

**The FOUNDATION study “Follow-Up
for NeuroDevelopmentally AT risk
Infants Of Neonatal care” - a qualitative
study on the views of parents and
caregivers**

Thesis submitted accordance with requirements of
University of Liverpool for the degree of Master of
Philosophy by Ayuko Komoriyama
23st September 2017

Acknowledgement

I would like to express my gratitude to my primary supervisor Dr Melissa Gladstone. I would not have found this course nor project without her guidance. Dr Gladstone provided me with the opportunity to conduct this qualitative study and kindly provided continuous support throughout the year. She linked me to the professionals who were able to aid me in my research. I am grateful to have spent my intercalated year with Dr Gladstone in a topic in which I have a genuine interest.

I would also like to thank my secondary supervisors, Dr Fauzia Paize and Dr Christopher Dewhurst. Many thanks to both for providing me with the opportunity to sit in clinics and join ward rounds. Thank you also for giving me an insight on current neonatal practise and follow-up services.

Thank you to Juliet Weston, Ann Oultram, Lorraine Isherwood, Helen Gedrim, Reshma Sule, Sue Fearn and Samantha Parry for introducing my study to parents in the community on my behalf. I would not have been able to conduct my study without their help.

I would also like to thank Ms Faye Moody for helping me with transcribing interviews.

I could not have conducted this study without help and support from the University of Liverpool, Liverpool Women's Hospital, and Alder Hey Children's Hospital. These

institutions have guided me through the ethical applications and given me permission to conduct this study in two superb tertiary hospitals.

This study could not have been done without the massive support provided by my family and friends. They supported me during times of stress, when I felt upset and burnt out over my ethical approval, and during the interview period and thesis. Thank you to those who proof-read my study over and over and gave supportive but constructive feedback.

Most importantly, I would like to thank all the families and health care professionals who gave up their time to take part in the interviews. I was grateful for the opportunity to listen to their experiences and views on the current neonatal and neurodevelopmental follow-up system. I have learnt crucial skills as a doctor; to listen carefully, pick up on patients' cues and to always be polite to patients. I will never forget what I have learnt through this study.

Abstract

The FOUNDATION study “Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care”- a qualitative study on the views of parents and caregivers,
Ayuko Komoriyama

Introduction: Infants born prematurely or who have had neurological complications are at increased risk of neurodevelopmental disorders. Early identification of infants with signs of neurodevelopmental delay is crucial to achieve their full developmental potentials. Currently, there is variable guidance on the follow up and referral process for such children. Little information is available on the needs of patients, families and health care of professionals regarding current practice and experience of follow-up.

Aims: To understand the present situation, the perceptions, and the views of parents and professionals who look after high-risk infants discharged from the NICU in relation to neurodevelopmental follow-up.

Methods: We undertook a qualitative study within the Mersey region using in-depth interviews with 23 parents of children, aged 0 to 3, born prematurely or with hypoxic ischaemic encephalopathy. We also undertook 11 in-depth interviews with doctors, nurses, and allied health professionals involved in the follow-up of at-risk infants.

Results: Five themes were identified: (1) What, (2) How, (3) Who, (4) When and (5) Capacity of the health care system. Most parents wanted preparation for a diagnosis and the future, and they appreciated a realistic and honest approach by professionals. Parents perceived that neonatologists tended to focus on short-term management and were reluctant to discuss long-term developmental outcomes with parents to avoid reducing the joy of having a baby. Long-term parental emotional support was felt to be neglected and many parents wanted to be offered counselling services. The lack of a standard referral process and variable care pathways frustrated both parents and professionals.

Conclusion: The quantity, content and quality of information given to parents at the hospital as well as in the community should be revised. More information on the risks of having developmental problems in high-risk children should be given. Many

parents felt anxious and depressed and some mothers had mental health problems such as panic attacks and post traumatic disorders. Professionals should provide increased emotional support on the NICU and throughout follow-ups.

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List of abbreviations

Liverpool Women's Hospital	LWH
Alder Hey Children's Hospital	AHCH
Neonatal Intensive Care Unit	NICU
Hypoxic Ischaemic Encephalopathy	HIE

Chapter One: Introduction to the study

More than 135 million babies are born every year however, global neonatal mortality rates are falling from 33 deaths per 1000 live births to 21 deaths per 1000 live since 1990.¹ In the U.K., the survival of the extremely premature infants (less than 32 weeks) has improved considerably from 40% to 53% between 1995 and 2006. Moreover, the standard mortality rate of infants born with very low birth weight (less than 1500g)² has decreased, along with rates of late onset infections, chronic lung disease and severe retinopathy of prematurity.³

Advances in neonatal care including technologies and medications have resulted in an increase in the number of infants who are surviving critical and complex conditions.^{2,4}

Infants born prematurely, those born with very low birth weights, or those who have had perinatal complications such as hypoxic ischaemic encephalopathy, can grow up to live without any complications. All of these infants are however, at risk of neurodevelopmental delay or disability meaning that many will require specialist assessment monitoring and input from a young age.

1.1. The High-risk Infants

There is no universal or nationwide standard definition for “the high-risk baby”. There are groups of children born with greater risks of developmental complications such as global developmental delay and cerebral palsy^{2,5} and it remains questionable as to how we should define, identify and follow-up these “high-risk” babies.²

Premature infants, especially those born below 32 weeks, and babies who have had hypoxic ischaemic encephalopathy (HIE) are commonly described as “high-risk”

babies. Brain development starts at the 3rd week of pregnancy and continues developing throughout the pregnancy and childhood.⁶ When infants are born prematurely, their brains are more prone to injuries due to the destruction of the complex normal growth of the nervous system. Intraventricular haemorrhage and periventricular leukomalacia are the most recognised brain lesions in extreme prematurity.⁷ These insults increase the risk of children suffering from developmental delays and disabilities.⁸ Hypoxic ischaemic encephalopathy is one of the most common complications of late preterm to term babies. It can cause death in 10-60% of cases, and 25% of survivors could be left with significant, devastating complications such as severe cerebral palsy (CP) and seizures.^{2,9}

1.2. The Importance of Follow-up Care

Despite the advances in medical care which lead to improvements in survival of babies born extremely preterm, the rate of severe impairment has remained high.^{5,10}

There are recognisable differences in neurological developmental status between high-risk infants and of those have no risk at all. Follow-up clinics may provide opportunities for professionals to identify infants with difficulties and may ensure the provision of treatments and support to those families who need it. Identifying high-risk infants through follow-up clinics enables professionals to refer them on to Early Intervention Programmes. These can help minimize developmental delay assessment and can ensure that treatment is given in a timely manner¹¹.

It is likely that follow-up clinics may have a positive impact on parents' mental health by providing them with a point of contact to seek advice, raise their concerns and be

reassured.¹² Families of children who were born prematurely or have had other complications could go through significant psychological distress such as depression, anxiety and post-traumatic stress symptoms¹³ therefore, providing continuous and consistent support by professionals at follow-up clinics may ensure the well-being of the families and children.

1.3. The Current systems and Guidelines

Currently, there are various nationwide follow-up strategies and referral criteria for children who have been born at “high-risk”. The neonatal units in the U.K. follow the National Neonatal Audit Programme (NNAP) and TOBY study recommendations for the care of premature infants and infants who have had HIE respectively. For infants at high-risk of neurodevelopmental delay, recommendations are that these infants are assessed by neonatal medical staff for up to 2 years.¹⁴ Referral pathways are yet to be standardised and the 2016 Annual Report by the NNAP has not made any recommendation as to how infants with likely developmental problems should be identified or referred on. The NICE guideline, “Early years: promoting health and wellbeing in under 5-s” does not mention neurodevelopmental follow-up. However, they recommended to refer anyone with speech and language delay according to the local defined referral pathway to ensure that children needing support can receive appropriate services.¹⁵

1.4. Rationale of the Study

An increasing number of high-risk infants are surviving now into beyond the neonatal period. Follow-up is known to be important in order to identify high-risk children early enough to prevent neurodevelopmental delays and disabilities from developing and get desirable outcomes for children, families and societies.¹⁶ Many studies have investigated parental stress relating to the NICU stay quantitatively. Some qualitative studies have examined parents' thoughts and feelings about their experience of NICU, parental education sessions and having been told their child's outcome.^{13,17-19}

The number of pure qualitative studies in the field of neonatal follow-up of high-risk children is very limited, and when available, most have focused on parents' views and opinions of the NICU stay and the care and parental education programmes in NICU. A number of qualitative studies have looked at the perspectives of parents' as well as professionals in neonatal follow-up for babies born prematurely. However, there has been a very small amount of studies that have given opportunities for parents and professionals to share their opinions, views and visions of the current healthcare system (e.g. neonatal follow-up and neurodevelopmental follow-up for high-risk infants) and make suggestion as to how the system could be changed or improved.

1.5. Research Question

What do parents of high-risk infants and professionals who work with these children perceive as barriers and facilitators to good neonatal and neurodevelopmental follow-up?

1.6. Aims and objectives

The aim of this study is to understand the present situation, the perceptions and the views of parents and professionals who look after high risk infants discharged from the NICU at Liverpool Women's Hospital in terms of what support they get in neurodevelopmental follow-up. This study aims to gain this information in order to consider how to develop better neurodevelopmental support and care systems for high-risk infants.

1.7. Outline of the thesis

Chapter Two will provide a literature review which discusses i) the present evidence on neurodevelopmental outcomes of high-risk children and ii) the effectiveness of early intervention for these children. It also outlines the current nationwide guidelines and local protocols regarding neonatal and neurodevelopmental follow-up in England as well as in Liverpool.

Chapter Three will provide the present evidence from the literature focusing on qualitative studies which i) explore parental perspectives of neonatal care and ii) those exploring parent's views of neonatal follow-up as well as other paediatric

services and support given to those children after being discharged in the hospital as well as in the community.

Chapter Four will provide the evidence on the methodology chosen for this study. It will provide information on the types of qualitative methodologies which could be used and justify why the methods chosen for this study were chosen.

Chapter Five: This chapter presents the methodologies that have been used in the FOUNDATION study. I will outline the recruitment process, study population and ethical considerations.

Chapter Six, Results. This chapter presents the findings from the interviews conducted for the FOUNDATION study providing information on the facilitators and barriers from the perspectives of parents and professionals – to a good follow-up and support system for their neonates.

Chapter Seven: This chapter outlines my discussion and conclusions. It contains a summary of the findings and discusses and compares the results with currently published literature. I also make recommendations to the current follow-up and support systems as well as to how information and diagnosis should be communicated to families.

Limitations of the study are also discussed and a summary of the study and future study directions are given.

Chapter Two: Current follow-up of high-risk infants

This chapter contains 4 main topics for review of the literature.

Firstly, I will describe literature on the need for follow up of high risk infants and will provide information on the definitions, prevalence and long-term outcomes of these infants. I will particularly focus on those infants born premature or with hypoxic ischaemic encephalopathy as they are the most at-risk populations in the U.K. Secondly, I will provide present available evidence for what should be included in follow-up of high-risk infants. This will include present literature on, how we should identify, assess, follow-up and support these infants. I will then provide the evidence presently available on how we should support parents and what we can do after identifying these high-risk infants. Finally, I will conclude by reviewing the current follow-up and referral guidelines in England as well as more specifically in Liverpool in order to provide evidence on the state of play at present in the setting where I am conducting this study.

All literature was searched on: DISCOVER, University of Liverpool library portal which searches literature over databases which include Scopus, PubMed and MEDLINE (list is shown in table 1), and Google Scholar between September 2016 and June 2017.

I searched only literature published in English where full text articles were available published over the past twenty years (January 1996 to May 2017). I chose the period of 20 years to explore evidence regarding high-risk children and their outcomes in long-term as I wanted to concentrate on recent data. Twenty-year worth of papers deemed feasible to identify good quality evidence (e.g. large sample size, multicentre

study, systematic review and meta-analysis) in that time available. Moreover, bibliographies of papers were used to retrieve other articles. Websites such as the World Health Organisation, Tommy's, Bliss, Premature Babies, and NHS Choices were also utilised as these sites had specific information for parents and professionals that were useful to this study. This literature gave insight into the significance of the problems worldwide but also into the specific information parents might read or look at in the U.K.

For this MPhil, I did not do a systematic review of the literature but I did do an extensive review of the literature to gain the most relevant articles that I could find in the time available.

The first literature search was carried out by using key words “prematurity” AND/OR, “hypoxic ischaemic encephalopathy” AND/OR “neurodevelopment” AND/OR “development” AND “long-term”. I also looked for the rates, prevalence and causes of prematurity and hypoxic ischaemic encephalopathy through the literatures search conducted using search terms above.

For the second review, I used key words “high-risk” AND “follow-up” AND/OR “neurodevelopment” AND/OR “effectiveness” AND /OR “identification”.

For the third review I explored, [1] The effectiveness of early intervention programmes and [2] the importance of multidisciplinary team approach for those identified as high-risk are also explored using key terms [1] “neurodevelopment” AND “early interventions” AND “outcomes” AND “effectiveness” [2] “Child Development Centre” AND “importance” AND/OR “neurodevelopment” AND/OR “development” AND/OR “outcomes”.

Figure 1: Key words used for literature searches

Finally, I will outline the current nationwide guidelines and local protocols regarding neonatal and neurodevelopmental follow-up in England as well as Liverpool. For this, I will use information from the National Institute of Clinical Excellence (NICE), the National Neonatal Audit Programme (NNAP) and the Department of Health databases to search for guidelines available in the U.K. I will also do a general search on the Liverpool Women’s Hospital (LWH) and Alder Hey Children’s Hospital websites and review the admission and discharge packages usually provided by the LWH.

