainee

I: Interviewer

- 300**: Anonymous Identification Number

4.2 General Clinical Factors

Uncertainty

Uncertainty was one of the most common factors, which influenced the neonatologists' decision to resuscitate. There were three main sources of uncertainty which emerged from the interviews: prognostic uncertainty, diagnostic uncertainty and uncertainty around parental wishes.

Prognostic uncertainty makes it is difficult to predict whether or not the infant will end up with severe disabilities as a result of the LST received in the intensive care unit. Although it is life saving, LST also has the potential to cause long-term sequelae such as cerebral palsy, deafness, blindness, abnormal psychomotor development, behavior problems and learning disabilities. There is a spectrum of severity of long-term sequelae, which ranges from none to mild to severe. However, the current technology is poor at predicting which end of the spectrum the infant will end up in, as the following neonatologist outlined:

> CN: "But at this point in time we don't have a test that does that. And so at this particular point in time I don't know if this child is going to be that 20% where actually 80% doesn't have a profound disability. And so you have to offer this child intensive care until such time as you can have a reasonable idea of what is going to be this child's future." – 30014

Another aspect of prognostic uncertainty was the difference between population based outcome statistics compared with outcome statistics that are tailored to the child. Four neonatologists mentioned the fact that the survival and outcome statistics given in the vignettes were population based. In other words, they are calculated to give a mean percentage based on a similar population and there is uncertainty around whether the outcome and survival statistics quoted fully apply to the infant in front of them. The reason for this is uncertainty is because there may be other factors specific to each individual case that will improve or worsen the outcome as the following neonatologist stated:

> CN: "The scenario where one has when one works with limited information, which is population based data and you're faced with a live infant, I'm keen to start treatment and then review. Each infant is slightly different and these numbers may not totally apply to that particular infant." - 30011

The second type of uncertainty related to the diagnosis and is called diagnostic uncertainty. Although the diagnosis was given to the neonatologists in the clinical vignettes, it was apparent that they thought there could be other reasons for the infant's presentation. The fact that some of the neonatologists felt uncertain about the diagnosis was not surprising, as most clinicians have been taught to think about a differential diagnosis until they have gathered enough clinical information to support one specific diagnosis. The following neonatal trainee discussed the diagnostic uncertainty for the term infant with an AVM:

> NT: "Because it seems like this is all happening acutely and we don't actually know if the cause of what's happening is related to the underlying cause or whether there is something else going on. So I think we'd need to investigate further and make sure that we were sure that the cause of this deterioration was actually related to the underlying structural abnormality. I think I'd have to be absolutely certain that what's happening now is related to the underlying condition and not something that's an infection or some other thing. And I think I'd want to be sure we'd explored all the options before we'd made that decision, so that we can give the best information to the parents to help them make that decision as well." – 3010

In the case of the CIEPI, the uncertainty was not related to the diagnosis, it was related to the diagnostic information about the gestational age. Although the CIEPI's gestational age was determined by ultrasound, four of the neonatologists discussed the fact that ultrasound can be inaccurate by up two weeks. Here is an example from the discussion by one of those neonatologists:

> CN: "I think one would always need to bear in mind that sometimes the medical information which we have is not correct, for instance. So although there seems to be reasonable certainty that this baby is of 24 weeks' gestation, sometimes actually that's not necessarily the case." – 3009

The third type of uncertainty was related to the fact that sometimes the parents were not present to digest the information and express their views about resuscitation. For example:

> CN: "The mum is sedated and neither mum nor dad have had a chance to really think about this so I would institute intensive care, I'd wait for mum to wake up and get in touch with Dad." – 3001

One neonatologist classified parents into three groups and when there was uncertainty around the parents' wishes, he made his decision based on what most parents would do – resuscitate.

> CN: "Finally, the mum is sedated and I have no idea what she thinks. In my clinical experience parents fall into three groups. The ones who are very sure they don't want anything done with their baby, if there is these kind of numbers. There are a few who would want everything done for an infant despite the numbers. The vast majority of them fall in the middle. They don't have very clear and definite ideas as to yes or no. They're willing to chance it on the grey area and just say well if the situation accumulatively gets worse, then we are very likely to withdraw but the initiation of life support is something that most people would say yes go ahead with it" - 30011

Uncertainty was a common theme, which emerged in all of the interviews and it affected how the neonatologists responded when asked whether or not they should resuscitate. Interestingly, uncertainty was also linked to the next general clinical factor, which is time. The next section will explore the relationship between time and uncertainty as well as how it influenced the neonatologists' decision to resuscitate in the absence of the parents wishes.

Buying More Time

Resuscitation decisions are usually made in a very acute situation and there is usually not enough time to collect all of the information, to explore the parents' views and to get the opinions of other healthcare professionals. All thirteen neonatologists discussed the importance of buying more time and it was referred to the most frequently out of all of the clinical factors. This section describes the ways in which the lack of time influenced the neonatologists' decision to resuscitate and describes how buying more time was used as a tool to mitigate uncertainty around the prognosis, diagnosis and the parental wishes.

This quote from a consultant neonatologist illustrated the difficulties of not having enough time to gather all of the clinical information and do a full assessment of the patient.

> CN: "I think we feel more comfortable when we have more information to make that kind of decision. And I think, beyond the kinds of things where we have a lot of numbers for, the difficulty for me is that in an acute situation, whether it's trauma or whether it's meningitis or whether it's something else, you haven't really got enough time to assess that patient in its entirety." - 30014

When a split second decision has to be made about whether to resuscitate or not, all of the neonatologists said their default would be to resuscitate in the absence of the parents wishes. Interestingly, twelve of the thirteen neonatologists thought of the default decision to resuscitate as a way to "effectively delay the decision" (CN: 3010) so that they could have the benefit of more time. In a sense, delaying the decision in order to buy more time was used as a tool to help the neonatologists mitigate the uncertainty around the prognosis, diagnosis and parental wishes. Three neonatologists perceived that withdrawing life-sustaining treatment was morally equivalent to not initiating it, which is why they felt the default should be to resuscitate with the option to withdraw later.

> CN: "I think that the baby's condition is such that you need to take action straight away to save that baby. If more information becomes available about how poor prognosis is at the time, then that would be the time to withdraw treatment. And I think that withdrawing intensive care after starting is the same as not starting

> intensive care. So I think those two are morally equivalent, so I'm happy to start intensive care and then stop should I need to. So I would start here." - 3006

All thirteen neonatologists discussed one benefit of buying more time it allowed them to gain a better clinical picture and allowed them to collect more clinical information in order to reduce the diagnostic and prognostic uncertainty.

> CN: "Well, the first thing is that you've got a child who is clearly ill and the major issue is survival. If you do nothing you will ensure not survival. If you do something you may well allow yourself to be able to assess things a bit more carefully when the baby gets to the intensive care unit. By doing that you take the decision making away from the hot side of A&E and actually you control the situation and then you assess and see if you can refine the prognosis for disability." – 3001

Another benefit of having more time was that it allowed for discussion with the rest of the multi-disciplinary team. This was especially important for the three trainee neonatologists who preferred to have time to consult the opinions of more senior colleagues. However, the importance of discussing the case with the wider team was also mentioned by a very senior consultant neonatologist. The NICU has a team-based approach to caring for patients and therefore it seemed important for the neonatologists to have time to discuss the care plan with the multi disciplinary team.

> NT: "I think the benefit of time, the benefit of a bit more information about what was understood antenatally and the benefit of being able to discuss the case with a wider group of multi-professionals. So being able to have the time to discuss this with everybody involved really." – 30017

The final benefit of buying more time was to give the parents the information about their child. This was important because in the acute situation when their child is critically ill, it can be very overwhelming and difficult to digest all of the clinical information. Giving the parents more time means that the decision can be made when the infant is more stable and when the parents have been able to better come to terms with what has happened. Interestingly, one neonatologist felt that buying more time also helped parents to feel they made a good decision that they can live with. This consultant discussed how, even if the medical team thought resuscitation was futile, he still thought it would be important to resuscitate to give the parents more time to come to terms with their decision:

> CN: "Because in many of those cases where, as a medical team, you feel the product of it is futile, especially in the acute phase, offering little more intensive care might mean that you prolong this a little bit, but the outcome will often be still the same, it might just happen a few hours or a day or two later. But that gives the parents enough time to come to terms with what's happening and gives them the feeling that they've advocated for the child and done the really best for their child. And it allows them to live with this decision 20 years later, by which time I will have forgotten all about that particular child." - 30014

This quote from a consultant neonatologist provided a summary of the different sources of uncertainty (prognostic, diagnostic and parental) and their relationship with time. It also illustrated the benefits of buying more time in order to explore the parents and the multi disciplinary teams views, to collect more clinical information and to refine the prognosis.

> CN: "So again, I think the fact that it's a very acute situation doesn't let us know if this baby is going to be on one side or the other of the spectrum of outcomes. And I would try to emphasize that and to explain that to parents. So these are just numbers and figures and they're not suitable for an individual. It depends a lot on the response to antibiotics, on the imaging, is there severe, I mean extensive brain injury or is this just meningeal involvement without too much brain tissue involvement? That makes a big difference. So I would try to explain that it's very

> early and they probably need more information. And we also need more information that only time, a little bit of time can give us, and I would try to emphasize that." – 3003

The previous section described the theme of General Clinical Factors, which arose from the interviews. The two factors that were cited by all of the neonatologists across all three clinical vignettes were uncertainty and buying more time. These general clinical factors influenced their decision to resuscitate the CIEPI, the CITI and the CI2MOI in the absence of parental wishes. The next section will describe the theme of Specific Clinical Factors.

4.3 Specific Clinical Factors

This section describes the clinical factors that the neonatologists cited which were specific to the CIEPI, the CITI and the CI2MOI that influenced their decision to resuscitate in the absence of the parents wishes. These specific clinical factors are summarized in Table 3 above and will be described in more detail below.

Clinical Factors Critically Ill Extremely Preterm Infant

Clinical Vignette CIEPI – See Appendix 3

Initial Clinical Presentation

Almost all (11/13) of the neonatologists cited the initial clinical presentation as a factor which influenced their decision to resuscitate the CIEPI in the absence of parental wishes. Basically, the neonatologists based their decision about whether to resuscitate or not on the clinical presentation of the CIEPI at birth. This consultant described how all CIEPI receive an assessment of their initial clinical presentation at birth and his decision to resuscitate depends on this assessment and the infants clinical presentation at birth:

> CN: “We would try to negotiate a situation where we would assess the child. In fact, that’s what normally happens. We assess the delivery. If they are a reasonable size, a reasonable condition, then we would try to initiate resuscitation.” - 3009

Eight of the neonatologists referred to certain signs that they evaluate which include heart rate, breathing, amount of bruising, weight, tone and skin color. Interestingly, the decision is a two step process: first, the neonatologist decides whether or not to begin the initial resuscitation based on the clinical presentation, the appearance and the vigor of the CIEPI, then the neonatologist decides whether or not to continue resuscitation depending on the CIEPI’s response to the initial resuscitation. This two-step assessment is described below:

> CN: “Yes I do. I think the baby should be resuscitated using intubation and ventilation. I think it depends then on the response to intubation and ventilation what happens thereafter. And I would only reverse that decision, which is probably going to be your next question, if there was a lack of response to intubation and ventilation.” – 30017

The response to resuscitation is also used by some neonatologists as a way to set limits on the degree of resuscitation they attempted for the CIEPI:

> CN: “Equally, if the child does not respond to that treatment, then I wouldn’t feel it’s right to continue doing vigorous things to this baby, just because mum is sedated and we can’t have a discussion with her, because that wouldn’t be right either. So there has to be some sort of limit of resuscitation for this child. Assessment of that response, if that succeeds then yes.” - 30014

The following consultant described how the response to resuscitation provides a pragmatic way of making resuscitation decisions by letting infants declare themselves. She also talked about how it would be quite difficult not to resuscitate an infant who was crying and breathing because she interpreted these signs as an indication that the infant would respond well to resuscitation.