<ul style="list-style-type: none"> • Academic Search Complete • Complementary Index • Scopus • MEDLINE with Full Text • Emerald Insight • Science Citation Index • CINAHL Plus • PsycINFO • Supplemental Index • ScienceDirect • British Library Document Supply Centre Inside Serials & Conference Proceedings • Social Sciences Citation Index • Business Source Complete • SPORTDiscus with Full Text • Directory of Open Access Journals • Communication & Mass Media Complete • AMED- The Allied and Complementary Medicine Database • The University of Liverpool Repository • University of Liverpool Catalogue • RILM Abstracts of Music Literature • Humanities International Complete 	<ul style="list-style-type: none"> • eBook Clinical Collection (EBSCOhost) • eBook Collection (ESBCOhost) • eBook Index • ClinicalTrials.gov • RILM Abstract of Music Literature with Full Text • PsycARTICLES • Computers & Applied Sciences Complete • Index to Legal Periodicals & Books Full Text • SwePub • NARCIS • ERIC • Teacher Reference Center • Agricola • Library, Information Science & Technology Abstract • Environment Complete • Dentistry & Oral Sciences Source • Art & Architecture Complete • Informit Health Collection • Informit Humanities & Social Sciences Collection • SciELO • Research Starters
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Table 1: List of databases on Discover by University of Liverpool

2.1. High-risk Infants and neurodevelopmental outcomes

2.1.1. Definition of high-risk infants

A massive amount of literature exists on the treatments, developmental outcomes and follow-ups of outcomes of “high-risk” infants. This includes a large body of literature on interventions that can be provided in the neonatal unit. It also includes a body of literature on the present numbers for children surviving and those having problems in the years subsequent to their admission to the neonatal units. Within this FOUNDATION Study. Ayuko Komoriyama

wide body of literature, the definition of a “high-risk infant” is very variable between studies as well as between settings across the world.

The list of conditions and circumstances considered “high-risk” includes not only those in the infants but also those associated with the mother. Examples of “high-risk” includes: those infants born preterm, those born with low birthweight, those born with a birth defect, those requiring oxygen supplementation and those needing subsequent general anaesthesia for surgeries and investigations such as MRI scans.^{2,5,20} Maternal factors relating to “high-risk” infants include those mothers who have abused drugs and alcohol, teenage mothers, those with major mental illness, physical disabilities and unfortunate social circumstances (e.g. poverty, homelessness and domestic violence).^{2,5,20-22}

At present, there are no national criteria for which infants are defined as “high-risk” in the U.K. Although there are numerous lists of conditions that define high-risk infants/children, for this study, I have decided to focus on “premature infants” and “infants who have had hypoxic ischemic encephalopathy (HIE)”. I have chosen “prematurity” because there is a high prevalence in the world and in Liverpool, therefore, I feel it is important for those babies to get adequate long-term follow-up and support. HIE was chosen for the study because it can leave children with significant sequelae and these children should be followed-up adequately and could benefit from early intervention programmes to help with vision, motor development, and establishing feeding.²³

2.1.2. Premature Birth

For this thesis, the World Health Organisation's definition of prematurity is used. A preterm infant is a baby who has been born before the gestational age of 37 weeks. This definition can then be broken up into categories. Babies born between 32 and 37 weeks are defined as moderate to late preterm. Babies born between 28 and 32 weeks are very preterm and any baby born below the gestational age of 28 is defined as extremely preterm.⁸

Epidemiology for premature infants

Worldwide, it is estimated that 15 million babies are born prematurely every year. This equates to more than 1 in 10 babies.²⁴

In 2014 in England, Scotland and Wales, 90,2253 babies were admitted to Neonatal Intensive Care Units (NICUs); of those, 39% of babies were born prematurely.²⁵

Globally, prematurity is increasing, and survival rates of premature babies have increased over the decades.²⁶ This is because of the advance in medical technologies such as precisely controlled incubators, medications that can facilitate growth, breathing and sleeping and more facilities are available to treat babies born prematurely.^{8,26} In England, the survival rate of very premature infants (gestational age below 32 weeks) has increased from 40% in 1995 to 80% in 2011.^{1,27}

Aetiology of prematurity

The aetiologies of premature birth are multifactorial.²⁸ Infections, cervical insufficiency, maternal-fetal hypothalamic-pituitary-adrenal activation, and multiple

pregnancies are some of the commonly identified aetiologies of preterm birth.^{25,28}

Twenty-five percent of premature births are planned because of maternal or fetal complications or are due to an emergency event; 30% are due to a premature rupture of membranes (PROM), and in 40% of cases, the cause is unknown.²⁷

Previously, babies who are born later than 24 weeks were treated proactively and aggressively however, the threshold of treatment has lowered. Although it is still controversial to treat 23-weeker or younger aggressively, healthcare professionals have now more proactively been saving infants by actively using steroids, and intubating and performing CPR, to those born before 23 weeks.²⁹

Long-term outcomes

Since medicine has been evolving, more small, premature and complex babies have been surviving. More than 75% of lives of premature infants can be saved by prompt and appropriate management such as antepartum steroids, respiratory therapy, antibiotics, and kangaroo care.²⁴ Babies born prematurely are not just at increased risk of mortality, but they are also more prone to serious long-term morbidity and complications including; developmental delay, heart and lung conditions and neurological conditions such as cerebral palsy.^{30,31}

It is not only physical or anatomical issues that affect children's development. Research demonstrates^{16,34,35} that the social and environment circumstances that a child is exposed to may influence child development dramatically, particularly more so for those children born prematurely. It has been found that children born to

families in a lower socioeconomic class had poorer growth, fine motor, language and social skills, lower intellectual abilities and more mental health issues.³² A longitudinal follow-up study on high-risk infants by Goyen and Lui³³ measured child's developmental outcomes using the Home Observation of the Maternal Environment (HOME) Scale. HOME Scale measures the adequacy of the stimulus at home for children to develop their physical, mental, cognitive and social abilities. Infants who had lower HOME scores had significantly worse gross and fine motor skills when assessed by Peabody Developmental Motor Scales at 18 months and 5 years. They also reported that a lower maternal education level was also associated with poor neurodevelopmental outcomes of high-risk infants.³³

2.2.1. Prematurity and neurodevelopmental delay

Development of the brain starts from the 3rd week of fetal development.⁶ When infants are born prematurely, their brains are more prone to injuries due to the destruction of complex normal growth of the nervous system.

Preterm infants are more at risk of developing intraventricular haemorrhages (IVH), and neonatal seizures and developing cystic periventricular leukomalacia (PVL).^{6,34}

Premature infants who have developed moderate to large IVH are likely to have more damage to the development of the brain. 85% of those patients develop cognitive impairments 75% needed to attend schools for children with special needs.² PVL is the most common ischaemic injury in premature infants and is readily detectable on a cranial ultrasound scan. Infants born before 34 weeks are

particularly at risk of PVL, and 70% of children with cerebral palsy are known to have PVL.

Some of the best and most comprehensive studies on outcomes of premature infants come from Sweden and have been conducted every few years over the last twenty to thirty years. One recent Swedish longitudinal study³¹ followed-up premature (less than 32 weeks) babies for 4 years and assessed them with the Bayley-III assessment tool at the age of 2.5. They found that the mean Bayley-III assessment score was significantly lower in the extremely premature group in comparison to the control group. (e.g. cognition: 94 vs 104 $P < 0.001$). 5% of extremely premature infants had a moderate cognitive disability in comparison to 0.3% in the control group ($P < 0.01$) with 6.3% of those infants having a severe disability as compared 0.3% controls ($P < 0.001$). Rates of cerebral palsy were 7% in the extremely premature group in comparison to 0.1% in the control group ($P < 0.001$). This study showed that only 42% of extremely premature group had no disability at all, 31% had mild disability and 16 % had severe disability. The authors suggest using these findings when consulting parents about future prognosis. Having 42% of chance of not having any disability at all can be very encouraging for parents.

Some large-scale longitudinal studies, the EPICure 2 studies¹⁰ (from the UK) found a lower rate of severe disabilities in the high risk population than those in Sweden. 576 babies were included between 1995 and 2006 and were followed-up using both the 2nd and 3rd edition of Bayley's assessment tools. 11.8% of babies developed

moderate neurodevelopmental impairment and 13.4% developed severe impairment. The outcome was associated with gestational age of the children and the prevalence of impairment reduced as gestational age increased.

A systematic review by Mwaniki *et al*³⁵ on the other hand, found higher rate of neurodisability in at-risk children. The review encompassed 153 studies and 22161 survivors of intrauterine and neonatal insults including premature birth and hypoxic ischaemic encephalopathy. They found that 39.4% children developed some neurodevelopmental problems such as poor cognitive, motor, hearing, and visual functions. The most common impairment was developmental delay and cognitive impairment (59%). However, this study was conducted in Kenya and they concentrated studies conducted especially in low to middle income countries. It is possible that at-risk children did not receive treatments available in high-income countries like Sweden hence the rate of neurodevelopmental complications were higher.

Children born prematurely are also found to have difficulties at schools not just in the first few years of life, but they can have more subtle problems when they reach school-age. Johnson *et al*³⁶ studied children born prematurely at the age of 11 and they found that extremely preterm children had lower scores in cognitive ability, reading, and mathematical skills in comparison with their peers born at term. For example, extremely premature children scored 27 points less than term children in mathematics. It has also been demonstrated that 13% of children went to special

school and 57% of those that went to main stream school needed special educational needs (SEN) such as one-to-one and psychological support.

The EPICure study conducted in 1995 showed that significantly higher prevalence of behavioural problems in extremely premature children than term children (19.4 vs 3.4%).³⁷ After adjusting with children's IQ levels, emotional, social and attention problems were 2 to 4 times higher in extremely premature groups in comparison to term children.³⁷ Because of these reasons, many children born extremely premature are likely to attend special schools. Hence, these studies highlighted the importance of long-term follow-up of preterm children by professionals such as educational psychologists and community paediatrics who can assess neurosensory, educational, psychological and behavioural problems of children and whether children need to attend special schools. They can also provide information regarding different types of schools that can provide appropriate support for the children and the families.

Prematurity can also affect people for their whole life. A Norwegian study conducted between 1967 and 1983⁴ showed that a significant number of the adult population who were born prematurely had medical and social disabilities, psychiatric conditions, and been receiving medical and disability pension. Individuals who did not have physical disabilities had lower educational levels, lower income and were on Social Security Benefit.⁴ Encouraging societies to learn and understand about prematurity

and disabilities may increase the opportunities for those people affected to be employed and sustain their quality of lives.

2.1.2. Hypoxic Ischaemic Encephalopathy

Hypoxic Ischaemic Encephalopathy (HIE) is a condition whereby an infant's brain is affected by inadequate oxygenation or perfusion.² In severe cases, up to 60% of affected infants die and 25% of those who survived can have long-term neurodevelopmental complications.⁹ Without appropriate treatment, a delayed neuronal death phase occurs involving; cytotoxic oedema, cell death the beginning of free radical damage. The injury is associated with encephalopathy and seizures.⁹

Epidemiology of Hypoxic ischaemic encephalopathy

HIE is one of the most recognised causes of deaths in neonates. It usually affects term and late preterm infants and is also one of the most important causes of cerebral palsy and other disabilities in children.³⁸ The incidence of HIE is approximately 6 in 1000 live births.

The incidence of hypoxic ischaemic encephalopathy is higher in developing countries than developed counties. In developing countries, such as South Asia or Africa, more women give birth at home where emergency care including appropriate resuscitations may not occur which leads to a poor outcome. Moreover, neonatal care is new to those countries, hence their quality of care is not as good as some counties where they have been practicing neonatal care for a longer period of time.

Aetiology of Hypoxic Ischaemic Encephalopathy

Infants born to the mothers who are suffering from increased maternal age, thyroid disease, viral illness, severe pre-eclampsia or had an abnormal placenta are identified as at risk of developing HIE.³⁹

Long-term outcomes

In recent years, brain cooling and total body cooling have become common practice to manage HIE to reduce brain damage which causes neurodevelopmental impairment.³⁸ The criteria for therapeutic cooling includes babies who had had Apgar score of less than 5, needed resuscitation at 10 mins, shown abnormal neurological sign such as abnormal reflexes and evidence of seizures.⁴⁰ During this treatment, the baby's body is cooled to 33-34 degrees with cooling blanket in the NICU.⁴⁰ There are a few adverse events that have been reported. For example, TOBY study had babies who suffered from intracranial bleeding, sepsis, major thrombosis, thrombocytopenia, and renal failure.⁴⁰

About a half of infants who are affected by a cerebral infarction have normal development or a minor long-term problem. Patients are unlikely to suffer from disabilities if they have not developed seizures due to ischaemia.⁴¹

Mwaniki and colleagues³⁵ systematically reviewed 27 studies and found that in a meta-analysis of studies, 45% of infants had developmental delay and cognitive impairment, 29% had cerebral palsy, and 17% had gross motor and coordination problems after they suffered from HIE.

Recent systematic reviews have recently reviewed the evidence and have demonstrated that total body cooling has a significant effect on moderate to severe HIE and reduces severe neurodevelopmental problems and mortality.^{42,43}

The Cochrane Collaboration evaluated 11 RCTs including the TOBY study, the very well-known multi-centre, randomised study that investigated perinatal asphyxia management.^{9,44} Their review encompassed 1505 term and late preterm infants who have had moderate to severe encephalopathy with the evidence of birth asphyxia. It has been found that the mortality rate and the rate of developing cerebral palsy were significantly reduced in the hypothermia group.⁹ Children who had a mild encephalopathy and had cooling treatment had similar IQ to their peers at the school. However, it has been shown that children with severe encephalopathy had the mean IQ of 68, which is significantly lower the average of the same age.⁴⁴

The findings and recommendations from the TOBY Study⁴⁴ are widely used in making guidelines and local policies including at Liverpool Women's Hospital.