> CN: "No, this is more a pragmatic way of trying to decide, in the delivery room, who is going to be the baby with the good prognosis. So it's basically that it's sometimes very difficult to decide: is this the baby that's going to do well or is this the baby that's going to do poorly? But response to resuscitation is one way of deciding: I think this baby is going to do well. If they respond to a little bit of resuscitation with vigorous movement and good response, then that's one indicator that this baby is in the category that might do better. So even at that age we have a really hands-off approach, in terms of the baby is born and if they've come out and they go, "I want to be here, yay," then we'll resuscitate them and take them to the neonatal unit. If they come and they're not great and they're not active and they're not breathing, then we would let them take that decision." – 3006

Harm of Intensive Care

One of the consequences of resuscitating CIEPIs is that they have prolonged stays in the NICU while their organs mature. The harm of intensive care may be greater for the CIEPI because he/she may endure a longer and more difficult journey - compared to the CI2MOI who may spend less time in the intensive care unit and have less invasive procedures. This consultant discussed how he considered the degree of harm of intensive care for the CIEPI compared with the CI2MOI when he decided to resuscitate:

> CN: "What is different about the Intensive Care that we offer in neonatal units is the intensity of what we do for the child. So the child with meningitis might spend a week, a couple of weeks on PICU. The 24 weeker, you can be guaranteed is going to spend months in intensive care." – 30014

The following consultant discussed how his perception of the harm of intensive care differed between the CIEPI and the CI2MOI. He felt that even though all three infants had similar prognoses, one difference between them was the degree of harm the CIEPI would endure compared with the CI2MOI:

> CN: “You have to think about the treatment that you’re doing and consider the invasiveness of it and the painfulness and the discomfort that you are doing to an individual who has no right, no ability to tell you not to do what you’re doing. So you have to consider that as well to some extent in what you’re doing. And I think that is one of the differences that you have.” – 30014

Clinical Factors for the Critically Ill Term Infant

Clinical Vignette CITI – See Appendix 3

Harm of Intensive Care

The harm of intensive care was also cited by two neonatologists as a factor, which they considered in their decision to resuscitate the CITI in the absence of the parent’s wishes. The following consultant discussed the fact that the course for the term infant will include operations, which entail more harm and a longer admission:

> CN: “Not only there is problem in managing them, what I’m trying to say is that it’s not just long term prognosis, but the course to that long term prognosis is riddled with operations. So there’s a lot of additional suffering on the way. It’s operative suffering and I think that would sway me.” – 30011

Similarly, this consultant emphasized the importance of considering the harms of intensive care in the case of the CITI:

> CN: “Because treatment for this child isn’t just the resuscitation. It means a lot of sedating, it then means having surgery, it means having postoperative care and then potentially risk left with residual problems. But even if you don’t have a lot of significant problems they will still have a significant risk of having some problems afterwards, and you may actually put this child through quite a lot of invasive treatment to get to that point.” – 30014

Lack of Expertise

Another factor which influenced four neonatologists decision to resuscitate in the absence of the parents wishes was due the fact that they did not have experience taking care of a CITI with an arterio- venous malformation (AVM) and thus felt uncomfortable making a decision and opted to resuscitate:

> CN: “I think so. This one, I haven’t met this situation before so I feel more uncomfortable. So, from a treatment point of view, I would resuscitate simply because I don’t know what, you’ve given me the numbers here…I would just need to give myself, to give the baby a chance to declare itself clearly and for me to find out what the actual chances are for survival and the disability of this child.” – 30016

Another reason why two of the neonatologists felt they were lacking in expertise is because they felt AVMs were quite rare and there is less population data to rely on whereas a preterm delivery is much more common so the data is more “robust” (CN: 30014)

> CN: “I don’t think you can know this actually. I don’t think you can know that if the child is resuscitated the probability of survival is 40 – 50%. I don’t think you can know this is any individual case actually because these sorts of events are too individual and too uncommon to have an idea of what is likely to actually happen in any individual case.” - 30019

Clinical Factors for the Critically Ill Two Month Old Infant

Clinical Vignette CI2MOI – See Appendix 3

Reversible/Treatable Illness

One differentiating factor between the CI2MOI and the other infants was the fact the CI2MOI had an infection which was both treatable and reversible and not a life limiting condition on its own. Five neonatologists mentioned this when I asked them to walk me through their reasoning for why they decided to resuscitate the CI2MOI in the absence of the parent’s wishes:

> NT: “Because it’s a reversible illness, so it’s something that can be treated. Yes, there are poor prognostic factors associated with it but it’s something that can be treated so it should be treated.” – 3007

Acuity

Another factor which one neonatologist cited was the acuity of the presentation for the CI2MOI. She felt that the speed at which she had to make the decision for the CI2MOI was much quicker because the illness was not something that could be predicted which is why she decided to resuscitate in the absence of the parents wishes.

> CN: “I think part of it is to do with the acuteness of the presentation. So actually it’s to do with the speed. Also this is the type of child who is deteriorating quickly and so you don’t have a lot of time to make that decision. So you don’t have a lot, and if this is the only information you’ve got, so this is a child who was previously healthy, two months old, and has literally just been dropped by an air ambulance with this clinical history, then with a 50%-60% chance of survival, whatever that survival entails, I think absolutely you would, yes, I would resuscitate this child without too much consideration at all, yes.” – 30017

4.4 Parental Wishes and Expectations

This section aims to explore neonatologists’ views about how the parental wishes and expectations influenced their resuscitation decision-making process. After the parents’ wishes were made known, the neonatologists were first asked whether and why they thought the consultant should or should not respect the parents’ wishes for non-resuscitation. After they provided their reasons, they were then asked how much weight they thought parental wishes should be given when making resuscitation decisions for critically ill infants.

All of the neonatologists responded that they would resuscitate against the parents wishes in the case of the CI2MOI (see figure 1), however the responses for the CIEPI were quite varied. In general, there were two groups of responses: those that did not give parental wishes more weight over their own clinical judgment in CI2MOI and in the CIEPI (six neonatologists) and those that gave parental wishes more weight over clinical judgment in the CIEPI but not in the CI2MOI (seven neonatologists). This section describes the reasons for these two groups of responses as well as the neonatologists' perspectives about the challenges of balancing the wishes of the parents with their own clinical judgment of what is in the infant's best interest.

Parental wishes not given more weight over clinical judgment – Non-Endorsement of the Differential Treatment of CIEPI

Six neonatologists said that, for all three clinical vignettes, the parent's wishes for non-resuscitation should not be acceded. They acknowledged the importance of parental views however they differentiated between acknowledging and taking on board the parent's wishes with putting all the weight of responsibility on them. One trainee described how he uses parents' wishes as one of many "tools" (NT: 30018) to help aid the resuscitation decision-making process. He also discussed how making a resuscitation decision shouldn't be only the responsibility of the parents' because it puts an unfair burden on them, which should be shared by both the parents and the medical team.

> NT: "I think if you decide not to resuscitate purely on the parents' decision then that puts a massive burden on the parents. And speaking as a parent, I think it's quite hard, sometimes you make these decisions in the stress of the situation, and it would be an awful thing to go back and look back and think, "Oh gosh, did I make the wrong decision?" And so I think the role of the doctor should be to make the decision based on the medically available facts. And one of those tools that they use to make the decision should be the parents' wishes, but the child always has to come first, I think. And putting all of that weight on the parents, I think that's a bit unfair to the parents. – 30018

Three neonatologists also discussed how they felt it was not appropriate for parents to have to make a decision "on the spur of the moment" (CN: 3006) about whether their baby lives or dies because they haven't had enough time to digest the information and make an informed decision which is why they chose to resuscitate the CIEPI. This neonatologist with over 20 years of experience discussed why he felt it was inappropriate to accede the parent's wishes for non-resuscitation:

> CN: "After a life time of doing this, I also think it is wrong to get parents to make decisions in the delivery room because if your trying to ask a woman in labor about whether her baby should survive or not what is she going to say? It is absolute nonsense when you sit and think about it. You're not allowed to get research consent from her when she's laboring so why should you be getting her to make a decision about whether her baby lives or dies." – 3001

Three neonatologists also discussed the fact that, in the acute situation, the parents may not be properly informed or have all the proper information necessary to make a decision about whether or not to resuscitate their child. This neonatologist discussed how she opted to resuscitate the CIEPI in order to ensure that the parents were properly informed and did not regret their decision later on:

> CN: "But they need to make that decision based on proper information. Because if they're not properly informed, I think they could potentially seriously regret this over time. And they're the ones – they could potentially really regret it without having proper information. From the child's perspective, we owe the child some, we have a responsibility to the child to look after its interests." – 30016

More Weight to Parental Wishes – Endorsement of the Differential Treatment of the CIEPI

The parent's views and wishes are very important because they know the context of the family situation and they also have the legal responsibility of caring for the child in the future. However, there is a balance between putting all of the weight on the views of the parents versus not including their views at all. Two trainees weren't completely sure where the balance should lie between these two extremes and felt that parental wishes should be assessed based on each individual case and that it should be a "partnership of care" (NT: 3007)

> NT: "So we have to guide them but it ultimately has to be their decision because they have to care for the children that are produced by a premature delivery and all the kinds of problems that come with it so I don't know where the balance lies. It's definitely a partnership rather than one person leads and another person doesn't but sometimes parents need to be guided more than others." - 30010

The following neonatologist explained that parental wishes are similar to pieces of a jigsaw puzzle that fit together with many other factors that can vary depending on each individual situation:

> CN: "I think they need to have the appropriate information. I think they need to be, I mean fit to make the decision, and sometimes that's not the case. Very occasionally we need to get other people involved because you don't feel that the parents are ready to make, prepared to make the decision. But if they are, and they have all the background and their experiences and so on, that's very important. So I think it is an element, one of the elements in the jigsaw puzzle that you consider when you're making such difficult decisions. And I wouldn't be able to give it a percentage …" – 3003

Interestingly, this consultant described the fact that physicians are likely to give more weight to the parents' wishes if they align with the physician's judgment. In other words, this neonatologist was more likely to accede the parent's wishes for non-resuscitation if she believed resuscitation was not in the infant's best interest:

> CN: "
> So it sounds wrong to say that you're more likely to involve the parents and give way to their thinking you can agree with, but I think ultimately in real life that's what happens. Because it's the strength of having unity in what you believe to be best interests will always be quite a powerful thing. And I think it gets a little bit more difficult when you and the family don't necessarily agree what the best interests of the child are, because then it's difficult. It's more of a challenge to take their views on what we should have to do, absolutely have to do, but it's difficult to quantify how much of their input you allow to sway your decision making." - 30017

Interestingly, one consultant with 15 years' experience felt that it was not about the weight given to the parents' views but instead about the importance of dialogue in order to come to a decision that is within what is considered reasonable.

> CN: "So it's not that we have to put a certain weight on there and give them special powers, we are not in favour of that. I think there has to be a dialogue. I think they have to walk along with us and I think we have to walk the middle path and path of reasonableness." – 30011

For another neonatologist, an important factor he considered in deciding how much weight to give the parents wishes was the likelihood of severe disability and the emotional, physical and economical costs to the family. Thus, if there is a high likelihood of severe and lifelong disability then he would give the parent's wishes more weight:

> CN: Yes I think it seems to me that it would be fair, reasonable to acknowledge that if there is going to be severe disability, lifelong disability, the burden of that, and I mean the emotional burden as well as the physical, financial burden and life changing burden that goes along with that, it is reasonable to acknowledge that the parents' views therefore have validity, you know, some validity, not necessarily total validity, but an important element of validity. – 3009

Two of the neonatologists felt that the parent's wishes should have more weight because they will be the ones who have to "live with the decision" in years to come (CN: 30014).