2.2. Follow-ups for high-risk infants

Most hospitals organise follow-up clinics prior to discharge. Infants who graduated NICU are typically followed-up by neonatologists, general paediatricians or primary care physicians depending on their severity of perinatal problems, medical intervention in the NICU, and progress after being discharged from the NICU.³² Many professionals use different assessment tools, but they all need to recognise and refer to the specialist if the children have neurodevelopmental delay.

In the first 3 years of life, the brain develops significantly and forms new neural pathways which justify the importance of following-up children at risk from early age to identify abnormal neurodevelopment.²⁰ Despite having advanced management such as total body cooling for severe encephalopathy, children may still suffer from significant neurodisability hence continuous and consistent long-term follow-up assessments and interventions are still required.

Further assessment enables identifying an aetiology for the delay or disability which would help parents understand in depth about their child's condition.⁴⁵

Follow-up after NICU and hospital discharge is increasingly becoming recognised as an essential aspect of healthcare for preterm and high-risk infants. Many healthcare professionals have studied the importance and the outcomes of the follow-ups.²²

Hospitals are trying to organise early intervention programs and use the multidisciplinary team approach to managing high-risk children in long-term. This also allows comprehensive management plans for children and their families. The pathways for follow-up and support networks for parents need to be tailored to each case so that the follow-up system can function in ways most beneficial to parents and their child.

Through high-risk infant follow-up (HRIF) programmes, delays and complications experienced by high-risk babies can be reduced by offering early intervention programmes in a timely manner.¹¹ Early intervention (EI) refers to targeted prevention-focused programmes for high-risk children which may physiotherapies and speech and language therapies. The HRIF can also provide opportunities to educate parents about EI that parents can do in everyday basis at home. This

includes keeping eye to eye contact, calling the child by his/her name and providing sound producing toys.⁵

2.2.1. Identifying high-risk children

It has been identified that up to 60% of high-risk infants (without cerebral palsy) get mild and moderate motor impairment.²² In order to identify children with developmental delay, effective follow-up systems should be in place.

Before I discuss what, how and when we should identify high-risk children at risk of developing developmental delays and disabilities, we should understand the difference between developmental surveillance and screening. Developmental surveillance is a continuous and cumulative process conducted by appropriately trained professionals to identify children who might have developed developmental problem and refer to appropriate tertiary services.⁴⁵

Developmental screening is conducted using developmental assessment tools, designed to identify high-risk children who should receive comprehensive diagnosis, assessment and treatments. This assessment can be conducted by anyone and can be one-off assessment as comparison to surveillance which should take place for a period of time⁴⁶ I will discuss different kinds of surveillance and screening tool below and in 2.2.2.

A cross-sectional cohort study by Tang *et al*⁴⁷ from the Stanford University focused on whether neonatal follow-up programmes could appropriately identify the high-risk children who needed to have support from early intervention programmes. In

California, most NICU are funded by California Children's Services (CCS) and they are required to provide follow-up programmes to all high-risk infants. This study reviewed 5,129 children identified by database, High-Risk Infant Follow-up Quality of Care Initiative. In follow-ups, professionals conducted developmental test or screening for every child. The Bayley Scale of Infant Development, 3rd edition, was used 71% of the time, the rest used other standardised tests such as Capute Scales (20%) to assess neurodevelopment of the high-risk babies. This study found that 34% of children from these cohorts who were highly concerned by professionals and needed support were not appropriately referred to early intervention programmes despite attending clinics specialising in the assessments of children with neurodevelopmental delay.⁴⁷ In this study, those who were assessed at an older age meant that they were less likely to be referred to the early intervention program and only 10% of developmentally delayed children received early intervention by 24 months. Furthermore, a referral was more likely to be made if the child was suffering from conditions such as chronic lung disease where the child needed home oxygen or if the child had a visual impairment rather than if they had developmental delay alone. Children who did have developmental delay whose mothers had higher educational levels (50% of them were college graduates) were likely to get referred to early interventional programmes more than those who did not.

This study highlights the difficulties of identifying the right babies and the importance of having a systematic and standardised pathway of identifying these infants. It can also be argued that it is difficult enough to identify the right infants and therefore it may be better to provide input and supportive programmes to all at-risk infants as

early as they are still at NICU. For example, Prechtl general movement assessment can be performed at one to three months corrected age and it can predict adverse outcomes in the future.^{34,48} Therefore, it can be used to identify children who might need extra support in the future in the NICU. The result correlate with abnormal MRI findings³⁴, hence Prechtl can be used to predict future neurodevelopmental outcomes earlier than the MRI and start interventions earlier before anything starts to develop. The detailed review of assessment and screening tools are discussed in 2.2.2.

2.2.2. Developmental Surveillance

Developmental assessment should not be done in snapshot but continuous assessment by appropriately trained professionals. Developmental surveillance in the U.S. has been defined by Dworkin as *“a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care. The Components of developmental surveillance include eliciting and attending to parental concerns, obtaining a relevant developmental history, making accurate and informative observations of children, and sharing options and concerns with other relevant professionals.”*⁴⁶ In order to pick up on children with developmental concerns, comprehensive developmental assessment at appropriate age is required.

Currently there is no clear definition from the U.K that defines developmental surveillance and screening.

What can we use to identify the at-risk children?

Over the years, different developmental screening and assessment tools such as Ages and Stages Questionnaires (ASQ), Bayley Infant Neurodevelopmental Screening Tool, and Battle Developmental Inventory Screening tool have been developed and used over the world. They are used to identify children with delayed development and can be used to record children's progress after having early interventions such as physiotherapy or speech and language therapies. Every screening tool requires trained professionals to obtain accurate and reliable score of a child.^{16,49} Opinions differ on which screening and assessment tools should be used in what kind of follow-up clinics. Parent report tools such as the Ages and Stages (ASQ) or the Parents Evaluation of Developmental Status can also be used as a developmental assessment tools.

There are a few assessment tools that can be used to assess neurological status before premature children are discharged from NICU. The table below summarises some examples of specific tools that can be used in the NICU.

Name of tools	Applications	Evidence
Lacey Assessment of the Preterm Infant (LAPI)	<ul style="list-style-type: none"> • A non-invasive assessment tool • It can predict the risk of developing cerebral palsy, monitor infant's development and identify abnormal neurological developments in premature infants (<33 weeks). • It can be used while infants are still in NICU and it has been advised to repeatedly assess children until they reach term age and used by trained physiotherapists.⁵⁰ • It can promote early referral to start targeted interventions 	<ul style="list-style-type: none"> • It has a sensitivity of 86% and specificity of 83% in predicting cerebral palsy at the age of 3 in preterm children.⁵⁰
Prechtl's Assessment of General Movements	<ul style="list-style-type: none"> • An assessment tool that can predict children's future neurodevelopmental outcomes (e.g. cerebral palsy) in premature infants.⁴⁹ • a non-invasive and cost-effective assessment tool which looks at rotational movements (limb movements in circle) of a child.⁴⁹ • Professionals can start assessing a child in the NICU. • The child's monotonous, rigidity and poor or absence of fidgety movements at the age of 3 to 5 months might indicate poor neurological outcomes in the future.^{22,49} 	<ul style="list-style-type: none"> • It has a sensitivity and specificity of 95%.⁴⁹

	<ul style="list-style-type: none"> • Any professional who has completed a training programme can assess a child.⁴⁹ • It has also been found that a child who had been identified as having poor and abnormal general movements are likely to have poor intellectual abilities.⁵¹ This assessment can be learnt easily and quickly and performed by any trained professionals. 	
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Table 2: descriptions of different assessment tools that can be used in NICU

If these assessments can predict future outcomes and identify those that may need additional support from specialists' services such as physiotherapy and occupational therapy, there should not be any reason as to why those children should wait until later neonatal follow-ups or scan results. Although it is clear that at this stage we are not able to prevent cerebral palsy once insults to the brain have occurred, early identification and interventions can prevent the secondary problems which are related to cerebral palsy and may help with general support to parents.⁴⁹

For example, regular physiotherapy can help prevent the development of contractures and regular support from a multidisciplinary team can help maximise the quality of lives.⁵² Therefore, continuous monitoring and screening of at-risk children is still vitally important.

Every child born in the U.K is followed up by primary care providers such as general practitioners and health visitors regardless of their follow-up pathways in secondary and tertiary care. One of the tools used by primary care providers is a Red Book, a personal child health record (PCHR) given to all the mothers at a child's birth. It contains forms and charts to record child's weight, height, head circumference and vaccinations.⁵³ The aim of the PCHR is to ensure that everyone in the country has the standardised monitoring of their growth, to document child's growth in one consistent place and to increase parents' awareness and understanding of their child's growth.⁵⁴ It is supposed to enable smooth communication between primary and secondary care and it was hoped that it might help to standardise the referral

criteria for children with delayed neurodevelopment. A cohort study⁵⁴ found that the most mothers in the U.K. used the personal child health record effectively in the first year of life. The poor social circumstances, for example, young maternal age, poor living conditions and low socioeconomic status were associated with poor use of the child health care record.⁵⁴ There has been a very good study in Japan on their screening books called the Boshi Techo (Handbook of mothers and children)⁵⁵ but none in the U.K. as far as it is known. Studies to assess the utility of the developmental screening items in the red book could influence the future face of this material for parents and families.

The table below describes 3 assessment tools that can be used by trained professionals in different stages of child's development.

Name of tools	Applications	Evidence and limitations
Ages and Stages Questionnaires (ASQ)	<ul style="list-style-type: none"> • A well-established screening tool, particularly used in the community settings such as by health visitors and by caregivers (parent reporting tool).⁵⁶ • Easy and quick to use and has been shown to elicit parents' concerns using these questionnaires.⁵⁷ • It encompasses 21 different age-specific questions regarding gross and fine motor and social skills, that can be completed by parents.⁵⁸ It has been used to identify developmental delay, however the validity as a screening tool has not yet been confirmed.²⁰ 	<ul style="list-style-type: none"> • The sensitivity is up to 75% and the specificity is up to 86%.
Parents' Evaluation of Developmental Status	<ul style="list-style-type: none"> • parents can complete this assessment tool⁵⁹ • consists of 10 standardised questionnaires about a child aged below 8. • It covers language, fine and gross motor and behaviour and social skills, self-care and learning.⁶⁰ • Can be used to elicit parents' concerns on development 	<ul style="list-style-type: none"> • The sensitivity can be up to 97% and the specificity can be up to 86%.⁵⁹ • Cannot accurately predict developmental status in school children.⁶⁰

	including motor skills, language skills, behaviours and social interactions. ⁶⁰	
The Bayley Scale of Infant and Toddler Development 3 rd edition	<ul style="list-style-type: none"> • validated the U.S • and it has been widely used in the world to assess child's general development between the age of 1 months to 42 months.²⁰ • It covers similar domains to ASQ⁵⁸; it assesses cognitive, language, motor, social-emotional, and adaptive behaviours. It is used children between the age of 16 days to over 3 and a half years old.²² 	<ul style="list-style-type: none"> • Accuracy is known to be moderate to good.⁶¹ • When performing a screening test, professionals should take cultural factor into account to get accurate results.²⁰

Table 3: Assessment tools that can be used in different stages of child's development

There are several other stools such as Griffiths Mental Developmental Scale and Denver Developmental Screening test that are used as screening tools to identify at-risk children worldwide. It has been argued whether Denver should be used as a screening tool or not. However, since this is not the focus of the thesis, I will not discuss other assessments further.

Surveillance and screening tools are useful in identifying at-risk children for developmental problems yet all tools have the same limitation. As children can perform differently depending on their mood, which affects their concentrations during assessments, and the environment they are in, screenings tools can be useful yet can also be very temperamental and capricious.

2.2.3. Optimal age for developmental follow-up

There is no clarity as to the optimal age and follow up frequency needed for neurodevelopmental follow up.

The importance of identifying developmental disorders has been emphasised as it has been found that the rate of detecting developmental disorders has been lower than actual prevalence.⁴⁵

As discussed above, there are assessments such as Prechtl's and Lacey that can be conducted while babies are still on the unit. There has been a debate as to whether we should be conducting these assessments early and identify at-risk children early to refer to tertiary specialised services.

The Council on Children With Disabilities⁴⁵ produced a Developmental Surveillance and Screening algorithm and suggested to conduct screening tests at the 9, 18, and 30 month (see figure 2). They suggested to screen every well child even if they do not have identified risks. They also have demonstrated that as early as at 9 months, practitioners can identify delays in communication skills and signs suggesting autism such as a lack of eye-contact and responses when a child is called his or her name.⁴⁵ They would argue that by 9 months, children should already been referred to early intervention programmes which provide opportunities to educate parents to pay attention and monitor child's communication skills. This policy paper reviewed number of studies regarding developmental tools and produced extensive algorithm. The algorithm is useful and easy to follow however, it is for the U.S. healthcare system and it did not discuss cost-effectiveness and sustainability of the pathways suggested in the algorithm. They are important factors to consider especially in the country like the U.K. where the health care is provided for free. It requires time and money to train the primary care professionals to be able to perform an extensive developmental surveillance and it also requires the time and the capacity in the primary care to perform assessment when they are under the huge pressure. Nevertheless, this algorithm may be able to standardise the surveillance and screening pathway in the U.K. and identify children more effectively.