'Do Everything' – Parental Expectations

There was a common theme, which arose in ten of the interviews around the expectations of some parents to "do everything" (CN: 30014) rather than to limit treatment or to request non-resuscitation. The following neonatologist discussed the challenges of having to balance the expectations of the parents with their own clinical judgment of what is in the infant's best interest:

> CN: "So people's expectations are very high. And sometimes what I'm finding especially challenging is that they will get angry with medical and nursing staff when things don't go right. And at the limit of viability things don't always go right, and it's part of what this process is about. People come incensed that their baby hasn't been the one to survive, and it's very, very difficult. And you've already said to them, "Look, your baby has got a very small chance of survival, you know, this is the rate for survival," And it still happens and people are still holding an enquiry and an inquest when actually this is part of what the realistic estimate was for the outcome for that baby in the first place. So that's a challenge dealing with high expectations from parents." – CN 3006

One consultant with over thirty years of experience discusses this situation and his view is that the pendulum has swung too far because some parents increasingly see physicians as technicians whose job it is to follow parental wishes exclusively, rather than to use their own clinical judgment to guide the decision making process:

> CN: "I think, when I first started, if I said to a mum, "Look, I think this is really awful. Your baby is likely to have a major disability and I think we should stop," and she'd say, 'Well, you know best, doctor,' and she'd stop. But actually, increasingly they're not saying that now. They're saying, 'Well, why do you say that?' And, 'I've been on the web and I've looked at this,' Parents have taken much more the locus of control away from the medical profession. And it's been something that has happened over the last 30 years, and it's got to the stage now where the doctor is almost a technician. And I hate that. I don't like that at all, because I don't think you are a technician. I'm not a technician when I look after these things." – 3001

It was apparent during the interviews that this parental expectation to "do everything" (CN: 30014) was a recent phenomenon which, the neonatologists felt was correlated with the societal trend towards parental autonomy and away from paternalism.

4.5 Conclusion

This chapter described the clinical factors, which influenced the neonatologists' decision to resuscitate the CIEPI, the CITI and the CI2MOI before the parents' wishes were known. It also described how the neonatologists weighed the parental wishes with their clinical judgment in order to decide whether or not to resuscitate whether or not to resuscitate against the parents wishes.

Section 4.2 described two themes that arose from the first part of the interviews: General Clinical Factors and Specific Clinical Factors. There were two main general clinical factors, *Uncertainty* and *Buying More Time*, which were cited by the neonatologists across all three clinical vignettes (the CIEPI, the CITI and the CI2MOI). Section 4.3 described the clinical factors that the neonatologists mentioned that were specific to each vignette (see Table 3).

Once the parents wishes were made known, there were two groups of responses: those who resuscitated the CIEPI and the CI2MOI despite the parents wishes for non-resuscitation and those who respected the parents wishes for non-resuscitation in the CIEPI but not in the CI2MOI. The neonatologists in the second group of responses endorsed the differential treatment described in Janvier et al.'s surveys. Section 4.4 described the neonatologists' reasons for these two groups of responses as well as their perspectives about balancing the wishes of the parents with their own clinical judgment when making resuscitation decisions for critically ill infants.

The next section describes the neonatologists' responses to Janvier's results, which showed that physicians were significantly more willing to overrule their own clinical judgment and respect the parent's wishes for non-resuscitation in the case of the CIEPI but not in the case of the CI2MOI. It also describes the neonatologists' reasons for the differential treatment of CIEPIs found in Janvier et al.'s surveys as well as their perspectives about two hypotheses from the literature for the differential treatment of CIEPIs.

Chapter 5: Reasons for the Differential Treatment of Critically Ill Extremely Preterm infants

5.1 Introduction

This chapter aims to provide an overview of how, in the second part of the interview, the neonatologists responded to Janvier's results and conclusions. The main purpose was to explore the neonatologists' reasons for the differential treatment of CIEPIs as well as to explore their perspectives on two hypotheses for the differential treatment taken from the literature.

After the clinical vignettes and the questions about the weight of parental wishes, the results of Janvier's surveys were presented and the neonatologists were asked to give reasons for why they thought the clinician's in Janvier's survey were significantly more willing to overrule their clinical judgment and respect the parents wishes for non-resuscitation in the CIEPI but not in the CI2MOI even though they had almost identical prognoses.

Three themes that arose from the neonatologists' answers included*:* *Personal and Clinical Experiences, Previous Training* and *Emotions*. Section 5.2 describes how experiences, training and emotions contribute to the negative perception that CIEPIs "don't do well" (NT: 3007) which in turn contributes to the differential treatment of CIEPIs found in Janvier's surveys.

In addition to perceptions, another theme that arose from the interviews were the fundamental attitudes towards CIEPI that lie beneath the differential treatment. There were three main attitudes: *Not So-Called Normal Babies, Its More Acceptable to Let Them Die* and *Children Produced By a Premature Delivery*. Some of these attitudes have been described in the literature however there is a lack of qualitative research exploring the reasons for these attitudes. Therefore, Section 5.3 describes these attitudes as well as the neonatologists' reasons for why they contribute to the differential treatment of CIEPIs.

During the interviews, it was apparent that some of the neonatologists did not exhibit these attitudes personally, however, they did acknowledge their existence both in society and in the medical community. Thus, these neonatologists were still able to provide valuable insights on the reasons for these attitudes and how they contribute to the differential treatment of CIEPIs.

Section 5.4 of this chapter describes the neonatologists' perspectives about two hypotheses, from the literature, for the differential treatment of CIEPIs. Firstly, Janvier's hypothesis that CIEPIs are considered in a separate and less moral category and secondly, Dominic Wilkinson's hypothesis that a newborn's interest in continuing life is weaker than that of an older child.

5.2 Perceptions of Critically Ill Extremely Preterm Infants

A perception is similar to an attitude in that both develop as a result of experience and both have cognitive aspects. However, the main difference lies in the fact that perceptions are in response to a stimulus. Thus perceptions are more transitory than attitudes because they change based on the immediate past experience and present state of the perceiver whereas attitudes are learned and more generalized. (Schiff 1970)

The neonatologists' responses revealed some very valuable insights about the how the negative perceptions that CIEPIs "don't do well." (NT: 3007) are influenced largely by the experiences, previous training and emotions of the physician rather than on the clinical evidence and/or on the survival and outcome statistics. The next section describes how personal and clinical experiences influence this negative perception of CIEPIs.

Clinical and Personal Experience - 'We contextualize the numbers based on our own experiences'

Clinical and personal experiences were mentioned by ten of the neonatologists as an explanation for the differential treatment of extremely preterm infants. They felt that there is a general perception that the majority CIEPIs have poor outcomes and low survival rates even though that is not necessarily accurate. When I asked them why they thought that was the case one neonatologist said "we contextualize those numbers through our own windows or our experience" (CN: 30011) meaning that each person perceives the statistics differently depending on their previous experiences with CIEPIs.

The following neonatologist personally reflected on how her clinical experience, rather than the survival and outcome data, affected her perception of the CIEPI in the vignette:

> CN: “And I would say that, not based on any published numbers, but just on my own experience as well, that I think there is quite a big difference. We’ve got one example on the unit at the moment that was extubated at a few hours old who is doing really well. And then you think of other babies who are much more mature, several weeks more mature, and they do a lot worse. – 30017

Neonatologists usually take care of the most critically ill CIEPIs and therefore may have a skewed perception of their outcome and survival as a population. The following neonatal trainee discussed how one reason for the negative perceptions towards CIEPIs could be explained by the fact that neonatologists have more experience taking care of CIEPIs and therefore they see more of the CIEPIs who end up with poor outcomes, which affects their perception:

> NT: “The two things that strike me, I mean, one; I think its personal experience and I think because we see a lot of extreme prematurity and threshold of viability and how they do that does influence the decisions and certainly when I started out I had a much more rosy view of every child deserves a life and how could you not resuscitate a baby. Whereas now when I see the terrible times babies have, you see it first hand how it’s not in the baby’s best interests always to do that. So I’m sure that’s shaped my practice and I’m sure its shapes other peoples.” – 3007

Six of the neonatologists shared personal stories about cases they had experienced which had a significant impact on them. As this neonatologist pointed out, some personal experiences stick more than others and therefore have a greater influence on their future perceptions of CIEPI:

> NT: “Yes, I still wonder what would have happened if I wasn’t walking through the hospital those two hours later. I wasn’t even planning to walk past; it was just that I was going by for something else and saw him. It’s frightening, it’s frightening, because actually that child is now in school and no residual effects. And he was intubated, I think, for a week in this ITU. And those cases stay with you.”- 30018

It was apparent during the interviews that some of the neonatologists more clearly remembered their experiences of taking care of the CIEPIs who had poor outcomes, which in turn affected their perception of the CIEPI in the vignette. Three neonatologists described the difficulty of seeing patients in the follow up clinic, especially those who ended up with severe disabilities. For example, the following neonatologist described how every time he sees a child with a poor quality of life in the follow up clinic he is reminded of his bad decision, which weighs upon his future decisions:

> CN: “And once we make those bad decisions where you resuscitate someone and then they end up having really poor quality of life afterwards, and you see them in clinic and you see what’s happening to them, what’s happened to the family, I think we all live in fear of those because that’s what we see and that’s what affects us most” – 30014

On the other hand, another neonatologist discussed the opposite scenario of an anecdotal baby where the infant had a horrible course on the NICU, got every single complication possible and a poor outcome seemed inevitable. However when he saw the child in the follow up clinic she had no disability and was completely normal despite the odds.

> CN: “The other thing which has always happened is the anecdotal baby that you get, that the numbers look horrible and everything looks bad, but you see them in clinic in two years and they actually escaped all of that. That to me weighs

> heavily because then you start thinking that would it be right to take those chances for a baby. It's a difficult moral dilemma" – 30011

ADD IN CONCLUSION

Previous Training – 'They carry on what they learned'

In addition to personal and clinical experience, three of the neonatologists commented that a clinician's previous training influences their perceptions of CIEPIs. For example, if during their training, they saw the majority of 24 week CIEPIs survive with good outcomes, then their perception of CIEPI would be different to those who didn't experience good outcomes for 24 week CIEPIs. In other words, they "carry on" (CN: 30016) what they learned or experienced in medical school or experienced during their specialty training:

> CN: "But for some reason people think preterm babies are different. I think it's because, when they trained, such small babies didn't survive." – 3005

Furthermore, because CIEPIs survival and long term outcomes are improving so rapidly, it is sometimes it is difficult for physicians to "keep up" (CN: 30017) with these advances.

Emotions - 'There is a Human Side to This'

Most parents expect to carry their infant to full term and deliver a healthy baby but when a mother suddenly goes into preterm labor, all of her hopes and expectations for her child change drastically. Therefore, resuscitation decision making for CIEPIs can be very emotionally difficult and draining. This quote from a consultant illustrated the emotional weight of a preterm delivery:

> CN: “Most people’s expectation in practice is that they are going to have normal children born at term. I suppose somewhere in the back of their mind they recognize that there is some chance that their child will not meet their hopes and expectations but they perceive those risks as small. But once you go into labour at 24 weeks those risks suddenly escalate into a very major risk. In fact, a fair, probably sort of an 80% certainty that their child will be a quite a long way short of what they would have been had they been at the normal time.” - 30019

In such difficult situations, it is inevitable that clinician will experience strong and varying emotional reactions to the birth of a CIEPI. The following neonatologist described how she found it difficult to find an emotional balance between being numb and emotionally unavailable with becoming too emotionally involved and losing objectivity:

> CN: “Well I can’t see how they could not be part of these decisions, because we’re all human beings. So if you completely cut off your emotions, I think I said to you at the beginning that it’s quite tough when you’ve spent the whole of a weekend telling parents you think their baby might die. And at the end of it you get a bit numb because you end up doing it in not the way that you feel that you should.” - 30017

Three neonatologists described how an emotional distance sometimes forms between the physician and the CIEPI. When I asked one neonatologist to explain why he thought there was an emotional distance, he found it difficult to put into words however he referred to the fact that there was a difference in the "emotional energy" that is put into CIEPI compared with an older infant.

> CN: "I have no explanation apart from saying that there must be something in us which naturally makes it difficult for us to look at a group of infants with the same emotional energy as you would look at a different group of infants. I often feel that we underestimate the impact of our own emotions when we make this decision, and often it is emotional but we seek a rational explanation once we have decided what's emotional." – 30011

This section illustrates the complexity of the "human" (NT: 30018) aspects of resuscitation decision-making for CIEPIs and how the personal experiences, previous training and emotions play a role in influencing the perceptions of CIEPIs in the context of resuscitation decision making.