A longitudinal multicentre follow-up study by Vohr *et al*¹⁶ conducted in 2003 explored the most appropriate ages for certain assessments. He recommended that the most appropriate time to follow-up is at 18-22 months corrected gestational age (CGA) as

this is the stage where professionals may be more certain about the signs of cerebral palsy.¹⁶ However, they failed to detail what kind of signs and symptoms of developmental delays or disabilities they should identify at 18 to 22 months.

He argued how early intervention programmes are more effective when they start at the age of 18 months for children with delayed language and motor development.⁴⁵

He also argues that it is not until the age of 3 to 4 years old that it is appropriate to assess a child's cognitive and intellectual abilities, and verbal and non-verbal skills.

At this age, they have developed more communication skills and are more interactive when carrying out various tasks and play based activities. Yet there are no appropriate and accurate assessment tools to examine cognitive and intelligence level for younger age group. Therefore, professionals could under or overestimate the cognitive function of children.

Vohr *et al*³² conducted another study in 2004 which reviewed experience with long-term follow-up of high-risk infants in the National Institute of Child Health and Human Development (NICHD) in the U.S. This study was conducted in 2004 when there was no standardised guideline on neonatal follow-ups for high-risk infants in tertiary care. They found that by 12 months corrected gestational age, children can perform various physical activities and have developed enough to assess some cognitive functions. However, they argued that even by 12 months corrected gestational age, it is still difficult to pick up on permanent neurodevelopmental delay and disability as some conditions identified at 12 months can be transient, some can improve or get worse. Hence, some might argue that it is questionable whether

medical professionals (and other multidisciplinary professionals) should conduct any developmental assessment until this stage.

Some suggest that school readiness should be a routine assessment for high-risk as well as no-risk children.⁴⁵ Moreover, this is the age when children are affected by parents socioeconomic status so professionals would be able provide more support if necessary.¹⁶ Since schools should have started for most children at the age of 6, professionals could ask children and parents about schooling and attention problems. From this study, it is evident that it is important to follow up for long term to assess children's development fully.

In conclusion, professionals are looking for different signs and symptoms in different stages of development. Different assessment tools in different stages serves different purposes and some assessment tools can predict future developmental abnormalities from as early as when the child is at 12 weeks of age. How we make early identification beneficial and change a child's and families lives depends on how established the follow-up for high-risk children is in local health care. It will be useful if professionals such as health visitors or community neonatal nurses who can establish close relationship with a child and family, are trained to use standardised developmental assessment tools and lead the team in the community to monitor and screen high-risk children.

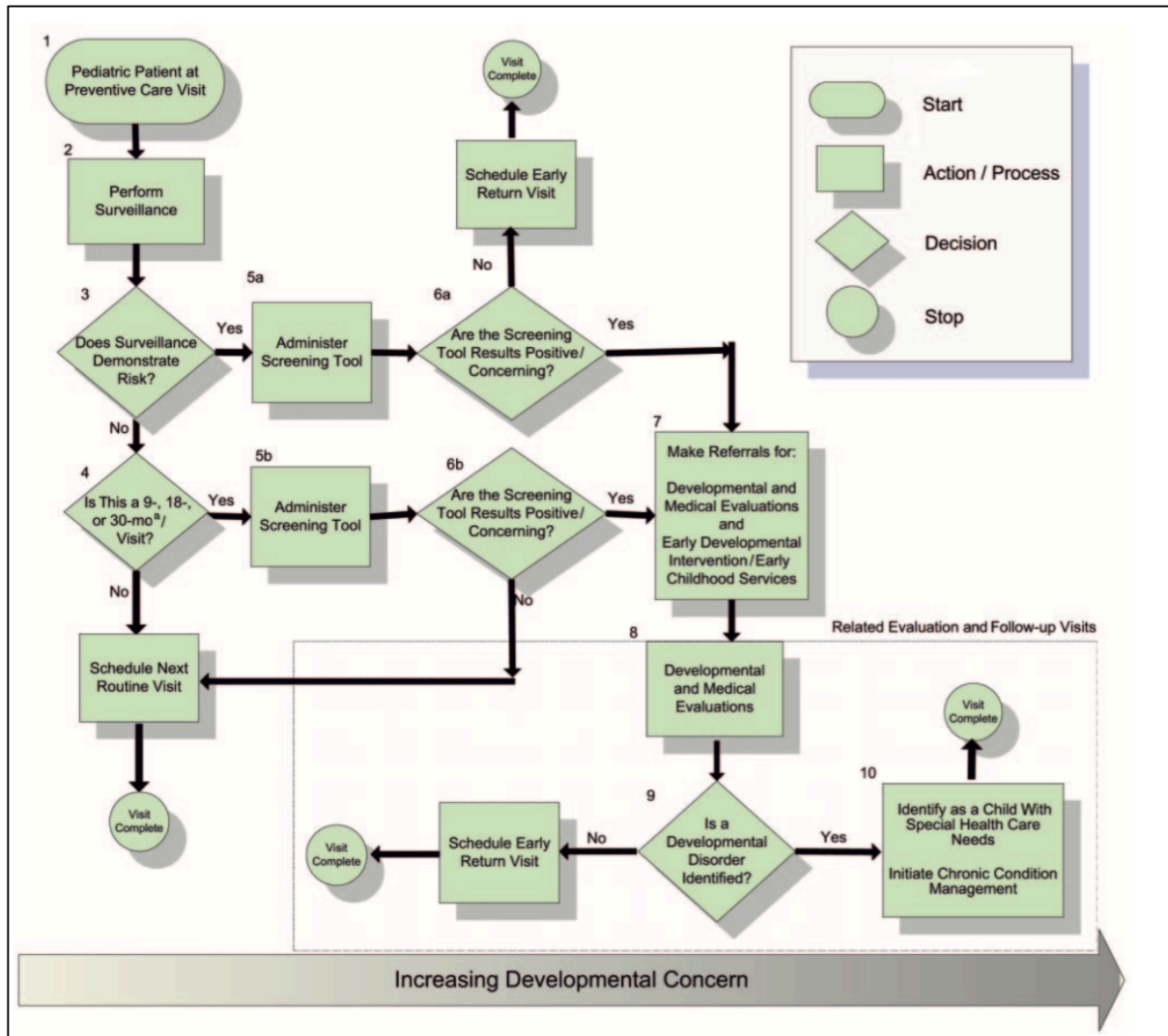


Figure 2: Developmental Surveillance and Screening algorithm in the U.S.⁴⁵

2.2.4. Parents' Mental Health and Follow-up

A follow-up appointment may provide an opportunity to identify children at most risk of developing neurodevelopmental problems.

Having a child born prematurely or have had other complications can affect parents' mental health. Depressive, anxiety and post-traumatic stress symptoms are commonly experienced by mothers of premature babies.¹³

Having a point of contact at the clinic may have a positive impact on parents' mental health as well as the developmental outcomes of children. A qualitative study found FOUNDATION Study. Ayuko Komoriyama

that parents often felt that the follow-up visits were reassuring and provide them with an opportunity to seek advice and ask questions.

A study by Benzies and colleagues⁶² focussing on maternal psychology in relation to early intervention programmes actually demonstrated that identifying at-risk infants improved maternal psychosocial outcomes in a way that left fewer mothers anxious and depressed. This in turn also helped to increase and sustain mother-baby relationships. Moreover, children who received their early intervention programme had better cognitive and motor development at 12 months of age.⁶²

I will discuss more literature review relating to qualitative studies focussing on parents' experience and views of having premature babies and babies with brain asphyxia and their NICU stay in more detail in Chapter 3.

2.2.5. Limitations of follow-up

There are a number of factors to follow-up which may limit the quality and availability of neurodevelopmental follow-up services for infants who have been born at high-risk. In some settings, a lack of qualified professionals and financial sources could limit the availability of the care.⁶³ This is particularly the case for multidisciplinary team follow-up which is time-consuming with evidence of the MDT approach being somewhat sparse and controversial as well as demanding more in terms of resource and funding allocation.²⁰ On the other hand in single professional follow up services, patients may get limited amounts of time in appointments. Some studies have shown

that professionals find these follow-up clinics short and stressful as they needed to ask many questions, including questions relating to the babies' general health, diet and nutrition, as well as needing to conduct physical and developmental assessments within a limited amount of time.¹¹ It is also clear that it may depend on the parents and children seen as to what kinds of services they need. Those parents who have more at-risk features themselves (socio-economic and mental health) may need more follow up than those who do not. Ballantyne⁶⁴ explored the predictors of attendance of neonatal follow-up programmes and found that single mothers who lived far from neonatal follow-up clinics, especially those with a previous history of drug and alcohol use, and parenting alone were less likely to attend the clinics as expected. This finding was also supported by a Canadian study.⁶⁴ On the other hand, mothers who had experienced very stressful moments during their infants' NICU stay were more likely to attend the clinics.⁶⁴ A Canadian study⁶⁵ which also explored the perspectives of parents with regards to barriers and facilitators to attendance at neonatal follow-up programmes found that attendance was problematic for mothers who had limited support structures at home, (emotional, informational and instrumental) from family as well as professionals.⁶⁵ Social factors such as transport difficulties or employment conditions were also barriers to attending clinics in this study.⁶⁵ It is clear therefore that even though some mothers have more need, the type of services that they require might be different and that home visiting services for some mothers may be better. Surprisingly, these same studies demonstrated that infant factors such as the complexities of the child's condition did not help to predict the likelihood of attendance at neonatal follow-up clinics.

Some studies from the United States have also looked at barriers to follow-up of neonates. A study by Tang *et al*¹¹ from the University of California highlighted the burden that continued follow-up appointments can have on family schedules. In some cases, mothers were attending different kinds of specialised clinics almost every day. Moreover, this study demonstrated that many parents found it difficult to remember the details of child development and the daily routines of their infants (e.g. bowel habits) when asked by professionals. This study highlighted the importance of having a care coordinator, a disability social worker or a link worker who could help coordinate patients' appointments by different specialists. There also should be a way that parents can document for example, a log book or questionnaires, child's developments and parents' concerns in these complex children who might have number of clinic appointments.

2.2.6. Conclusions

Only a few qualitative studies have explored the views and experiences of parents of high-risk neonates and professionals working with them in terms of neurodevelopmental follow-up services in the U.K. as well as in the world.

Most of the studies discussed in this review come from the U.S. It is not clear if parents have similar views in the U.K. Views of parents may differ as the capacity of health care services in the U.K. setting is very different from that in the US and may contribute to many barriers and facilitators in this setting which are different from those in the U.K.

2.3. What should we do to those children identified as high-risk children?

Follow-up services give opportunities for multidisciplinary professionals such as doctors nurses, speech and language, physiotherapists, and occupational therapists to identify the numerous complex and intricate risk factors which can be linked to developmental disorders.³⁴ Many would argue that early detection of children at risk of developing disorders enables children to be placed on the most effective follow-up pathway. In this section I discuss the benefit and outcomes of early intervention programmes that are offered to at-risk children worldwide.

2.3.1. Early Intervention Programmes

Increased number of preterm children and children with complex health care needs are surviving. About a half of extremely premature infants develop neurodevelopmental short-term and long-term disabilities such as cerebral palsy, visual or hearing impairment, cognitive impairment and behavioural problems.³⁴

Here, I discuss the effectiveness of early intervention programmes for high-risk children and their families.

Blauq-Hospers *et al*⁶⁶ systematically reviewed 34 studies with a total of 3,255 children to evaluate the effects of early intervention on motor development. Two RCT presented that Newborn Individualised Developmental Care and Assessment Programme (NIDCAP) had significant effects on child's neurodevelopmental outcomes. Professionals were able to give medical interventions and support

development regularly according to the results. Developmental support by a developmental psychologist and specially trained nurse involved education sessions (e.g. synchronising feeding and sleeping with child's sleep and wake cycle and lying a child in flexed position), joint planning with parents and implemented individualised care. Infants as a result, had better medical outcomes such as shorter duration of hospital stay, earlier establishment of feeding and less incidence of complications (e.g. pneumothorax). Infants also had significantly better neurodevelopmental outcomes at 9 months when assessed with Bayley Mental and Psychomotor scores (118.30 vs 94.38), in comparison to infants who did not receive NIDCAP.⁶⁷ This study highlighted that early interventions can take place in NICU for those at risk and promote significantly greater neurodevelopmental outcomes as a result. However, this research did not study beyond 2 years old and other studies did not demonstrate significant effects of NIDCAP at 5 ½ years. They did not find that one of the early intervention programmes called neurodevelopmental treatment (NDT) which took place between discharge and 9 months post discharge, had a positive outcome on motor development.⁶⁶ Only one study out of 8 studies which studied outcomes of NDT found positive effect of NDT on children with cerebral palsy however, some reported that NDT improved parents-children interaction. They concluded however that professionals need to offer age-specific early intervention early intervention programmes to maximise the impact of the programme and enhance child's development.

Orton et al⁶⁸ showed that the mean IQ of pre-school children aged between 3 and 5, who received an early intervention had higher mean IQ than children received standard follow-up. However, at school age (between 5 and 13), the outcomes were non-significant in the intervention group.

An Australian study⁶⁹ on the other hand found a significant difference in an early intervention team. Children in the intervention team had significantly higher score at 4 months adjusted age in the Test of Infant Motor Performance (TIMP) than the control group (mean difference -3.071, $P < 0.001$) and scored similar to the non-at-risk preterm children.⁶⁹

Recent Cochrane review by Spittle *et al*⁷⁰ encompassed 25 studies with 3,615 participants and found similar results to studies discussed above. Early interventions used in the studies included: educating parents to pick up on infants' cues, physiotherapy, neurodevelopmental therapy, and infant stimulation programme which includes visual, tactile and auditory stimulations. In conclusion, early stimulations improved children's cognitive function at infancy and preschool age. Motor function was improved only slightly and early intervention from early childhood did not reduce the incidence of cerebral palsy. There has been too little study that examined the long-term cognitive and motor outcome of children who received early intervention programmes to draw a conclusion as to whether early intervention programmes are beneficial in long-term.

Benzies et al⁶² reviewed 11 studies on the effectiveness of early intervention. Early intervention programmes often involved parenting advice, parents emotional support, parents education including how to observe and evaluate children's growth, and therapeutic child development support found that early interventions promoted better maternal mental health. Maternal anxiety was reduced significantly in many studies when measured by the Hospital Anxiety and Depression scale (220 points vs 190 in control group). The programmes also reduced parents' depressive symptoms and improved self-efficacy.

A child's condition could also make the results of early intervention vary. A Norwegian RCT study⁷¹ which focused on the outcome of the early intervention for low birthweight infants found that the programme did not improve motor nor cognitive function at 2 years. However, it helped to decrease parental stress level significantly. Similar results were found in the study by Kyono *et al*⁷² from Norway. It has been shown that information, advice and support that parents received through Mother-Infant Transaction Program (MITP) reduced parents' stress and increased parents' confidence about caring preterm children. This study focused on parents' perspectives of early interventions and was a small study. It would have been useful to know their views on how this programme might have benefited the child and how the relationship between the child and parents have changed or improved by this programme.

For any intervention, parents' compliance played an important role. Guralnick⁷³ conducted a review of 15 RCT studies of preventive interventions for premature children. Some interventions such as sensitive-responsiveness of the parents promoted short-term benefit on social and cognitive abilities but parents did not continue for longer period hence, the longer-term benefit was not shown. Like this, sustainability of interventions tended to fail after the intervention was complete or for a longer period of time therefore, the effect of interventions also diminished.

In conclusion, early intervention brings significant benefit to high-risk children short-term and promotes parents' well-being.

2.4. Follow up guidelines in the U.K.

2.4.1. Government policy paper

The Department of Health provides policies which outline the important health services that are available to everyone in the U.K.

The Healthy Child Programme (HCP) has been developed to enable every family to review and discuss several important health promotion issues for their child. This includes; immunisations, screening tests and the two-year review.⁵⁷

The HCP particularly emphasises the importance of two reviews at the age of 2 and 2 ½ years. These ages are identified as crucial times to identify children with neurodevelopmental delay, as well as those who may have difficulties with social and emotional well-being or parent-child relationship problems.

Children with disabilities are more likely to miss immunisations, suffer from obesity and poor dental hygiene.⁵⁷ Therefore, the HCP stresses the importance of health care planning for those with disabilities to ensure their quality of lives and physical and psychological wellbeing reach their potential.⁵⁷

In the U.K., health visitors play a crucial role in the Healthy Child Programme, monitoring all infants including that discharged home from hospitals. In this programme, it is also advised that child growth should be monitored until children reaches the age of 5 years.⁷⁴ One of the assessment tool called the Early Years Foundation Stage was recommended by the HCP to assess and screen child's development in 6 different areas (socio-emotional development, communication, problem solving, understanding of the world, physical and creative development) which would give health visitors as well as parents a good picture of the child's ability and developmental potential. The two-year review should detect children with delayed development and refer for more detailed assessment if present.⁵⁷

2.4.2. The importance of the National Neonatal Audit Programme (NNAP) and its recommendations

This audit programme was established in 2006 by the Royal College of Paediatrics and Child Health. Approximately, 1 in 8 babies born in the U.K. is admitted to a NICU in England, Wales and Scotland in each year. The NNAP emphasizes the importance of monitoring neonatal units to ensure that every baby has a chance of surviving and reaching their best developmental potential.¹⁴ This audit programme facilitates the standardisation of care by making recommendations from their audit findings to

specific units who may need support and to make changes in how they conduct their care.

The NNAP recommends following up extremely and very preterm babies for 2 years. The annual report in 2016 found that 60% of babies born below the age of 30 weeks had a record of a follow-up consultation.¹⁴ The various assessment tools which are used across the country in the follow-up clinics led by neonatologists or other professionals is very variable and not standardised. It is hoped that the forthcoming NICE guidelines for neurodevelopmental follow up of premature babies will standardise the developmental assessment (or outcome) tools used by neonatologists/professionals in these clinics. In the next section, I will review and evaluate the forthcoming NICE guideline on premature infants.

2.4.3. Review of National Institute for Health and Care Excellence (NICE) forthcoming guidelines

The National Institute for Health and Care Excellence (NICE) has just released their draft guidelines on "Developmental follow up of children and young people born preterm". This guideline will be published in 2017 and is the first NICE guideline created for the developmental follow-up for premature infants.⁷⁵

This guideline highly recommends that local authorities need to "have a responsibility to promote the well-being of children and reduce health inequality both at hospitals and community".⁷⁵ NICE also describe the importance of longitudinal follow up as

well as the importance of making appropriate referrals and offering intervention programmes early for those infants identified as having problems.³⁴

The draft guideline, “Developmental follow-up children and young people born preterm” outlines the common conditions that preterm infants are most likely to suffer from and provides advice on what professionals should review when they follow-up at risk children. In this guideline, professionals are encouraged to provide a clear discharge care plan and to “communicate parents about the potential child’s level of developmental needs, education level and emotional and psychological support”. The guideline also proposes an “enhanced two-year surveillance programme”. This is a comprehensive developmental follow-up program up to the age of two years, (using a multidisciplinary team (MDT) approach), for any child who is at risk of developing neurodevelopmental delay or a disorder. If the child was born below the age of 28 weeks, this surveillance is advised to be continued till 4 years of age.

Furthermore, the NICE draft guidelines recommend a minimum of 2 follow-ups for anyone with “developmental concerns”. A child with “developmental concerns” includes infants born prematurely or with conditions that require babies to stay in the NICU. It is not clear that why two appointments are thought to be adequate and appropriate to screen for developmental problems and over what time period these follow ups should be conducted.

NICE recommend the use of the Parent Report of Children's Abilities - Revised (PARCA-R) at 2 years of age (corrected) and the Weschler Preschool and Primary

Scales of Intelligence 4th Edition (WPPSI) test at a corrected age of 4 years at a minimum. Furthermore, they recommend the Strengths and Difficulties (SDQ) at the age of years for assessing social and behavioral development. NICE do not name the professionals who should conduct these assessments and the evidence for the use of these assessment tools in detecting developmental disorders is not cited.

This is only a draft guideline however, and these recommendations may change once professionals review them.

The draft guidelines at present expressed the importance of information being consistent to avoid confusion between professionals and caregivers, however recommend any information sources. Although the guideline mentions that online source of information is a possible source of information, NICE do not suggest specific websites. It also adds that information about opportunities to join local peer support groups as well as online based group should be made available, however again, they failed to list the groups that professionals can use to introduce to parents. Since inappropriate websites can make parents more worried and anxious, these incomplete and vague suggestions may not be helpful.

It also tells professionals to inform parents about neurodevelopmental problems of those born preterm. However, only one moderate quality study out of 15 studies explored parents' views on information of long-term prognosis. They found that parents wanted detailed information regarding long-term prognosis and the course of developmental progression.

They concluded that timing and the format of information are most important and the contents and depth of information should be tailored to individuals accordingly to their educational levels, fluency of the language and spiritual or cultural needs.⁷⁶

Parents also need to be informed about developmental follow-up by professionals who have experience in working in follow-up of premature children.

In conclusion, the NICE draft guideline, “Developmental follow-up children and young people born preterm” made it clear that antenatal, perinatal and acquired complications of premature birth may increase the likelihood of developmental problems in these infants. The guidelines therefore promote the idea that professionals should identify the “high-risk” infant. (even if the evidence for doing so is still sparse). The guidelines promote the need for identification and the appropriate follow-up for children who were born preterm. This will be helpful when services are aiming to gain more funding for their services. On the other hand, some recommendations from the draft NICE guidelines regarding the assessment and surveillance are still vague, and will not necessarily add anything to what professionals are doing at this moment. A final version of the NICE guidelines on the “Developmental follow up of children and young people born preterm” will be completed in August 2017.

2.5. Situation at Present in Liverpool

The high-risk infant should be approached by a multidisciplinary team which includes paediatricians, physiotherapists, neurologists, psychologists, social workers, and

speech and language therapists.⁵ In this section, I will therefore introduce the current follow-up system in Liverpool. It is important to understand the present situation before the researcher interview parents who have experienced care from these hospitals. This will also enable me to put my results from my qualitative study in context.

2.5.1. Follow-up systems in Liverpool

I. **Liverpool women's hospital**

Liverpool women's Hospital (LWH) is a tertiary centre for neonates with complex medical needs. The neonatal unit takes care of babies born in Merseyside, Cheshire, North Wales Isle of Man and other areas of the country if required. About 8,000 babies are born at LWH each year. The unit provides 12 cots for the intensive care of the new born, 18 for high dependency, 20 for low dependency and 6 for transitional/intermediate care.⁷⁷

The NICU has developed a follow-up protocol referencing the National Neonatal Audit Programme and other studies. Neonatologists follow-up high-risk children up to the age of 2 and the frequency and the length of follow-up is decided upon depending on the development of the babies when seen and complexity of the cases. Neonatologists and Advanced Nurse Practitioner lead these consultations where they crudely check the milestones without the use of a specific tool. The aims of these clinics are to identify any early signs of developmental delay and refer on for

appropriate treatment, to ensure good growth, to discuss any new medical problems or follow-up investigations and to review medication.

The unit works closely with the Bliss, a U.K. charity working to support premature or sick babies and their parents, who provide support for mothers going through difficult times.

II. Alder Hey Children's Hospital

Alder Hey Hospital (AHCH) is one of the biggest children's hospitals in the U.K. They care for more than 270,000 children and their families in a year.

Moreover, babies who go home with oxygen from the LWH NICU are followed-up by the Alder Hey respiratory team who will check their growth as well as respiratory functions.

III. Community paediatrics and neurodisability clinics

Community paediatricians work as parts of teams of multidisciplinary professional which includes, physiotherapy, occupational therapists and speech and language therapists – all who are now also employed by AHCH. They run clinics in local areas for the follow-up of children who have complex conditions such as genetic abnormalities, metabolic diseases and neurologically complicated cases. They also follow-up anyone who has developed signs of developmental delay and disabilities. These clinics can take place at the AHCH, local health centres, schools and GP surgeries. These teams link with Liverpool Community Health trust where health visitors are employed.

IV. Social workers and family support workers

There are different types of social workers working closely with children and their families, although these are very limited with recent budget cuts to council services in Liverpool. Here I focus on a disability social worker and a family support worker who work with children and their family with special needs.

A disability social worker and family support worker joins a multidisciplinary team when a family need more support to meet patient's complex needs and sustain good a quality of life. A disability social worker provides information and guidance on services available in the community that the family could use, and it also offers "short break services" for parents or carers.⁷⁸ A family support worker takes care of less complicated cases than a disability social worker. A disability social worker and family support worker get involved when a family is experiencing problems for taking care of children with disabilities and oversees the care provided by healthcare professionals to ensure that family is getting enough support from appropriate service providers.

Although a social worker and family support worker are very important in managing family, due to a limited capacity in Liverpool, it is only offered to children with highest complexity of need.

2.5.2. Support systems and discharge care-packages for high-risk infants discharged from the Liverpool Women's Hospital's NICU

On the LWH Neonatal Unit

Whether a child needed hospital care or not parents might need extra support outside from the hospital care.

Bliss is a charity organisation that founded in 1979 by a group of parents who had concerns in care of premature and sick babies.⁷⁹ Bliss website provides information on antenatal care, labours, support systems, developmental problems and charity events and networking site called Netmums forum where mothers could share their experiences and issues.⁷⁹ Furthermore, at the LWH, a local Bliss Champion visits NICU once a week to talk to parents and provide information and emotional support.⁸⁰ She also organises group sessions for mothers who had premature babies to share their problems and experiences on the ward.

After discharge

Every parent of babies who stayed at the LWHs' NICU receives an information pack at the time of admission and discharge. However, this lacks information on parental support groups at hospitals or in the community, development and milestones, follow-up clinics and names of the professionals who could get involved in the care.

When babies suffered from complications such as intraventricular haemorrhage or hypoxic ischaemic encephalopathy, doctors and nurses go through conditions, prognosis and future development and provide supportive information such as leaflets. For contents of the information pack, see Box 1.

When discharging a baby especially if she/he has complicated health issues or other risk factors such as environmental and social issues, it is very crucial to plan health care and support services.² At the LWH, community neonatal nurses, health visitors and community midwives visit a family as early as a day after they had been discharged to make sure that the family is settling down well with the baby and provide an opportunity for the family to ask questions and talk about issues. If necessary these professionals could refer to the specialists' services therefore, these professionals play significant roles in discharge care planning.