5.3 Fundamental Attitudes Towards Critically Ill Extremely Preterm Infants

In addition to perceptions, the neonatologists described the fundamental attitudes towards CIEPIs that lie beneath Janvier's observations of differential treatment. An attitude can be defined as an individual's organized feelings and beliefs, which influences their behavior. (Schiff 1970) Therefore, an attitude is made up of both cognitive and behavioral components, which predisposes an individual to react in a certain way.

This section describes some of these attitudes as well as the reasons neonatologists gave for why they exist and how they contribute to the differential treatment of CIEPIs. The reasons are summarized in Table 4 below:

Table 4 Reasons for the Attitudes Towards Critically Ill Extremely Preterm Infants

	Not so-called normal babies	**More Acceptable to let them die**	**Products of a premature delivery**
Reasons	Different appearance	Proximity of gestational ages at which abortions are performed	Other specialties only involved with infants with poor outcomes
	No baseline of normal health	Ingrained cultural and historical practices	Unnaturally thrusting infants into the world
	Born at a disadvantage	Under umbrella of bodily autonomy	Creating disability
	Don’t have a treatable disease	Not meant to be here	

‘Not So-Called Normal Babies’

One attitude that exists among the parents and among other medical specialties is that CIEPIs are not “so-called normal babies” (CN: 3005) There are many reasons for this attitude including the fact that they have a different appearance to other babies or because they have never had a period after birth where they were healthy or due to the fact that they are born facing challenges that other babies don’t face or because they don’t have a real treatable disease. Although others may not see CIEPIs as normal, it was apparent during the interviews that this was not the case for the neonatologists. This consultant describes her frustrations about how this attitude doesn't exist for other patient populations:

> CN: "But I think the little 'premmies' don't look like babies always. And all through their time growing up, if they've got complications they are, "Well they were premature. What do you expect?" And I just don't think they can see the preterm baby and their trajectory as the same as a normal child. But of course they are. They're children, they're babies; they are normal by definition because they're here. But I think a lot of paediatricians outside neonatology think that we're creating problems by keeping babies alive that perhaps didn't need to be kept alive. So that's kind of the attitude to prematurity, I think, which is very interesting. Because we don't have that attitude to children with congenital heart defects or surgical gut defects that need a lot of intervention. So it's something to do with being born early." – 3005

As the previous quote illustrated, the appearance of the baby is one of the reasons for this attitude. CIEPIs can look quite different to term infants: they are much smaller with less body fat, they have thin and wrinkly skin, their heads are shaped differently, sometimes their eyelids are sealed and they are often in an incubator connected to monitors. Three of the neonatologists discussed how appearance has a strong influence on attitudes, especially for CIEPIs. The following consultant reflected on how it can be difficult to completely ignore their appearance in order to see their potential.

> CN: "I think we're ingrained, as human beings, to see a big, chunky baby as being something that is normal. And physically to look at, a tiny 23-24 weeker, they just look fragile, feeble and vulnerable. And I think it's quite difficult to see the potential beyond that. And I think we do see that when we see these children come back to clinics and things: it's almost difficult to turn your mind back and remember what they looked like. And I think we do. Physically what infants look

> like is quite difficult to ignore when they're in front of you, and it's seeing beyond that to see what their potential is, I suppose." – 30017

Another reason for the attitude that CIEPIs are "not normal" is because they did not have a period of being healthy before becoming sick. In a sense, they are born critically ill compared to the CI2MOI who has had two months of good health before becoming critically ill. When a child is ill, physicians commonly refer to the child's baseline of good health. However, for the CIEPI there is no baseline of normal health to work towards which contributes to this attitude.

> NT: "But I think in the two month old you've got this history where they've been absolutely fine, and so you've kind of got that to fall back on. Whereas the 24 weekers, all the history is so short, you're basing what you're doing on actually more what the patient looks like in front of you right now, because you haven't got anything to fall back on. It's more like, it's still none of this should have happened, but there is nothing before that where you can think, "Well I might be able to get back to that." – 3010

Four of the neonatologists referred to the disease process of CIEPIs as another reason for this attitude. In the case of the meningitis, it is a treatable or reversible disease process, which is quite different from the disease process of the CIEPI, which is not treatable per se. Instead, treatment for them involves supporting their bodily functions until they are mature enough to do it own their own.

> CN: "Yes, it's not something that you can treat to take away. You support. Which to me is a different physiology that you're correcting in the 24 weeker. You can only support them as they grow on." – 30018

'It's more acceptable to let them die'

Another attitude that emerged in eight of the interviews was that it is seen as more acceptable to let CIEPI die than to allow the CI2MOI to die. A variety of reasons were given for this attitude such as ingrained cultural and historical practices, confusion around the mother's right to bodily autonomy and the fact that they are not meant to be here. However one common reason that eight neonatologists mentioned as a reason that allowing CIEPI to die may be seen as more acceptable than letting older critically ill infants die was because abortions are legal up until 24 weeks for "psychological reasons" (CN: 30017)

> CN: " The fact that you're only, at 24 weeks, a very short period, days away from where you couldn't ethically… you can legally terminate, you can in this country anyway, you can legally terminate a pregnancy for psychological reasons." Okay, it is sort of saying that foetuses before that stage aren't morally valuable, which I probably would feel a bit uncomfortable about saying. But, yes, I guess that's what we are saying, as society, aren't we? We're saying we'll terminate your pregnancy at 22 weeks, but at 25 weeks we'll resuscitate your baby unless we've got a good reason not to." – 30017

The following trainee discussed a difficult case from medical school, which illustrated how the overlap of premature birth and permissible abortion contributes to the attitude that it is more acceptable to let the CIEPI die. During the interview, it was obvious that the abortion law in the UK was a source of moral distress for this neonatal trainee because on one hand he felt a strong duty towards the extremely preterm infant as his patient but on the other hand he felt it was not his place to question the societal norms.

> NT: "But then I was involved in an ethical discussion at university about a mother at 32 weeks wants to have an abortion and should she be allowed that abortion on

> psychological terms, or should the baby be delivered and then taken into foster care? And I was told at the time that there is no definite yes/no answer, and legally the child doesn't have any rights until it's born and all this kind of stuff. But it's difficult really, because that child, if it was born, could certainly have a normal life at 32 weeks. But if it's impacting on the health of the mother, how do you go about dealing with, deciding what's right or wrong? I don't know what the answer is. It probably doesn't come into this interview but I know that we offer late terminations for certain things. And I think that realistically society has decided that, in terms of abortion law that when the baby is inside the mother then ultimately the mother can decide what happens inside of her body. And whether that's right or wrong, that's what society has decided and that's what our job is to, not enforce, that's the wrong word, but support, support." – 30018

In a similar vein, two neonatologists discussed the fact that there is often confusion between the mother's legal right to bodily autonomy when the infant is in utero and the CIEPI having his or her own individual rights at the point of birth:

> CN: "At the point of birth they become an individual, and that individual has rights the same as any other individual. And that's why I think you can't confuse the issue of a mother's right to consent to treatment for the foetus inside her womb to what parents' consent and parents' wishes for treatment are once the baby is born. Under current law, when the baby is inside the mother's womb the mother gets to say what she wants to do up to a certain point. But at whatever gestation, once they are born, the parents are the parents but, like I said, they can't tell you not to offer treatment if that is going to be beneficial for the child." - 30014

However, not all of the neonatologists felt that the abortion laws were the reason for this attitude toward CIEPI. One consultant discussed why they are "different situations" (CN: 3001):

> CN: Because I think one is all about a woman's rights in her pregnancy over her own body with something that's inside her own body. And there are real issues around risk and issues around that, but those are rather separate to issues around in a situation where we are faced with a delivery of a baby who presumably is

> someone who is going to be loved as their life goes on and actually has a potential for a normal outcome. I think it's a different situation." – 3001

Another neonatologist felt it had to do with cultural practices that still exist in some communities, with high infant morality rates. For example, some cultures don't name their children until they have gotten through the neonatal period. She described how some of these cultural practices may be ingrained in our society and contribute to this attitude that it is more acceptable for CIEPIs to die:

> "And I think in some cultures as well some children aren't named, for example, until several weeks after birth. And I think that dates back from the fact that you weren't sure that your child was going to survive until it was several weeks old, so the naming and being part of the community didn't happen until the children were several weeks old. So newborn babies did have a very high death rate and weren't considered part of the community straight away." – 3006

Two neonatologists felt it may be due to the fact that, until relatively recently in the Western world, it was common for CIEPI to die because there was not neonatal intensive care medicine:

> "And that the natural process through most of history is that a 24 week gestation baby is to die. Most babies born at 24 weeks gestation in the world will die. So there is in one sense a difference." – 30019

'Children produced by a premature delivery'

Another attitude that emerged from five of the interviews was that other medical specialties might view CIEPIs as "products of the NICU" (CN: 3005) because most other medical specialties only become involved with CIEPIs who have complications or poor long-term outcomes. The following neonatologist described the unpopularity of CIEPIs among other medical specialties professionals and how that contributes to the attitude that they are products of the NICU:

> CN: “I think that may be true if you take the globality of doctors, for example, in the healthcare system. So we sometimes hear rather irritated comments about how we produce, or we discharge babies with lots of problems. And I do have the feeling that some people see our specialty as that. I mean the type of babies that we look after sometimes end up with problems that are chronic and longstanding difficult and need further admissions and further medical care and lots of difficulties. And that, I think, is quite unpopular amongst other specialists. ” – 3003

Similarly, another neonatologist described how other medical specialists have the attitude that neonatologists are “thrusting children into the world” (CN: 30019) who are not meant to be here and thus are left with complications and disabilities. However, when I asked him what he thought about this attitude, he discussed why he felt this was an inaccurate attitude towards CIEPIs and towards neonatology:

> CN: “I’m not sure that’s entirely true. Actually if you perform intensive care, you inevitably spare some children disability who would have had it. You end up with this margin, John Wyatt use to talk about it, between children who die and are disabled and normal. Whatever you do with intensive care you shift this group around but you always end up with this group in the middle who are disabled who would have died had you not done your intensive care. You probably can’t do much to change it. You are going to end up with a group of children who are disabled either way but you end up with more survivors. Good intensive care means there are more survivors, disabled children who would have died and normal children who would have been disabled roughly speaking.” - 30019

It was obvious that this attitude was problematic for neonatologists mainly because it did not exist in other patient populations or medical specialties. This neonatologist described how “there are worse things than preterm babies” (CN: 3005) and why she felt this attitude towards CIEPIs was unfair and biased:

> CN: “Yes. I mean you could just as well say for an anorexic teenager who has got a third of a chance of dying, third of a chance of being chronic anorexic with a ruined life and a third of a chance of surviving, why would you bother putting a tube down and feeding them? You know, because the next five years is going to be awful and they’ll miss school and they’ll never have a job and they’ll never be able to have children. And the ones that are chronic will just be sloping around looking skinny and miserable, having no quality of life at all. So they’ve got a much worse prognosis. There are an awful lot of conditions, but we still try. You know, its not just… there are worse things than preterm babies. When I say worse things, worse conditions and worse effects on a family than having a 24 weeker that we have to manage as doctors, some horrible things.” - 3005

5.4 Responses to the Literature – Janvier and Wilkinson’s hypotheses

At the end of the interview, the neonatologists were asked to give their comments on two hypotheses for the differential treatment of CIEPI from the literature: Firstly, Janvier’s hypothesis that CIEPIs are considered in a lesser and separate moral category and secondly, Wilkinson’s hypothesis that a newborn infant’s interest in continuing life is not as strong as that of an older child. The data revealed that one neonatologist agreed with Janvier and Wilkinson’s hypotheses and twelve neonatologists disagreed with both of these hypotheses. This section describes the neonatologist’s reasons for their perspectives on these two hypotheses.

Janvier’s Hypothesis – Lesser and Separate Moral Category

Janvier’s hypothesis for the differential treatment of CIEPIs is that they are considered in a lesser and separate moral category. The responses of the neonatologists to Janvier’s hypotheses were strikingly quite similar because eleven neonatologists' disagreed with the fact that CIEPI are in a separate and lesser moral category.

One consultant with over twenty years' experience commented on the fact that there may be a difference between the parental perception of moral status versus the social perception of moral status, and that this difference contributes to the differential treatment of CIEPIs.

> CN: "Well I think there is a perception that a baby at 24 weeks is worth morally less than a 2 month old. The reason for that is challenging but it also occurs through pregnancy in that you attribute greater moral worth to a baby at full term than you do to a baby at 24 weeks than you do to a fetus at 13 weeks. Actually you attribute different moral worth to a fetus at 13 weeks, 24 weeks and full term in such as you allow people to undertake abortion up to 24 weeks. Something happens at 24 weeks, I'm not quite sure what it is, that says well we shouldn't really abort after 24 weeks but actually the problems have started well before 24 weeks in the abortions. And actually if the child has a major malformation then that abortion can occur right up to full term. It is interesting how we perceive the moral value of each of those things relatively differently." - 3001

Another consultant discussed that CIEPIs may have been considered in a lesser and separate moral category in the past, but he felt currently it is not the case because the survival rates have improved:

> CN: "Not nowadays. I think in the days when 24 weekers didn't often survive then there probably was. When I trained 28 weeks was the limit. So, no, I might feel that way about a 22 weeker or a 21 weeker. But because it's so common in neonatal units to look after 24 weekers, they're standard bread and butter patients. And we know so much about them and we're improving the way they turn out all the time. I don't think they have less moral standing. I think they're a human being like everybody else." - 3005

The following neonatologist was unsure about Janvier's hypothesis and this quote illustrated the incongruence between what she thought was morally right and what may sometimes, in her view, possibly happen in practice:

> NT: I think, if I sit here and think about it logically, then I don't think there should be any difference. I can't see why. [Looks pensive - - - -] Do I think there is any difference? I don't think there should be any difference. But I think we do, we still do do it differently, and I don't know why we're programmed to do that." – 3010

The following consultant was quite troubled by the possibility of whether Janvier's hypothesis was true:

> CN: "I'd like to think we don't. As a neonatologist, that's a horrible thought that we would think of our patients as being lesser moral beings than we are. That's pretty terrifying actually." – 30017

Another trainee discussed how CIEPIs were in a separate medical category but not in a separate moral category:

> NT: "They are in a separate category but it's not a moral category so I don't think, well I'm certainly not saying that a preterm infant's life is worth less than a term infant's life and I don't think anyone would or should say that so I don't like that term moral category. They're in a different category, they're in a different medical category because they've got different things wrong with them and different hurdles but morally any life is equal to any other life. I think that's clear whether you're 23 weeks or whether you're 60." – 3007

This consultant discussed how the moral value of CIEPI is equal to any other critically ill infant because of the fact that we have the ability to care for them in the NICU.

> CN: “It’s life, there shouldn’t be a moral difference at all. Why should there be? I mean you are providing care for a 24 weeker. It’s immoral to provide care for a 24 weeker if you place less moral value on its life as compared to a two month old. That’s not a tenable position, morally speaking I think.” - 30011

In summary, the majority of the neonatologists I interviewed disagreed with Janvier’s hypothesis that CIEPIs are in a different and lesser moral category than other infants however two of the neonatologists were unsure of the reasons why they disagreed. One neonatologist agreed with Janvier’s hypothesis on the basis that the parents perceive a difference in moral value between a CIEPI and an older infant.

Wilkinson’s Hypothesis – A Newborn’s Infant’s Interest in Continuing Life is Not as Strong

The neonatologists were asked to respond to a quote from Dominic Wilkinson’s book, which hypothesized that for many people, a newborn infant’s interest in continuing life is not as strong as that of an older child. One neonatologist agreed with Wilkinson’s hypothesis on the basis that the CIEPI’s interest in continuing life was dependent on the parents’ interests. Twelve neonatologists disagreed with Wilkinson’s hypothesis and this section describes the reasons for the neonatologists’ responses to Wilkinson’s hypothesis about the differential treatment of CIEPIs.

The following consultant discussed that there is no evidence for that position, and that the statement misunderstands the whole concept of being an infant:

> CN: Well, what evidence have you got for that? There's no evidence at all of that. A newborn baby faces – is much more vulnerable to external influences, things happening, than an individual who is prescient and can actually make decisions for themselves. And there is some point in your life when you start to be able to think for yourself, consider yourself and refer to yourself and get yourself out of situations where you don't want to be, and babies are not in that position. So actually to make that statement misunderstands the whole concept of being an infant. And there's no, there's absolutely no reason to make that statement at all."
> – 3001

Four neonatologists expressed similar views that there is a "continuum" (CN: 3006) between an infant and an older child, which is the basis for their interest in continuing life. This neonatologist discussed fact that an infant has the potential and will ultimately become an older child and therefore it is not possible to choose a point at which the weight of their interests differ:

> CN: "The older child has to become an older child and was a newborn baby at one stage. All they had at that stage was potential, and that's all any baby has really, is potential. But it has been said, hasn't it, that the moral quality of a society, to some extent, can be judged by the way it treats those individuals and assesses the importance of their potential." – 3009

In a similar vein, one consultant interpreted an infant's interest in continuing life as the right to life, which he viewed as inherent to all human beings. He discussed how the weight of a CIEPI's interest in continuing life does not change between infancy and childhood:

> CN: "Because whether you're a newborn or an older child, you have an inherent right to life and a right to be able to live and to be able to experience the joys and sorrows of life. I think that doesn't change; whether you are a newborn or an older child it's the same. So, no, I wouldn't agree with that statement that a newborn

> child has got less of a right to life than an older child. If that was the case then we would have situations where people who had a child before, the sibling has got cancer, take and kill the child. We don't do that. So, no, I think we do offer newborns the same right." – 30014

This trainee discussed how she felt it was inappropriate for physicians to make value judgments on an infant's interests in continuing life because it was subjective and not part of a physician's job:

> NT: "Because it's what I was saying to you before, you can't, you know compare lives and say who is worth more. We shouldn't do that, its not for us to do that, we're medical people, we're not anything more or greater than that so you can't put a value on that life so no I disagree." – 3007

In summary, twelve neonatologists disagreed with Wilkinson's hypothesis for the differential treatment on the basis that it misunderstands the concept of being an infant which requires more protection of their interests in continuing life, it is not appropriate for physicians to make subjective assessments about the weight of an infant's interest in continuing life, an infant's interest in continuing life does not change because it is inherent to each human being and lastly because an infants interest in continuing life is based on the potentiality of an infant to become an older child/adult.

Chapter 6: Conclusions and Discussion

6.1 Introduction

In this chapter, I critically reflected on the findings of my research and I provided a summary of the key findings. I also summarized my main conclusions, discussing them in light of the literature and ethical guidelines. Finally, I made recommendations for further research.

6.2 Key Findings

My findings included fifty quotes, which were selected from the total population of sixteen hours of interviews involving 360 pages of transcripts from the interviews with thirteen English neonatologists. During these interviews, the neonatologists responded in a way that was consistent with Janvier et al.'s surveys as approximately 60% of neonatologists gave more discretion to parents wishes for non-resuscitation of the CIEPI compared with the CI2MOI (see Figure 1).

My findings were presented in chapters 4 and 5. Chapter 4 provided a description of the clinical factors (both the general and specific clinical factors), which influence the resuscitation decision-making process for critically ill infants of different ages (i.e. my first research question). The first general factor that was cited by all thirteen neonatologists was uncertainty. The neonatologists discussed three main sources of uncertainty: prognostic uncertainty, diagnostic uncertainty and uncertainty around parental wishes. Another general clinical factor that emerged in all thirteen interviews was the availability of time. The neonatologists discussed the importance of time and the benefits of time as a tool to help mitigate uncertainty. In addition to the above noted, general clinical factors, the second section of Chapter 4 described the clinical factors, which were specific to each critically ill infant. (See Table 3)

The third section of Chapter 4 offered insight into the ways in which the parents' wishes influenced the resuscitation decision-making process and answered my second research question. The data revealed there were two groups of responses: those that did not give parental wishes more weight over their own clinical judgment in CI2MOI and in the CIEPI (six neonatologists) and those that gave parental wishes more weight over clinical judgment in the CIEPI but not in the CI2MOI (seven neonatologists). The reasons for these two groups of responses were described as well as the neonatologists' perspectives about the challenges of balancing the wishes of the parents with their own clinical judgment of what is in the infant's best interest. The neonatologists' discussion of their approach to weighing the parents wishes revealed the challenge they have of trying to satisfy the many different parents whose wishes range within these three categories: those parents who want to "do everything" possible for their infant compared to those parents who want non-resuscitation for their infant and those parents who are uncertain what they want.

My third and final research question was answered in Chapter 5. It described the neonatologists' reasons for the differential treatment of a CIEPI compared with a CI2MOI when both require resuscitation and have similar prognoses.

The first section of Chapter 5 described the neonatologists' different perspectives about how personal and clinical experiences, previous training and emotions influence the negative perception that CIEPIs have poor outcomes and therefore contribute to the differential treatment of CIEPIs. The second section of Chapter 5 described three fundamental attitudes towards CIEPIs that contributed to the differential treatment, namely: *'Not so-called normal babies'; 'It's more acceptable to let them die"; and Products of a premature delivery'.*

Some of the reasons for these attitudes included: the fact that they are born at a disadvantage; the proximity of gestational ages to the dates that abortions are performed in the UK; the lack of interpersonal attachments and emotional reciprocity with the parents; historical infant mortality rates, the lack of a baseline of health; the physical features of CEIPI. (See Table 4)

6.3 Discussion of the Results

Clinical factors influencing the resuscitation decision making process: Research Question 1

There were two general clinical factors uncertainty and the benefit of buying more time. Uncertainty was the most commonly cited factor that influenced the neonatologists' clinical judgment. Prognostic uncertainty characterized the clinical context for CIEPI because the estimates of gestational age have wide margins of error. (Janvier et al. 2008c) Furthermore, the estimates of long-term outcome at the time of birth may not be fully applicable because there are many factors besides gestational age which influence prognosis. (Brunkhorst et al. 2014) During, the interviews it was apparent that the neonatologists were cognizant of the uncertainty around the survival and prognostic information given in the vignettes as well as the possible uncertainty about the CIEPI gestational age. Interestingly, they also expressed uncertainty around the prognosis and diagnosis for the CITI and the CI2MOI, which, explains why the thirteen neonatologists unanimously opted to resuscitate the CIEPI, the CITI and the CI2MO in the absence of parental wishes. The neonatologists responses were in line with the current ethical guidelines which recommended that "where there is uncertainty over the degree of future impairment, the RCPCH advises that the child's life should always be safeguarded until these issues are resolved." (Royal College of Paediatrics and Child Health 2004) (Royal College of Paediatrics and Child Health 2004)

Furthermore, when an infant is critically ill and it is not clear how to proceed, physicians should opt for the decision that is more easily reversed. (Mercurio 2011) It was clear that the neonatologists preferred to air on the side of caution and thus all chose to resuscitate with the view there was an option to withdraw LST later when the outcome and the diagnosis became more certain with the passage of time. Due to the difficulties of not having enough time to gather all of the clinical information and do a full assessment of the patient, the second general factor buying more time was used as a tool to mitigate the uncertainty around the prognosis and diagnosis, as well as the uncertainty of the parental wishes.

Discussion of the Weight of Parental Wishes: Research Question 2

When the scenario changed and the parents' wishes were made known, the neonatologists in considered ethical factors including the best interest principle, parental authority, the harm of intensive care and the rights of the infant. By introducing another variable to the vignette and asking the neonatologists an open-ended question about the weight of parental wishes, their answers shifted to incorporate the ethical factors. Interestingly, the neonatologist's responses mainly followed two lines of ethical thinking; those who strictly adopted the best interest principle and did not give more weight to parental wishes in the case of the CIEPI and those who gave more weight to the parents' wishes over their clinical judgment in the case of the CIEPI.