Admission packet at NICU at Liverpool Women's Hospital contains:

- Babies in special care units- screening tests for your baby
- Information for parents- Neonatal Unit
- BLISS Family Handbook
- Feedback Card
- Application for free Car Parking
- Communication And Information- for parents who have infants on the NICU
- Baby Link information – BadgerNet Baby Diary, guide for parents

At the time of discharge from NICU at Liverpool Women's Hospital, parents are given:

- Parent's questionnaire
- Basic infant resuscitation
- Leaflet from Fire& Rescue Service
- A quick guide to childhood immunisations for the parents of premature babies by NHS
- A card – Safer sleep for baby
- A card- Meningitis Baby Watch by Meningitis Research Foundation

Figure 3 Contents of information packs given at the LWH at the time of admission and discharge

2.6. Conclusion

There has been a significant amount of research into neurodevelopmental outcomes of premature infants and HIE. It has been shown that these children are at-risk of long-term developmental complications.

Many developmental assessment and screening tools have been developed. Lacey and Prechtle developmental assessment tools can identify children at-risk early and predict future neurodevelopmental outcomes which helps lead those at-risk children and families to appropriate follow-up and intervention pathways early. Although identifying and following-up children at risk of developmental complications cannot prevent conditions such as cerebral palsy from happening they can prevent secondary complications by early interventions. Moreover, follow-up and early interventions were found to be beneficial for parents' mental health.

The NICE guideline will be published summer 2017 and it is hoped that follow-up of high-risk infants will be standardised and everyone can receive interventions such as physiotherapy at appropriate times. This guideline will also help fund the hospitals to organise follow-up services in the hospitals as well as in the community across the country.

**Chapter Three:
Literature review
focused on qualitative
studies on neonatal
follow-up**

Many parents find having a child as a very challenging and life-changing experience. Parents who have babies who are born prematurely or with hypoxic ischaemic encephalopathy (HIE) must find this even more challenging. All of these babies start their life having care from the Neonatal Intensive Care Unit (NICU). The quality of NICU care has improved (Epicure studies) over recent decades and due to this parental experience has improved and parental stress has reduced.¹⁸ Despite this, many parents find their experience with their baby in the NICU a very worrying and overwhelming time.⁸¹

In this chapter, I review the qualitative literature relating to following six aspects of neonatal care:

[1] perspectives and experiences of parents and professionals, regarding neonatal intensive care unit (NICU) care;

[2] what, how and when parents received information in the NICU

[2] perspectives and experiences of neonatal follow-up clinics of high-risk infants

[3] experiences and views of parents and professionals around neurodevelopmental follow-up;

[4] experience of receiving diagnosis at neonatal and neurodevelopmental follow-ups; and

[5] experiences of follow up in different paediatric systems.

The key words used in my search are shown below. Once a search of the literature was conducted, each title was reviewed and then abstract to find those most relevant to my area of interest.

[1] perspectives and experiences of parents and professionals, regarding neonatal intensive care unit (NICU) care

Key words: “qualitative” AND “perspectives” AND/OR “experiences” AND “parents” AND/OR “professionals” AND “NICU”

I also added in[1] “prematurity”, “premature”, or “premature baby” and [2] “HIE” or “hypoxic ischaemic encephalopathy”

[2] what, how and when parents received information in the NICU

key words: “qualitative” AND “information” AND “NICU” AND/OR “quality” AND/OR “quantity” AND/OR “content” AND/OR “source of information”

[3] perspectives and experiences of neonatal follow-up clinics of high-risk infants

Key words: “qualitative” AND “perspectives” AND/OR “experience” AND “neonatal” AND “follow-up”

[4] experiences and views of parents around neurodevelopmental follow-up;

Key words: “qualitative” AND “perspectives” AND/OR “experience” AND “neurodevelopment” AND “follow-up”

[5] experience of receiving diagnosis at NICU and neonatal and neurodevelopmental follow-ups

Key words: “qualitative” AND “experience” AND/OR “receive” AND “diagnosis”

[6] experiences in different paediatric systems.

Key words: “qualitative” AND “experience” AND “paediatric”

Figure 4: Key words used to search literatures

3.1. Qualitative studies in Neonatal Intensive Care Unit (NICU)

In this section, I review qualitative studies on parental experience in NICU.

3.1.1. Experience of NICU and Having a premature baby

I reviewed 11 studies which focused on parental experience of NICU and having a premature baby. I identified 5 common themes in these studies which I discuss here.

Stressful

Parents of babies born prematurely often describe the whole experience of birth and transfer to NICU as “shocking, stressful and unexpected”.⁸² They also may feel guilty and ashamed of having a baby born early.^{83,84} Parents describe how the anxiety and having not being able to relax, and having to go to unfamiliar places provoked stress.⁸¹ Parents worried most about their child’s health, management plans and long-term prognoses.⁸¹

Parents describe the extreme distress they experience by having their child admitted to the NICU particularly after waiting for their baby for months.⁸¹ Mothers often describe how it takes a few days to fully accept their very small infants and how their previous expectations for being a new mother were not fulfilled. Mothers describe that in these circumstances, they are unable to ponder happy moments and often experience sadness and disappointment⁸² and loss of control of their baby.⁸³

Parents often questioned “what if’s”: what if the baby is ill or injured? What if the baby does not survive? And what if the baby has defects?⁸² These anxieties can stop

parents from believing that their babies progress is good. Some parents describe their fear of handling their own babies.

Some mothers chose not to mix with mothers of term babies because this could remind them of how experience could have been different.⁸² As expected, mothers with the sickest infants have the highest depressive and anxiety symptoms.⁸⁵

British Association of Perinatal Medicine (BAPM) standards dictate that infants in intensive care should receive one to one care from their nurse.⁸⁶ Nurses rotate between NICU areas, perceived by some parents as “stressful” due to lack of continuity added to by the struggle of getting to know a different nurse every day.⁸⁷ Although this qualitative study was conducted in only two locations in Norway and only interviewed 9 set of parents and 2 mothers , it is likely that this is generalizable in the U.K.

Many parents find seeing their children in hospital as mentally exhausting. Mothers of preterm babies are more likely to suffer from postnatal depression than those of full-term. Parents of infants with lower gestational ages and lower birth weights are more stressed with younger mothers experiencing this more than older mothers.¹⁸ This evidence comes from a meta-analysis of 38 studies which encompassed 3025 parents of preterm and low birth weight infants and is likely to be reliable.

Isolation and feeling detached

Parents are not often able to stay with their babies on the NICU. Parents describe how stressful and frustrating this can be with some mothers describing how they only

ever had a few seconds to hold their babies before they were taken to the NICU.⁸²

This can lead to a feeling of detachment from their own baby with parents feeling as if the baby belonged to the units and the nurses rather than themselves. Some parents describe this as a “power struggle” for ownership of the baby.⁸⁸

Some parents have described how staying at the hospital can make them more worried and restless as they frequently think about their children’s future and fear the consequences.⁸¹

Family life can be disrupted by having a baby in NICU. Mothers often need to leave their other children at home, a difficult compromise particularly when other children/siblings do not understand the situation very well. Hence, they felt better when their baby was able to be transferred to a tertiary unit closer to home⁸⁷

Although parents understand that NICU care is intricate, they often feel as though they are not included in care planning and given inadequate information in regards to their child’s care.⁸⁷ The focus for parents can often be on machines, technologies, competency of professionals being involved in baby’s care and medical terminologies. The focus only shifts to the baby when parents felt comfortable with the environment.⁸⁸

Positive experience

Support from NICU staff is important for parents such as giving opportunities to have conversations.⁸³ A good relationship between parents and nursing staff is considered very important and affects parents’ experiences of NICU.^{87,89} The feeling of being

accepted by kind staff at NICU can make parents feel comfortable and confident that their babies are in good hands. Parents also appreciate nursing staff who actively include parents in caring their baby.⁸⁹

Parents who were able to spend longer with their infant at the unit had a more positive experience of NICU.⁸³

In some cases, parents and babies are transferred to a regional tertiary centre located far from home. This can be difficult and many parents are glad to when they can be in a local NICU enabling them to see their family members.⁸⁷ These studies are small qualitative studies and may be very situational.

Differences Between Mothers and Fathers

Mothers and fathers may perceive or experience the same situation differently. Mothers may experience more stress than fathers. It is unclear why this is but it may be due to the traditional gender related parent roles.¹⁸ Traditionally fathers are expected to leave emotional roles to mothers hence they tend to have less involvement in infants' care in the NICU.¹⁸ Research may be biased however, in that even if fathers experience stress, they may report it less than mothers.¹⁸

The cultural setting may change how parents perceive or manage care in the NICU. In Asian countries, fathers may be less involved in parenting and finding it easier to balance work and parenting than mothers.¹⁹ Fathers may be more comfortable leaving their children at the hospital with nurses and are less likely to feel guilty.⁸¹ A

Korean study¹⁹ found that mothers are more likely to get involved to stay at the NICU during the day and to have more responsibility and control over their child's care. On the other hand, some fathers may feel as if health care providers only communicate with mothers and can feel ignored and neglected.

There are limited number of studies that focus on paternal experience of NICU.⁹⁰ A qualitative study from Germany⁹⁰ describes how although fathers may think their child is beautiful, only a small proportion of fathers thought their child was enjoyable when they first met their babies in the NICU. The majority of fathers in the German study⁹⁰ said that NICU staff encouraged them to take care of babies to the way mothers care for their babies. On the other hand, a few fathers felt they were unnecessary in NICU care and described how they felt that their main duties were giving physical warmth to their infant, providing support to the mothers, and managing everyday family life. Visiting hospitals alongside their job were found to be tough and challenging, and fathers said visiting NICU for their babies had an impact on their working lives.⁹⁰ Some fathers feel guilty for leaving the child and partner in hospital whilst they work.⁹¹

Parents Education sessions

Many parents say that they feel more comfortable knowing what to expect about their children's growth, development and medical conditions.^{72,92} Furthermore, when NICU teams involve parents appropriately, they can feel more relaxed when they leave the

hospital as they had been taught about the children's condition thoroughly.⁹² Support like this can also encourage more involvement from the wider family.⁸¹

Skin to skin (STS) method is taught by nursing staff in NICU. One study⁹¹ demonstrates how STS can enhance the fathers' relationship with their babies enabling them to feel more protective. In some circumstances, this intervention may enable fathers to feel more of a central role in the care of their babies.

3.1.2. Getting Diagnosis in NICU

Birth Asphyxia and Hypoxic ischaemic encephalopathy

Birth asphyxia is an emergency condition that occurs during delivery where foetuses and/or babies do not receive sufficient blood and/or oxygen.⁹³ Babies are born in poor condition and require resuscitation. This is often when parents first realise that there is something wrong with their babies. Parents may experience a feeling of suddenly being thrown into a chaotic situation.⁹³ These babies usually taken away to the NICU soon after the delivery and although many parents witnessed their children being resuscitated in the delivery room, they were often not told about their babies' condition until later. Some of the experiences described in this study from Gothenburg are heart-breaking and demonstrate a lack of focus on the parents particularly in these emergency situations.⁹³

Some parents thought their babies looked dead and were not sure whether their baby could survive the first night or not, continuously hovering between feelings of hope and despair. Many parents in this study have described how they feel that doctors or nurses have little time to explain the situation with their child.⁹³

Parents normally surrounded by many experienced staff and could talk to some parents that were in similar situations while they stay in the NICU. On the other hand, when parents and babies went home, they felt very lonely. With no monitors at home, they felt very anxious about their babies' saturations and other vital signs.⁹³ Parents found it very difficult to console their babies for the first 2 years.⁹³ This may be something that staff from NICU or follow-up clinics could have supported or offered help. Further qualitative studies are required to explore views of follow up clinics of parents of babies who suffered from birth asphyxia.

3.1.3. Qualitative Studies for Professionals in NICU

A group of Swedish researchers interviewed 20 health care professionals involved in NICU care focussing on the pros and cons of parental participation in child care in the NICU.⁹⁴ In this study, professionals perceived that washing, dressing and feeding babies on behalf of parents would speed up their own jobs. Many professionals found it difficult to know what limits to set for what parents in terms of cares but realised that in supporting parents in parenting, this was important.

On the other hand, some professionals wanted more input from the child's parents not always feasible for some parents who have other responsibilities at home or at work.

This study described how some professionals experience difficulties finding the balance of closeness and distance with parents.⁹⁴ Whilst working closely with family might increase job satisfaction, it made it difficult to shut off personal feelings.

The difficult balance between completing tasks and spending time with parents was also highlighted as an issue for NICU nurses in this study.⁹⁴

Even parents who have been neonatal nurses and therefore understand the system can find it hard to cope with the lack of control over the situation for their babies in NICU.⁸⁴

3.2. Information

Studies show that parents are provided with important information regarding medications, investigations and long-term outcomes about children who are admitted to NICU.⁷² It is important for health care professionals to tailor content and quality of information depending on parents' need and their child's gestational age.⁷² This allows parents to make decisions, to feel part of the team, and feel well-supported.^{81,94} A fine balance of realistic and hopeful approaches may be required in such stressful and sentimental times.

3.2.1. Quantity of information

There are a number of issues which need to be considered when providing information in a single consultation.