It was apparent that the neonatologists who gave more weight to parental wishes over their own clinical judgment might have been using the restricted relational model of the best interest standard described by Loretta Koppelman. (Kopelman 2007a) One of Kopelman's necessary features of the best interest standard is that decisions are made using a "minimum threshold of acceptable care" or in other words what is judged as reasonable by an informed person of good will. (Kopelman 2007b) Two of the neonatologists discussed how although the parents' wishes differed from their clinical judgment, they were still considered to be in the "spectrum of reasonableness" (CN: 30011) which is why they were prepared to accede their wishes. Another feature of Kopelman's best interest standard is that all decision makers do not have to reach identical decisions about what is in the infant's best interest as there are different interpretations of weighing the benefits and burdens. This could explain why the neonatologists were willing to over rule their clinical judgment because although the parents' judgment of what is best was different to theirs, it still came under the umbrella of what would be considered reasonable or acceptable.

Kopelman acknowledged that the best interest standard has features that differ depending on each individual case, however she argued that all similarly situated individuals must be given equal consideration for the same or similar treatment in order to avoid eroding our justice systems. This is similar to the ethical guidelines in the UK which state:

> "Just as we find no difference in the moral status of a child of six days, months or years, we find no morally relevant differences between disabled and able-bodied children and adults. Each must be given equal consideration." (Nuffield Council on Bioethics 2006)

Interestingly, those neonatologists who endorsed the differential treatment of the CIEPI did not give equal consideration to two similarly situated individuals. This begs the question; why were they willing to accede the parents wishes for non-resuscitation in the case of the CIEPI but not in the case of the CI2MOI? It may be that instead of using the principle of best interest, they were using the harm principle to justify their decisions. Douglas Diekema advocated for the use of the harm principle in order to "identify a harm threshold below which parental decisions will not be tolerated." (Diekema 2004) The use of the harm principle ensures that decisions being made do not cause significant harm to the infant. Therefore, the neonatologists may have judged that the parents' wishes for non-resuscitation placed the CI2MOI at a significant risk of serious preventable harm compared with the CIEPI.

The neonatologists may have had questions around the capacity or characteristics of the parents of the CI2MOI to make the decision. This is similar to findings by Marcello et al., which showed that physicians' willingness to comply with parental wishes was not solely determined by their estimation of the infant's best interest. Instead, the weight given to parental wishes varied according to the familial characteristics. (Marcello et al. 2011) Although there was no specific information about the parents in the clinical vignettes, it may be that neonatologists were extrapolating certain characteristics to the parents of the CI2MOI and thus felt they did not have the capacity to make the decision.

It was interesting that thirteen neonatologists from the same country and in some cases from the same hospital had such differing applications of the best interest principle when deciding whether or not to resuscitate the CIEPI. Such variability between neonatologists is worrying and has also been argued to be ethically problematic. (D. Wilkinson and Truog 2013) It is also very worrying that physicians are often unaware of this variation and may also not see their own bias. (Salter 2012) Therefore, the neonatal medical community, through open and honest dialogue, should come to a consensus about how to apply the best interest principle when making resuscitation decisions for CIEPIs or whether to use something other than the best interest principle such as the harm principle.

Discussion of the Reasons for the Differential Treatment of CIEPIs: Research Question 3

The next part of the interview involved presenting the results of Janvier's surveys in order to expose the inconsistency and thus the differential treatment of CIEPIs. At this point, the neonatologists were able to understand the context of Janvier's results and conclusions because the first part of the interview took them through the same thought experiment that she used in her surveys. Therefore, when the focus was shifted towards other people's responses, the neonatologists were very open and honest about giving their reasons for what may "lie behind" the differential treatment of CIEPIs. (Jones 2008)

My literature review explored some possible hypotheses for the differential treatment of CIEPIs which included: an evaluation of reduced personhood, confusion surrounding moral status, protective grief mechanisms, the proximity of gestational ages at which abortions are performed, the harm of intensive care, different health care systems, the perception of saving versus creating, weaker or no interest in continuing life and negative perceptions of prognosis. The interview data also revealed the neonatologists reasons for the differential treatment of CIEPIs, which are discussed in light of the literature below.

Eight of the neonatologists discussed how the differential treatment of CIEPIs could be due to the fact that abortions are undertaken up to 24 weeks and in some cases right up to full term in England. It seemed that the legal limit of abortions at 24 weeks creates confusion regarding the moral status of the CIEPI. This is consistent with other qualitative studies, which also demonstrated confusion regarding the moral status of CIEPI and foetuses at the margin of viability. (Collyns et al. 2009; Williams et al. 2001) Furthermore, it is similar to Janvier's hypothesis that the resuscitation decisions for CIEPIs may still be considered in the domain of reproductive choice. (Janvier et al. 2008c) (Janvier et al. 2008a)

Interestingly, three of the neonatologists discussed a prevailing attitude that CIEPIs are not seen as normal because they are born at a disadvantage and have not gone through the full developmental process. One neonatologist suggested that physicians attribute less moral value on a life that starts at a disadvantage compared with a two-month-old infant who was born normally with a 100% chance of surviving. Two other neonatologists' commented that it was because there is no period beforehand where the CIEPI was not critically ill and thus there is no baseline of good health to use as a target to get back to. This is similar to other hypotheses in the literature which claim that the decreased sense of duty towards CIEPI stems from the fact that "they haven't really lived yet." (Janvier et al. 2008c)

Three of the neonatologists described the parental perception of moral value and how it is correlated with their attachment to the infant. The fact that CIEPI are in a box and there is less 'reciprocal interaction' creates an emotional distance between the parents and the infant. This emotional distance contributes to the decreased value they attribute to their infant's life. Although it is true that individual's attribute greater value to people they are attached to, it does not explain why physicians unrelated to these CIEPIs might value them less than the CI2MOI. Having a history of forming relationships and being integrated as part of a family in a sense gives the infant membership to the moral community. Thus, CIEPIs who have not 'written' a lived biography are not seen in the same moral category. As one neonatologist described it, there has been less familial 'investment' in the CIEPI. Furthermore, because there has been less familial investment, the emotional weight and tragedy of death is less for CIEPI.

In conclusion, the neonatologists were able to provide multiplicity of reasons for the differential treatment of CIEPIs. It was evident through the themes that arose from the interviews that some of the hypotheses from the literature review were confirmed by the neonatologists. Specifically, the proximity of gestational ages at which abortions are carried out, the lack of interpersonal attachments, the perception of saving versus creating the protective grief mechanisms and the negative perception of prognosis. However, these interviews also revealed other reasons for the differential treatment of CIEPI that were not discussed in the literature such as; the not so called normal infant, the acceptability of letting the CIEPI die, the familial investment, the uphill challenge and the absence of a baseline of good health.

The final part of the interview was designed to explore the neonatologists' perspectives on some of the hypotheses from the literature, specifically Janvier's hypothesis about CIEPIs considered in a separate and lesser moral category and Wilkinson's hypothesis that newborn infants have a weaker interest in continuing life.

One hypothesis for the differential treatment of CIEPIs is that they exist "in a separate and lesser moral category" and thus are devalued compared to critically ill older infants and children. (Janvier et al. 2007) (Janvier et al. 2008b) The literature review (Chapter 2) demonstrated that there were different views on when an individual attains full moral status or in other words how much one's interests should count. Some hold that moral status is located in an individual's capacities for self-conscious awareness of the future

(P. Singer and Kuhse 1985) while some believe moral status is intrinsic to an individual from the time of conception based on their potential capacities (Camosy 2010; George and Tolefson 2013) while others believe that an individual incrementally accrues moral status from conception as biological development progresses. (Collyns et al. 2009) Nevertheless, the Working Party rejected these views and recommended the moment of birth as the point at which an individual is awarded moral status. (Nuffield Council on Bioethics 2006) The analysis of the interviews revealed that eleven of the neonatologists held the same view on moral status as the Working Party. One neonatologist agreed with Janvier's hypothesis on the basis of accepting the gradualist view of moral status. Another neonatologist agreed based on the dependent model of moral status whereby the parental acceptance of the infant confers moral status. The majority (11/13) disagreed with Janvier's hypothesis based on the fact that, at the time of birth, CIEPIs become legal individuals who have the potential for the self-conscious awareness. During the interviews, it was obvious that these eleven neonatologists felt quite strongly about the fact that they saw no moral difference between CIEPI and the CI2MOI. It seemed that this reaction was linked to the sense of duty they felt toward CIEPIs as their patients. However, if a difference in moral status does not explain the differential treatment of CIEPIs then one must ask whether there are other relevant differences, which explain Janvier's results?

Another hypothesis from the literature highlighted the difference in strength given to the interests of others relative to the interests of the infant. Dominic Wilkinson's hypothesized that "the interest of a newborn in continued life are somewhat less than those of an older child." (D. Wilkinson 2013) This hypothesis is based on Jeff McMahan's account of time relative interests whereby interests change in strength over time as the individual becomes more psychologically invested in and connected to their future selves. (McMahan 2002) Interestingly, the neonatologists were almost unanimous (12/13) in their disagreement with Wilkinson and McMahan's hypothesis for the differential treatment of CIEPIs. One of the most commonly cited reasons for disagreeing was based on the dependency and inherent vulnerability of CIEPIs compared to that of an older child. The neonatologists' views were similar to Chris Kaposy's view that "we begin our lives in a state of extremely vulnerability in which virtually all of our needs must be met by others." (Kaposy 2007) Therefore, based on vulnerability, the CIEPIs interest in continued life should be equal to, if not stronger than, that of an older child.

Another reason the neonatologists disagreed with Wilkinson and McMahan's hypothesis was because they deemed it inappropriate for an individual make value judgments about the strength of a CIEPI's interest in continuing life because those value judgments are essentially subjective. This is similar to the view of the Working Party which stated that: "There are serious dangers in seeking to define some point in postnatal development at which the life of a child begins to command full respect and which strengthens the grounds for sustaining his or her life." (Nuffield Council on Bioethics 2006) Furthermore, even if the time relative interests account provides a plausible explanation for the differential treatment of a critically ill newborn infant compared with a critically ill older child, it does not clearly differentiate the strength of a CIEPI's interest in continuing life compared with a CI2MOI's interest in continuing life. Thus, we must look for alternative explanations for the differential treatment of CIEPIs demonstrated in Janvier's surveys.

6.4 Conclusions

My qualitative research was, to my knowledge, the first of its kind because it used semi-structured interviews with English neonatologists as a way to explore the reasons for the differential treatment of CIEPIs. Qualitative research seeks to understand how events, actions and meanings are shaped by the unique circumstances in which these occur. It also emphasizes the importance of understanding the process by which events and actions take place. In other words, the focus is less on the outcomes and more on the process, which lead to the outcomes. The analysis of these interviews allowed me to gain an understanding of the process of resuscitation decision making for critically ill infants, which in turn allowed me to make a significant contribution to the literature. My research can in other settings and with other specialties of physicians in order to further explore the differential treatment of CIEPIs and the process of resuscitation decision making for critically ill infants.

In conclusion, my qualitative research has shown that the resuscitation decision-making process for critically ill infants is extremely complex and thus, even within a homogenous specialty of physicians from the same country, there are many diverse reasons for the differential treatment of CIEPI. My research also pointed to the fact that resuscitation decisions frequently involve complex behavioural decisional processes and involve factors that differ depending on an individual's personal and clinical experiences, previous training and emotions. Finally there have been many interpretations of how to apply the best interest principle when making resuscitation decisions for critically ill infants. Drawing on these findings, I conclude that the neonatal medical community, through open and honest dialogue, should come to a consensus about how to apply the best interest principle when making resuscitation decisions for CIEPIs as well as to determine whether the differential treatment of critically ill extremely preterm infants in the context of resuscitation is ethically justifiable

6.5 Next steps and suggestions for future research

The main findings of this research will be shared among the medical community as well as published in clinical ethical journals. I hope that this research will be used among the neonatal and paediatric medical community as a springboard for further dialogue and debate so that they can to come to a consensus about whether the differential treatment of CIEPIs is ethically justifiable and its implications for clinical practice and the ethical guidelines.

This research was conducted on a small scale with thirteen neonatologists from four different NHS Trusts. Although an effort was made to select a diverse sample of interviewees, it would be useful in the future to conduct similar research on a larger scale to ascertain if the responses vary based on background, country, religious beliefs and medical specialty. Therefore, further research is needed on a larger scale in other countries with different types of medical professionals to determine if these results translate to other settings.