One study described how parents find that there was too much information given in a short period time and another study describes how fathers find it difficult to choose relevant information from the given resource.^{95,96}

3.2.2. Content of information

Parents generally wanted to have definite, honest and realistic information to reduce their uncertainty but studies describe variability in how much parents wanted to know. Some parents want detailed information regarding development but some feel that all they want is to know how they could spend their time with children comfortably and happily.^{97,98}

Graungaard and Skov⁹⁹ studied parents' reactions and coping mechanisms after being informed that their child is disabled through the use of longitudinal in-depth interviews. Communicating that their child is disabled is very challenging and difficult for professionals especially if the baby has moderate to severe disabilities.⁹⁹ Parents found it emotionally challenging to retain hopes and imagine a future. In this study parents expressed that they were more satisfied with information when professionals were engaged and empathetic when the diagnosis was given.⁹⁹

Having specific diagnostic information can increase parents' knowledge.⁹⁶ One study describes how parents of children who had HIE found MRI one of the best information sources as it showed what was going on in the brain and could give a better idea of prognosis to parents and professionals.⁹⁸

Being given information early can have a positive impact on father-infant relationship.⁹⁶ This includes basic information on practical skills for fathers.⁹⁰

A study⁹⁸ exploring the perspectives of neonatologists and paediatric neurologists on their provision of information on the prognosis of HIE children described the dilemma that professionals face. Many professionals report that they aim to provide an honest approach to the long-term consequences of these children perceiving that parents do not want any uncertainty. Many professionals reported feeling hesitant to make definitive statements about the child's quality of life in front of parents particularly as poor neurological outcomes do not necessarily mean a poor quality of life. This can be complicated as projecting a child's quality of life may affect decision making with regards to medical management particularly ventilation options. This study highlighted how important it is that professionals are responsible for the content and quality of the information they provide and need to tailor this to the individual parent.

3.2.3. Quality of information

In emergency settings such as the NICU, this may be difficult and options cannot always be discussed at the time of serious illness. so. This is particularly the case in emergency situations.¹⁰⁰ It may therefore be important for doctors and nurses to consider when the best and most adequate time is for communicating information.¹⁰⁰

Studies have shown that parents tend to cope better when they are given clear and straightforward information about their child's condition and progress on a frequent basis.⁹³ Parents also appreciate when health care professionals describe routines in the NICU (ward rounds, feeding, and changing).⁹³

The timing of information giving is associated with how much and how well parents can take in the information and understand the situation.⁹³ Parents emphasise the importance of disclosing and discussing the information at an appropriate time when they were prepared to receive sensitive and serious information.¹⁰⁰

Body language and facial expression is also an important part of communication. Parents describe that it is easier to prepare for the worst when they are faced by the serious appearance of a professional.⁹³

3.2.4. Source of information

Accessibility and availability to good information sources can affect how parents come to terms with having their child's stay in NICU. This may also affect attachment between parents and their child.¹⁰¹

There are many ways that parents can receive information. This includes directly through health care professionals, leaflets, peers and the internet.^{101,102}

During the perinatal phase, parents identified nurses and obstetricians as sources of information regarding their child. When neonatologists provide information regarding NICU care parents are less anxious and there can be better professional-parent relationship.¹⁰² Parents see neonatal nurses and neonatologists as primary information sources when staying in the unit.¹⁰¹

Examples of other sources that parents utilised include, parents peer support group and online information.¹⁰¹ One example is a peer to peer support group formed in the breastfeeding room. Most parents felt this provided a space to communicate worries and stresses not often realised by family members and friends.^{85,103}

3.3. Experience at Neonatal and Neurodevelopmental Follow-up Clinics

Here I review any available the literatures on the parental perspectives of neonatal follow-up.

3.3.1. Contents of follow-up clinics

Neonatal follow-up clinics allow a space to optimise medications and appropriate interventions as well as to conduct neurodevelopmental assessments and referral.⁸⁵

Many parents admit that they are not aware of the purpose and importance of follow-up but also which professionals are involved and the structure of assessments and examinations which might take place.⁸⁵ In some qualitative studies, parents described this one-to-one follow-up beneficial and reassuring.⁷² In this setting, health care professionals have a space to provide more information regarding development and can offer opportunities for parents to ask questions.⁹³ Studies also show that parents appreciate when doctors are honest and told parents clearly what exactly they should expect to happen in the future regarding development.⁸⁵ Although many parents are satisfied with verbal information during the consultations, studies show that many would prefer to also receive written information to take home as a

reminder.⁸⁵ On the other hand, some parents in a Canadian study conducted in two tertiary neonatal follow-up clinics, describe that follow-up clinics were repetitive with professionals explaining the same thing over and over again. Often doctors mention “...everything is normal” when parents want to hear more specifically how their babies are doing.⁷² Some parents in another Canadian study by Wong *et al*¹⁰⁴ also felt that there was a lack of explanation regarding developmental milestones, early stimulations to promote child’s development, and parenting.¹⁰⁴

3.3.2. Quality of follow-up clinics

Many parents describe how experienced clinic staff can allow a space for parents to raise concerns.⁶⁵ Preterm infants often need some support from professionals such as physiotherapists and occupational therapists who play a significant role in infants’ neurodevelopmental follow-up to ensure that preterm infants can reach their developmental milestones. In some cases, parents have felt that community services involving professionals such as public health nurses or health visitors were not be equipped with a sufficient knowledge about prematurity.⁷² This stops them being able to support parents fully and results in parents feeling community follow-ups is a waste of time.⁷²

This balance between community level care and expertise is a difficult one to get right.

The frequency of follow-up clinics favoured by parents may depends on the period after discharge and the seriousness of their child’s condition. Parents anxiety and stress reduces once steady growth and development are established.⁷²

Flexibility of scheduling for follow-up clinics is important as it can minimise disruption to family and work life.⁸⁵ Moreover, accessibility to professionals in between appointments, for example, by phone calls can be well appreciated by parents.⁸⁵

3.3.3. Consistency

Parents often desire to see the same paediatrician at the follow-up as they can build a continuous relationship.^{85,104} Moreover, different professionals may provide inconsistent information which leaves parents worried and confused.¹⁰⁵ On the other hand, some parents find seeing different professionals useful as they can gain different opinions about the same issue.⁸⁵

3.3.4. Referral from follow-up clinics

Parents often described a difficulty or delay in referral to other services such as physiotherapy and speech and language therapy. Many parents describe how necessary referrals could be provided in more timely manner.⁸⁵

Interestingly, some parents misunderstand the meaning of rehabilitation and feel it is a term reserved for adults who have suffered from stroke, making parents reluctant to take their child to physiotherapy appointments.¹⁰⁵ This highlights the importance of communicating adequate information about the roles of other professionals and therapies.¹⁰⁵

3.3.5. Conclusion

In order to maximise parents' engagement with follow-ups, professionals need to ensure parents get involved in the infants' care frequently during their NICU stay and they are also fully informed about their infant's future needs.¹⁰⁶

There is clear evidence from qualitative studies to demonstrate the importance that both parents and professionals place on follow-up in order to enhance children's neurodevelopment. It is clear however that parent satisfaction is associated with the neurodevelopmental status of their child.¹⁰⁴

3.4. Parent experience of paediatric follow-up clinics in other settings

I have focused on experiences at NICU and follow-up clinics however, it is important for me to review parents' experiences in other paediatric systems to understand what they are doing differently, similarly or better in terms of promoting positive outcomes and experiences for children and parents.

3.4.1. Qualitative study at Paediatric Intensive Care Unit (PICU)

Studies reporting on the views of parents who have had a child in Paediatric Intensive Care Unit (PICU) describe similar experiences to those in NICU settings. Parents report great stress in having to shift their parental responsibility to paediatric nurses who become more in-control of their children.¹⁰⁷ Parents complained that handover from the PICU and medical wards were not thorough and staff on the medical wards sometimes were not used to certain medical interventions

such as trachea cannula care.⁹⁷ Some parents felt that a more comprehensive discharge plan led by PICU would have helped parents to cope better in the future.⁹⁷ Most parents described the stay in PICU as “living in a mist” or “being in the dark”.⁹⁷ The way the diagnosis and prognosis was communicated by professionals also affected parents’ experience of PICU stay. Fathers tended to favour realistic, clear and honest information which they could only obtain through deeper questioning of clinicians.

Reviewing parents’ perspectives on PICU helped me get an insight as to what parents experience in such a physically and emotionally challenging situations and this is likely to be similar with parents of children born at high-risk in the NICU.

3.5. Conclusion

It is apparent that the qualitative literature exploring parental experience of having a premature baby and staying in the NICU is expansive. Qualitative studies which explored parents’ experience of having a child with hypoxic ischaemic encephalopathy (HIE) or who have developmental delay or disabilities are more limited. Furthermore, there are limited studies looking at the perspectives of parents with high risk infants (particularly those with HIE) once they have been discharged home. To my knowledge, there is such limited number of studies that specifically looked at parents’ as well as professionals’ perspective son the neurodevelopmental follow-up.

Numerous studies have shown that many parents felt shocked, stressed and guilty having their children born early and then seeing them admitted for aggressive treatment in an NICU.

A feeling of isolation is experienced by many parents in the NICU but experiences differ between men and women.

Mothers tend to describe more stress and guilt than fathers but fathers describe more isolation and lack of importance in the NICU.

It is clear that parent' education sessions may help parents feel less stressed and less helplessness but it is not clear exactly what the best mechanisms might be to utilise these sessions particularly in building confidence for parents on the future discharge and monitoring of their babies.

Most of the studies reviewed have been conducted in the U.S. The different health care system and management guidelines mean that the situation may be very different in the U.K. This is a gap in the literature and one that my study will aim to address in part.

Clearly, many studies from different countries have investigated parents' perspectives on the information provided in NICU regarding the future prognosis and development of their child. These studies point out the importance of parental knowledge on the longer-term risks and highlight how it is useful for parents to

understand this in order to keep an eye on signs of developmental problems (e.g. developmental delays, early hand preference, and increased tone in the limbs).

When reviewing qualitative studies, it is clear however that most information given during NICU stay is focussed on the short-term medical management. These studies describe how some parents are overwhelmed by the quantity of information at this stage, particularly regarding neurodevelopment. My study will aim to gain a deeper understanding of whether parents appreciated being told about future neurodevelopmental risks on the NICU.

Studies demonstrate that many parents find follow-up reassuring but that parents need to know the purpose of follow-up services and how it can benefit child's neurodevelopmental status. In my study, I will aim to explore whether the parents view on this.

In reflection of the present literature, the following aims and objectives for my study are as follows:

Aim: The aim of this study is to understand the present situation, the perceptions and the views of parents and professionals who look after high-risk infants discharged from the NICU at Liverpool Women's Hospital in terms what support they get in neurodevelopmental follow-up.

Objectives

Objective 1: To understand through in-depth interviews the perspectives of parents who have had high-risk infants and children aged 0-3 years in the Merseyside area and multidisciplinary professionals from hospitals, the current situation of neonatal and neurodevelopmental/community follow-up, how it has been benefited families and how it can be improved.

Objective 2: To explore through in-depth interviews of parents and professionals, where, how and who they get their information from regarding development and future outcomes.

Objective 3: To understand through in-depth interviews of parents and professionals, what kind of support and information regarding support groups have been given and the accessibility of support group at the hospitals and in the community.

Chapter Four: Qualitative Methodology

*“Reaching the parts other
methods cannot reach”
Catherine Pope¹⁰⁸*

4.1. Background

Historically, qualitative methodology has been more commonly used and well-accepted as a study method in the field of sociology and anthropology. There has been resistance in qualitative methodology being recognised in the “hard” science fields and qualitative researchers have been called “journalists” or “soft scientists” and their work described as subjective and unscientific.¹⁰⁹

It is only recently that qualitative research methods have been recognised in medicine and health care research.¹¹⁰ Qualitative research can be described in many ways depending on researchers, but Denzin and Lincoln summarise it below as:

*[1] a commitment to some version of the naturalistic, interpretive approach to its subject matter and [2] an ongoing critique of the politics and methods of postpositivism.*¹⁰⁹

My epistemological position underpinning this study is one of interpretive subjectivism based on real world phenomena and the understanding that the world does not exist independently of our knowledge of it. For this study, I will come from a position of relativism - a view that reality is subjective and differs from person to person. Our realities are mediated by ourselves and without consciousness the world is meaningless. Reality emerges when consciousness engages with objects already pregnant with meaning.

In this chapter, I start by reviewing the advantages and disadvantages of qualitative methodology. This helps me to understand each qualitative method and provide a justification of my study method. Then I outline different types of qualitative methods

through a review of the review. I conclude this chapter by discussing quality assurance and the ethical considerations in qualitative work.

For this review of methodology, I used The DISCOVER (University of Liverpool library portal) and Google Scholar between September 2016 and June 2017. Detail of these databases were described in Chapter 2. I also obtained information from the taught course I attended for my masters at the Liverpool School of Tropical Medicine. I looked for literature in English and full text available which were published between January 1996 to May 2017 using key terms: “qualitative” AND “Methodology AND/OR “advantages” AND/OR “analysis”. The references of literature are also used to find the original articles which some of were dated before 1996.

4.2. Qualitative methodology- advantages and reason of its use

Qualitative methods include;, interviews, focus groups and observations, all which enable the researcher to obtain descriptive data on a situation or behaviour.¹⁰⁸

A qualitative approach allows the researcher to ask open-ended questions and enables participants to express their perspectives and experiences in their own language. This allows the researcher to gain a true reflection of participants’ views on a particular topic in natural rather than in experimental settings.¹⁰⁸ It also enables the researcher to explore the views of participants by using “How”, “What” and “Why” questions in more depth of than the “in the scale of”, “how much” and closed questions which one would use in quantitative research.^{108,111} In qualitative research, an investigator can pick up on the cues or language that participants use during the

interview to achieve more holistic understanding of the participants' views. In addition, qualitative methods (particularly, in-depth interviews), provide an opportunity for interviewees to express different answers each time unlike a structured grading system, questionnaire or survey which provides the same answers to the interviews every time they are asked.¹¹²

Some even say that quantitative studies can reduce many dimensions of clinical experiences and that studies and results can be misled by only measuring numbers.¹¹⁰ Quantitative methods may not always be able to answer the “appropriate and worthwhile” questions in a study as sometimes these are not measurable in numbers.¹¹⁰

As I have outlined in previous chapters, there is limited research that has been conducted on the parent's or professional's perspectives of the current neonatal neurodevelopmental follow up. There are no quantitative scales available to measure this information and none which would enable participants to express or evaluate their experience of different follow up pathways and even different early intervention that they may have received. To enable me to gather the most meaningful information, I have, therefore chosen to use qualitative methods to provide me with the concepts and ideas and material which may be useful in understanding which themes and topics are most important and relevant to parents and professionals in this area of work.