Furthermore, the reasons for the differential treatment should be examined in light of a thorough and honest appraisal of prevailing ethical standards in order to determine whether they stand as an ethical justification for the differential treatment of CIEPIs in the context of resuscitation. It would also be interesting to conduct a conceptual analysis of this empirical data in order to develop a theoretical argument about whether or not there is a morally relevant difference between a CIEPI and a CI2MOI in the context of resuscitation.

This research also provided some insight into neonatologists' perspectives about the current ethical guidelines and their relevance to clinical practice. Further research is needed to evaluate and analyze the current ethical guidelines to determine their relevance to practice and to determine whether they require updating.

Lastly, this research indicated the existence of certain attitudes and perceptions towards CIEPIs. Since attitudes are learned, they may be acquired the same way other things are learned: namely, by being taught openly, or through conditioning, or through observation, or through experiences, or through societal norms. Therefore, further work is needed to explore how these attitudes are learned within the medical profession and whether they can be attributed to gaps in the bioethical curriculums and whether these gaps might be closed by further education.

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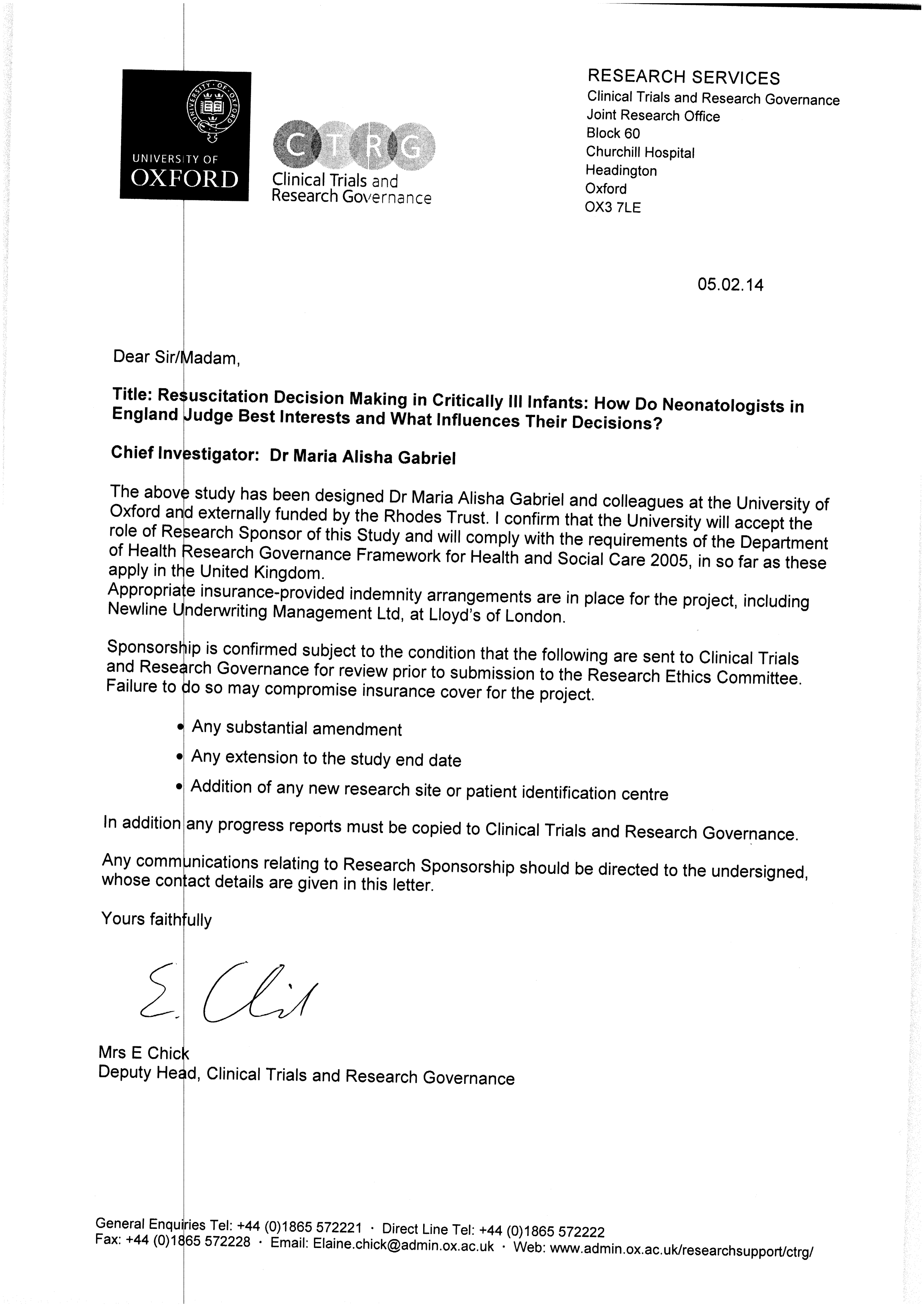
Appendix: 1 Ethics approval letters



UNIVERSITY OF
OXFORD

CTRG
Clinical Trials and
Research Governance

RESEARCH SERVICES
Clinical Trials and Research Governance
Joint Research Office
Block 60
Churchill Hospital
Headington
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OX3 7LE

05.02.14

Dear Sir/Madam,

Title: Resuscitation Decision Making in Critically Ill Infants: How Do Neonatologists in England Judge Best Interests and What Influences Their Decisions?

Chief Investigator: Dr Maria Alisha Gabriel

The above study has been designed Dr Maria Alisha Gabriel and colleagues at the University of Oxford and externally funded by the Rhodes Trust. I confirm that the University will accept the role of Research Sponsor of this Study and will comply with the requirements of the Department of Health Research Governance Framework for Health and Social Care 2005, in so far as these apply in the United Kingdom.
Appropriate insurance-provided indemnity arrangements are in place for the project, including Newline Underwriting Management Ltd, at Lloyd's of London.

Sponsorship is confirmed subject to the condition that the following are sent to Clinical Trials and Research Governance for review prior to submission to the Research Ethics Committee. Failure to do so may compromise insurance cover for the project.

- Any substantial amendment
- Any extension to the study end date
- Addition of any new research site or patient identification centre

In addition any progress reports must be copied to Clinical Trials and Research Governance.

Any communications relating to Research Sponsorship should be directed to the undersigned, whose contact details are given in this letter.

Yours faithfully

Mrs E Chick
Deputy Head, Clinical Trials and Research Governance

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Fax: +44 (0)1865 572228 · Email: Elaine.chick@admin.ox.ac.uk · Web: www.admin.ox.ac.uk/researchsupport/ctrg/

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13 May 2014

Dear Dr Gabriel

Letter of access for research

This letter confirms your right of access to conduct research through **Oxford University Hospital NHS Trust** for the purpose and on the terms and conditions set out below. This right of access commences on **13th May 2014 and ends on 1st August 2015** unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

The information supplied about your role in research at **Oxford University Hospital NHS Trust** has been reviewed and you do not require an honorary research contract with this NHS organisation. We are satisfied that such pre-engagement checks as we consider necessary have been carried out.

You are considered to be a legal visitor to **Oxford University Hospital NHS Trust** premises. You are not entitled to any form of payment or access to other benefits provided by this NHS organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through **Oxford University Hospital NHS Trust**, you will remain accountable to your employer **Intelligent Ultrasound** but you are required to follow the reasonable instructions of **Dr Dominic Wilkinson** in this NHS organisation or those given on her/his behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with **Oxford University Hospital NHS Trust** policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with **Oxford University Hospital NHS Trust** in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on **Oxford University Hospital NHS Trust** premises. You must observe the same standards of care and propriety in dealing with patients, staff, visitors, equipment and premises as is expected of any other contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust Fiona.parker@ouh.nhs.uk prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you MUST stop undertaking any regulated activity immediately.

Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

Oxford University Hospital NHS Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

If your current role or involvement in research changes, or any of the information provided in your Research Passport changes, you must inform your employer through their normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely

Fiona Parker
Research Support Services Manager
Oxford University Hospital NHS Trust

cc:

Maxine Grout, HR Advisor - Medical Support, Block 229, Carillion Building, JOHN RADCLIFFE HOSPITAL, Headley Way, Headington
Oxford, OX3 9DU

Appendix 2: Study information sheet and consent form

Oxford University Hospitals NHS
NHS Trust
The Ethox Centre
Nuffield Department of Population Health

UNIVERSITY OF OXFORD

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Rosemary Rue Building, Old Road Campus, Headington, Oxford OX3 7LF
Tel:+44(0)7547 852964, E-mail: maria.gabriel@hertford.ox.ac.uk

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Participant Information Sheet for Consultant Neonatologists

We would like to invite you to take part in a qualitative clinical ethics research study, which we are conducting with The Ethox Centre at Oxford University. Before you decide whether you would like to participate, please read the following information carefully. This information outlines the aims of the study and methods of the research. If you have any questions please do not hesitate to contact us with the contact details provided below.

Who is organising and funding the research?

My name is Dr. Alisha Gabriel. I am a Masters student working with a team of researchers based in The Ethox Centre at the Nuffield Department of Population Health at the University of Oxford. I am also a physician currently training in Paediatrics at the London Children's Hospital at Western University in Ontario, Canada and I hope to pursue a future career in Neonatology. This research is funded by a Rhodes Scholarship from the Rhodes Trust.

What is the purpose of the study?

The main aim of this study is to explore your views about the moral status of critically ill infants. We are also interested in exploring your insights around the ethical dilemmas that can arise when making resuscitation decisions for critically ill infants. The study will use standard social scientific methods in the form semi-structured qualitative interviews. Conducting qualitative interviews allows the use of conventional qualitative thematic analysis in order to draw out conceptual frameworks and themes from personal insights or experiences. We would like to carry out approximately fifteen face-to-face interviews with Consultant Neonatologists who work in a level three Neonatal Intensive Care Unit in England (for further details see below).

Why have I been invited?

You have also been invited because, as a Consultant Neonatologist, you are one of the few physicians who take care of critically ill infants on a daily basis. Therefore, you have the most experience about how these ethically difficult decisions are made in practice, which makes your perspective invaluable to this study.

Do I have to take part?

It is up to you to decide whether or not you would like to be involved in the study. If you would like to discuss this further please do contact us. If you decide to take part, we will ask you to sign a consent form before the interview and we will give you a copy of the consent form to keep. You are free to change your mind after you have signed the consent form and may withdraw from the study without giving any reason. If you withdraw, any information you provided will be destroyed, including the recording/transcription. There will be no penalty for withdrawing from the study.

After the interview you will be given the option to review the interview transcript. If you find there is anything that you do not want included in the study it will not be published.

What will happen if I take part?
The interview will be divided into two parts. During the first part, you will be given some clinical vignettes to read which will be followed by a short survey about the vignettes. The second part of the interview will be comprised of open-ended follow-up questions that will probe more deeply into the answers you gave during the first part of the interview.

Ideally, the interviews will take place in a quiet room in the hospital; however, if your schedule does not allow for a face-to-face meeting, you will be given the option to conduct a telephone or Skype interview. The interview is likely to last approximately 30 - 40 minutes and you will be given a gift card as a token of thanks. The interviewer will ask your permission for the interview to be tape-recorded and transcribed so that it can be analysed later. Your name will not appear on the recording or on the typed copy of the interview. You may refuse to answer any questions during the interview and you can end the interview at any point. You will be given the chance to review and correct the transcripts once they have been transcribed.

I am a researcher working with a team of researchers in the Ethox Centre at the Nuffield Department of Population Health at the University of Oxford. The data that will be collected from the interviews will be used for my MSc (by research) in Public Health and the data from the interviews will be published (anonymously) in academic journals and presented at conferences.

What are the possible disadvantages of taking part?
There is a small possibility that you will feel uncomfortable during interview, as some of the questions cover some sensitive and emotional topics. It is possible that the vignettes will be similar to cases you have come across and therefore may cause you to remember some difficult past experiences. If you find yourself in any way uncomfortable then you can; take a break from the interview, ask to not answer a specific question or end your participation in the study.

Also, as the population of Consultant Neonatologists in England is small, there is a very slight possibility that others in your field might be able to recognise that you took part in this study. This would only be the case if someone in your field knows you very well and would be able to recognize you by the quotes used from your interview. In order to minimise the possibility of this happening, we will anonymise all quotations and the quotations will be marked as ‘ Consultant Neonatologist 1’ and no geographical or institutional information will be attached to quotations.

What are the possible benefits of taking part?
This study will give you an opportunity to share your unique experiences about a very complex and difficult ethical issue that is not well understood practically. It will also give you an opportunity to provide valuable insights about the ethical challenges of making these decisions in practice. This study will contribute to improving and expanding the field of Neonatal Bioethics.

Your thoughts and insights may also contribute to help improve best practice recommendations as well as help to improve the clinical guidelines. If you wish, you will also have the opportunity to receive a summary of the results of the study when it is completed.

Will my taking part in this study be kept confidential?
You will not be identified in any published material but your occupational status will be reported together with the quotations. We hope to publish the results of the research in academic journals. This may include using direct quotations from what you have said. You will be given the opportunity to review the typed copy of your interview in order to exclude anything that you do not want quoted.

The collected data and typed copies will be kept in password-protected files on the Ethox Centre's secure network. A coding key will be kept which links the data to the participant information so that the typed copies can be returned to you to review them. Once the review has been completed the key will be destroyed. My supervisors and myself will be the only researcher who will have access to identifiable information.

Responsible members of the University of Oxford or–host NHS Trust(s) may be given access to anonymised data for monitoring and/or audit of the study to ensure we are complying with regulations. Research data will be kept for no longer than 5 years after the study has ended, after which point the data will be destroyed.

Whilst this is very unlikely, there is of course the possibility that my data could identify serious harm or wrongdoing. Were such a situation to arise, I would discuss this with my academic supervisors (Professor Michael Parker and Dr. Ruth Horn) and take action according to the Oxford University Hospitals NHS Trust requirements.

Will I be paid to participate?
You will not be paid to participate in this study however you will be given a gift card as a token of thanks for participating. The interviewer will travel to your location to conduct the interview; therefore participating in the study will not incur any expenses to you.

What will happen if I don't want to carry on?
You have the right to withdraw from the study at any time. If you decide to withdraw from the study your interview will not be included in the results or the analysis and any information you provided from your interview will be destroyed. A reason for your withdrawal is not required; however, if you are willing to give a reason for withdrawal, it will be recorded in the study records.

Who has reviewed this study?

All research has been reviewed by, and received ethics clearance through, the University of Oxford Central University Research Ethics Committeeis in order to protect your safety, rights, wellbeing and dignity.

What if there is a problem?
If you take part, we very much hope that you will find this a positive experience and will value the opportunity to share your insights and thoughts. If you have a concern about any aspect of this project, please speak to the relevant researcher, Dr. Maria Gabriel (Tel: +44(0) 7547 852964 , email: maria.gabriel@hertford.ox.ac.uk) or her supervisor Professor Michael Parker Tel: +44(0) 1865 287 884 email: Michael.parker@ethox.ac.uk who will do his/her best to answer your query. The researcher should acknowledge your concern within 10 working days and give you an indication of how he/she intends to deal with it. If you remain unhappy or wish to make a formal complaint, please contact the chair of the Research Ethics Committee at the University of Oxford (Chair, Medical Sciences Inter-Divisional Research Ethics Committee; Email: ethics@medsci.ox.ac.uk; Address: Research Services, University of Oxford, Wellington Square, Oxford OX1 2JD). The chair will seek to resolve the matter in a reasonably expeditious manner

However, if you have a concern about any aspect of the study or you wish to complain about the way in which you have been approached or treated during the course of this study, please contact Dr. Maria Alisha Gabriel (Tel: +44(0) 7547 852964 , email: maria.gabriel@hertford.ox.ac.uk); or you may contact the University of Oxford Clinical Trials and Research Governance (CTRG) office on 01865 572224 or the head of CTRG, email ctrg@admin.ox.ac.uk.
The University of Oxford, as Sponsor, has appropriate insurance in place in the unlikely event that you suffer any harm as a direct consequence of your participation in this research.

Contact details for further information
Dr. M. Alisha Gabriel
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University of Oxford
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OX3 7LF
United Kingdom
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Email: maria.gabriel@hertford.ox.ac.uk

Thank you for taking the time to read this information.

Oxford University Hospitals NHS
NHS Trust

UNIVERSITY OF OXFORD

The Ethox Centre
Nuffield Department of Population Health

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INTERVIEW CONSENT FORM: Consultant Neonatologists and Specialist Registrars

Resuscitation Decision Making in Critically Ill Infants: How Do Neonatologists in England Judge Best Interests and What Influences Their Decisions?

The aim of this study is to develop an in-depth understanding of how Neonatologists and Specialist Registrars in England judge best interests when making resuscitation decisions for critically ill infants. We are especially interested in exploring the similarities or differences that exist across a range of ages and in exploring what factors influence your decisions in practice.

Please initial boxes

1. I confirm that I have read and understand the information sheet (version……….; dated……….) for the above study. ☐
2. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
3. I am happy to be interviewed for this study and agree to the use of tape recording during the interview. ☐
4. I understand that if I wish I can review and correct the transcript. ☐
5. I understand that the research results will be published in academic journals and that any personal data will be anonymised. ☐
6. I understand that my particpation is voluntary and I understand that I am free to withdraw at any time without giving any reason and that my legal rights will not be affected. If I do withdraw, any information I have provided will be destroyed. ☐
7. I understand that this project has been reviewed and approved by the University of Oxford Central University Research Ethics Committee. ☐
8. I understand how the data from the interview will be stored and that data will be will be kept for no longer than 5 years after the study has ended, after which point the data will be destroyed. ☐
9. I understand how I should go about making a complaint if I am concerned about any aspect of this study. ☐

UNIVERSITY OF OXFORD

Oxford University Hospitals NHS Trust

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Dr. Maria Alisha Gabriel, MSc (by research) Population Health Candidate, Rhodes Scholar
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8. I understand that data collected during the study may be looked at by authorised individuals from the University of Oxford or Host NHS Trust(s) where it is relevant to my taking part in this research. I permit these individuals access to my research records. ☐

9. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of person taking Consent 1 for participant; 1 for research file	Date	Signature

Oxford University Hospitals NHS
NHS Trust

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Extremely Preterm Infant - Catherine

A G1P0 32 year old, previously healthy woman presents to the delivery room in pre-term labor at 24 weeks gestational age. She has had an unremarkable pregnancy thus far and denies smoking, drinking alcohol or using illicit substances. Her ultrasound scans have been normal and there is no family history of congenital anomalies or preterm births. The gestational age is accurate and was determined by early ultrasound.

The delivery was precipitous and the infant was born three minutes ago via normal spontaneous vaginal delivery. The infant weighs 650g. There is no time for prenatal counselling as the mother is sedated and the father has not arrived yet. The infant's HR is 106 but she is not breathing efficiently, has poor tone and has low oxygen saturations. The Consultant on call has arrived.

If life sustaining treatment is initiated it can be estimated that survival rate is between 55-70% depending on individual hospital practice and country. If the infant survives, there 15%–20% chance of major neurological disability (either deafness, blindness, cerebral palsy, or significantly abnormal psychomotor development). There is 30-40% chance the infant will develop a form of attention deficit hyperactivity disorder or a learning disorder.

QUESTIONS

1. Assuming that this is all of the information the Consultant has access to at the time, do you think the Consultant should resuscitate, intubate and admit to the ITU? Why or why not?

2. Let's suppose that there was time for prenatal counselling and the parents understood all of the information presented to them. However, after the discussion, they refuse to give consent for resuscitation, intubation and admission because they fear the consequences of having a severely disabled child. Should the Consultant respect their decision? Why or why not?

3. What would need to be different for you to change your mind?

Oxford University Hospitals NHS Trust

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Two Month Old Infant with Bacterial Meningitis - Samantha

A previously healthy two-month old infant presents to the emergency department via air ambulance. She has had a two-day history of fever (40°C), lethargy, decreased appetite and decreased urine output. On examination, the infant looks toxic and has a bulging fontanelle.

The second year Paediatric trainee obtained intravenous access, sent blood for culture and sensitivity and gave a 15ml/kg bolus of normal saline. Prophylactic IV antibiotics were started. A lumbar puncture was done and CSF analysis (low glucose, high protein and low WBC count) confirmed a preliminary diagnosis of bacterial meningitis. The preliminary report of the blood culture showed gram positive diplococcic and blood tests show signs of septic shock.

The infant begins to have atypical seizures in the Emergency Department. The seizures are difficult to control with benzodiazepines. The trainee asks the Consultant on call to come down and assess the infant. When the Consultant arrives the seizures have stopped but the infant looks cyanotic, has poor capillary refill and has minimal respiratory effort. The parents have not arrived yet.

Current evidence shows that, with multiple poor prognostic factors, there is a 50-60% chance of survival. If the infant survives there is a 15-25% chance of developing one of the following: deafness, blindness, CP, or significantly abnormal psychomotor development. There is a 25-30% chance of the infant developing a minor disability such as attention deficit hyperactivity disorder or a learning difficulties in the future.

QUESTIONS

1. Assuming that this is all of the information the Consultant has access to at the time, do you think the Consultant should resuscitate, intubate and admit to the ITU? Why or why not?

2. Let's suppose that the parents came in the air ambulance and the Consultant had time to talk to them and they fully understood all of the information presented to them. After the discussion they refuse to give consent for resuscitation, intubation and admission to ITU because they fear the consequences of having a severely disabled child. Should the Consultant respect their decision? Why or why not?

3. What would need to be different for you to change your mind?

Oxford University Hospitals NHS
NHS Trust

UNIVERSITY OF OXFORD

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Term Infant with AVM – Nevaeh

A full term infant was born today via planned caesarian section to a 30 year old G3P2L2 woman. The 20 week anomaly ultrasound revealed a cystic intracranial mass. Colour Doppler imaging and MRI/MRA/MRV later confirmed a diagnosis of a cerebral ateriovenous malformation.

The infant's birth weight was 3500g, head circumference was 35 cm and length was 54 cm. The Apgar scores were 8 and 9 at 1 and 5 minutes, respectively. Vital signs were stable and the newborn exam was completely normal. She did not require any respiratory support.

The infant was admitted to the level three NICU to be observed. The Consultant is called to the bedside because the infant suddenly becomes cyanotic, bradycardic and has a decreased level of consciousness. The mother is on the maternal ward at the time the infant decompensates.

Based on the available literature, it is estimated that if the infant is resuscitated the prognosis for survival is 40-50%. There is a 30-40% chance of developing a minor disability such as attention deficit hyperactivity disorder or learning difficulties and a 15-20% chance of developing deafness, blindness, CP, or significantly abnormal psychomotor development.

QUESTIONS

1. Assuming that this is all of the information the Consultant has access to at the time, do you think the Consultant should resuscitate, intubate and admit to the ITU? Why or why not?

2. Lets suppose the mother and father were at the bedside and the Consultant had time to talk to talk to them and give them information about what would happen if their baby decompensated. They refuse to give consent for resuscitation and intubation. Should the Consultant respect their decision? Why or why not?

3. What would need to be different for you to change your mind?

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QUESTIONS AFTER VIGNETTES

1. How much weight (if any) should we give parental interests when making resuscitation decisions for critically ill infants?

2. Annie Janvier a Canadian Neonatologist has done survey's with similar cases and her results show that Neonatologists are more prepared to follow parents refusals in the extremely preterm infant and the term infant compared with the 2 month old. Why do you think that might be?

3. She suggests that the reason for this variation in treatment is because "we put newborns (both term and preterm) in a special and lesser moral category." Do think there is a moral difference between the 24 weeker/term AVM and 2 month old? Why or why not?
4. How should our society award moral status to preterm infants?

5. Do you think we should treat them differently than older infants/children? Why or why not?
6. I am going to read a quote from the literature; "For many people a newborn infant's interest in continuing life is not as strong as that of an older child." How would you respond to that
7. Have you encountered any cases similar to these in your practice? How did you resolve it?
8. Is there anything you would like to tell me about which I haven't thought to ask you?