There are different types of research methodologies with different epistemological underpinnings that answer different types of research questions.

A qualitative approach can give strong, important and necessary evidence to health care research.¹¹³ Originally, the Cochrane Collaboration did not include qualitative studies into their reviews because these studies were considered as inappropriate and non-generalisable.¹¹⁴ Jennie Popay argued that despite there being a better and wider recognition of qualitative methods, the absence of standard criteria for qualitative studies means that quantitative methods have often been seen as superior and Randomised Controlled Trials (RCT) as the “gold standard”.¹¹⁵ Her work in 1998 showed that qualitative methods are a rigorous method that should be included in review articles such as systematic reviews.¹¹⁵

Since then, the high impact medically-orientated journals such as the British Medical Journal (BMJ), the New England Journal of Medicine (NEJM), and the Journal of the American Medical Association (JAMA) started publishing qualitative articles.¹¹⁴

4.3. An Overview of Different Methods on Collecting and Generating Data in Qualitative Research

There are many ways to conduct and generate data for a qualitative study. Methods can include; one-to-one interviews, focus groups and observational methods and physical and virtual documentary sources. The right method should be used depending on the type of data that researchers are looking to collect.

In this section, I will outline different types of data collection methods, commonly used in health care research settings. These include; interviews, focus groups, observational methods, the use of documentary sources and questionnaires. I will conclude by justifying why I chose the methods I have for my studies.

4.3.1. Interviews

Interviews are used in much qualitative research in many different fields of study including the social sciences, psychology, anthropology and health care. An interview allows a researcher to direct the interview questions in the way to ensure that key topics are covered and discussed in order to answer the research questions that they are looking to answer. Language problems may become a barrier in qualitative research and this is particularly more difficult in cross-cultural settings where a researcher may not speak the language of those he or she is wanting to interview.¹¹¹

Interviews are usually conducted in a one-to-one or a small group setting. This approach is commonly used in health care research to explore interviewees perspectives on a particular topic.¹¹²

There are different ways which interviews can be conducted. This includes; in-depth, semi-structured or narrative interviews.

An in-depth interview is most appropriate when the researcher wants to explore and understand the interviewee's thoughts and behaviours. This method helps the interviewer to get an in-detail picture of how, what and why things happened in the way it did.¹¹² Moreover, it can provide a more relaxed atmosphere as a comparison to other qualitative methods or quantitative methods. This may help interviewees to be more open about their opinions and feelings on a topic. Some would argue that in-depth interviews can be time-consuming, biased and non-generalizable. It may be biased when an interviewer and/or interviewee is from the same health care system

or area of interest. Moreover, it requires the interviewer to build a good rapport with the interviewee to explore in depth and gain rich data. The interviewer needs to be trained to conduct interviews in the most effective way to ensure there are no leading or closed questions.¹¹²

Semi-structured interviews are used when the research questions are clear, and the researcher knows what questions to ask interviewees. The main question stems are set and probed, but interviewers also have freedoms and flexibility to ask questions depending on the answers.¹¹⁴ The interviewer and interviewee can also diverge from answers to discuss the interviewee perspective in detail.¹¹⁶

A narrative interview is unstructured in comparison to a semi-structured interview which has structures and uses topic guide to facilitate the interview. It asks fewer and more open to questions to help the interviewee tell the story.¹¹¹ Narrative interviews have also been used in health care research where the researcher lets participants talk and discuss their health issues and make decisions.¹⁰⁸

As there is no previous qualitative study conducted purely with parents of at-risk children and professionals who have been taking care of those children to explore their honest opinions and perspectives regarding follow-ups and support system, I considered it was difficult to structure the interviews. I would not have been able to structure or formulate appropriate questions without having a look at previous studies.

I also wanted to have the opportunity of being flexible depending on the situations and interviewees. Therefore, I chose to conduct in-depth interviews.

4.3.2. Group Interviews

Group interviews is a better way of understanding the social interaction and social knowledge relating to a subject, more than one-to-one interviews.¹¹¹

When conducting a group interview, the researcher can observe the social interactions of those groups, who talks the most, who other participants agree with, and who was seen as an important figure. Secondly, this method allows people to express positive as well as negative experiences and opinions. In a one-to-one situation, the interviewee may hesitate and feel threatened to give honest negative views or talk about dissatisfied services especially if the interviewer is from the service provider whereas in a group, they may feel more enabled to be honest about their feelings.¹¹¹

On the other hand, a group can feel intimidating and can sometimes stop participants feeling honest about their feelings.

Group interviews can be useful when the research topic deals with sensitive issues. Jerry Kitzinger, with his research with HIV and AIDs patients actually found that some issues were more readily discussed by participants in a group rather than individually.^{111,117} Due to the nature of having a few different people in a focus group, people could help each other in developing opinions, bringing up the topic, recalling experiences and completing underdeveloped issues.¹¹⁷

There are several ways of conducting a group interview including, consensus panel, focus group, natural group, and community interview.

A consensus panel is useful when making decisions or discussing issues. For example, making clinical protocols, commissioning resources making agenda in clinical settings.¹¹¹ This method targets those with expertise in the field due to the purpose of the method.

A focus group has been used in qualitative research for many years. It was originally used in the field of market research and customer services.¹¹⁸ Since 1970, this method started being utilised in health care settings with similar purposes. This method is usually used to evaluate health educations, health interventions and health care systems.¹¹¹ The group normally consists of 6 to 12 people with a facilitator or researcher and discuss the research topic. The participants may come from different background, and this would ensure the researcher to gather a broad range of ideas and different experiences. One of the biggest advantages of this method is that you could get extensive data in short period.¹¹¹

Traditionally, a focus group consists of people who have not met before. A natural group on the other hand, is a group of people who have usually have met before or who have known each other already before the study. For example, a natural group might be a family and could be used when investigating how disease or illness can affect a family. Interviewing people in the family provide different views and

experiences depending on their roles and how the decisions are made in the family.¹¹¹

4.3.3. Observational methods

Ethnography is known to be the most natural way of obtaining qualitative data and is considered the best way to understand how and why people behave and communicate in a way that they do in particular settings.¹¹¹ Ethnography is an in-depth observational process which requires researchers to live, work or stay together with the participants or in the community for a period of time to understand the culture, beliefs and political system in the community.¹¹⁴ It has been known as a “gold standard” of qualitative research.¹¹¹ This method is useful when a community is what is being analysed and when you are trying to understand a phenomenon within a group of people rather than the experience and perspectives of single individuals.¹¹⁴

Although it is a gold standard research method, it is not appropriate for all qualitative studies due to the amount of time and number of individuals involved. However, some argue that it is important to have a component of observational study in every qualitative study to understand the study population.¹¹¹

For my study, I chose to use some observational methods to add to my other qualitative methodology in the hope that it would provide me with information that I might not get in these other ways. For this purpose, I attended ward rounds in the

NICU, and neonatal and neurodisability follow-up clinics to observe how information was given to parents and management plans were discussed. I have kept research diaries where I wrote down my own experience and interpretation of the situations. This experience helped me formulate the research questions, develop a research design but has provided me with an untold insight that I was unable to gather through my other methodology.

4.3.4. Physical and Virtual Documentary Sources

These research methods are unique from the other methods discussed above in a way that this do not generate primary data and the data is not created by the researcher.¹¹¹ These methods use data that already exists in physical documentary sources such as health records, published literature, diaries or blogs.¹¹¹ For example, diaries and blogs describe personal experiences and opinions and they are readily available online. Similarly, online forums where people disclose their perspectives and experiences on different subjects such as treatments, products and hospitals can also be used to collect data that answer research questions.¹¹¹

As you are not collecting or generating primary data, the time taken to conduct this study can be short and therefore an efficient way of conducting qualitative data.¹¹¹

However, in this methodology, the reliability of data can be variable since the data is generated for different reasons other than of the purpose of the study hence the data may be fragmented, incomplete or not generated in the manner to answer the research question.¹¹⁹

Since there is no existing primary data that could answer my research question, this study method was not considered as suitable for my study.

4.3.5. Questionnaires

A questionnaire helps obtaining qualitative as well as quantitative data. Asking them a closed question or to scale their experiences can produce quantitative study but asking them open ended questions can generate qualitative data.

For my study, I used pre-interview questionnaires. By collecting data from different sources including, in-depth interview and pre-interview questionnaire, which helps triangulate the study. The meaning of triangulation will be discussed in section 4.9.

The questionnaire for the study included questions relating to the child's gestational age, birth weight, types of professionals that they were involved with and so on. You can view this in Appendix D.

It should be clear questionnaires can be less relevant to a study when the writer is not familiar with the context and the background of the study subject.¹²⁰ For this reason, I conducted literature review before I wrote the questionnaire to ensure that all questions which I asked served a specific purpose within my study.

4.3.6. Conclusion

Considering the research questions, research populations and what I am aiming to get out from the in-depth interview seemed most suitable and feasible. I want to keep questions as open as possible so that interviewee could share a lot of information in as much detail as possible. This would also facilitate me to explore interviewees

experiences and needs in more depth and broaden up and give diversity to my data. Moreover, in-depth interview allows uncovering issues that were not originally anticipated by the researchers.¹⁰⁸ Specific sampling method, sampling matrix, inclusion/exclusion criteria for the study are discussed in Chapter 5.

4.4. Sampling in Qualitative Research

In quantitative research, statistical sampling calculations are often made in order to generate correct sample size to test hypotheses. The sample size calculation ensures that the study produces generalizable results.¹²¹

Both probability and non-probability sampling methods can be used in qualitative studies. Probability sampling ensures that everyone in the population has an equal chance to be selected to participate in the study.¹¹¹

On the other hand, purposive sampling, the most common way of sampling in qualitative research, purposively selects a population or representatives of those with certain characteristics or features of interests of the study.¹¹¹ The aim of purposive sampling is to select “information-rich cases for study in depth”.¹²² Patton¹²² lists 16 ways of sampling purposefully. This includes; extreme case sampling, intensity sampling, maximum variation sampling, homogeneous sampling, typical case sampling, stratified purposeful sampling, critical case sampling, snowball or chain sampling, criterion sampling and theory based sampling. Extremely sampling concentrates on special and unique cases to ensure that the study has information-rich sources. Homogeneous sampling means that a small group of

people with certain characteristics are sampled. This sampling method is used to study certain subgroups in depth and is utilised when sampling for focus group discussions. Snowball sampling is a way of sampling purely by asking people whether they know anyone who is suitable to take part in the study. The sample size gets bigger as more people take part and ask others, however the sample size tends to converge towards the end.¹²²

There are two other common methods to sample in qualitative research: convenience sampling and theoretical sampling.¹²¹ Convenience sampling is the least complicated and least time-consuming method compared to purposive and theoretical sampling as the researcher samples individuals according to their convenient accessibility.¹²¹ Because this is not a systematic approach to sampling data, the quality is usually poor and it is difficult to ensure credibility of this data.¹²¹ Theoretical sampling uses grounded theory and it selects a sample in a way that theory can be generated through analysis rather than aiming to represent the population of interest.^{121,123} It samples similarly to purposive sampling as it selects people with particular features. .

For this present study, I have decided to use purposive sampling methods to sample parents of children born prematurely and who have had hypoxic ischaemic encephalopathy (HIE). I also will sample professionals who have been involved in taking care of these children. This approach has enabled me to gain more robust

data than convenience sampling would have done.¹²⁴ Sample sizes, matrices and inclusion and exclusion criteria for participants are discussed in detail below.

For my study, I will use a method which comprises of 7 steps in purposive sampling.¹²⁴ This is outlined in Figure 5.

To undertake this method, first, [1] one decides on research questions, aims and objectives of the study. Next, [2] I considered the type of information to be obtained from the research. So, I considered the aims and objectives of the study carefully.

One of my aims is to understand the present situation, the perceptions, and the views of parents and professionals who look after high-risk infants discharged from the NICU in relation to neurodevelopmental follow-up. [3] Then I decided on the qualities of informants (participants). In my study, I aimed to focus on mothers and fathers, who live in Merseyside, of babies who were born prematurely and/or who have had hypoxic ischaemic encephalopathy. I aimed to interview both mothers and fathers to understand how experiences can be different depending on the sex and the roles in the family. The study area focuses on Merseyside, particularly in three areas; Liverpool, Sefton and Knowsley. [4] I aimed to find the participants with those qualities - I undertook purposive sampling of my populations. It was impractical to randomly sampling the whole community and this was not needed for this study. In order to do so, I talked to the community neonatal nurses who work at the Liverpool Women's Hospital and community physiotherapists who work for Alder Hey Children's Hospital. They were in the best position to identify potential participants that fulfil the inclusion criteria of the study. Sampling method of the study is

discussed further in Chapter 5. [5] As Tongco et al¹²⁴ suggested, I then considered reliability of the study and my competency in assessing data obtained from interviews. Reliability is normally described as dependability and consistency in qualitative research (detailed description in 4.9.). I made sure that my study is consistent by only myself interviewing the participants and analysing the interviews. In this way, the style, depth and the interpretation of interviews would be consistent. The competency of the researcher was not formally assessed. I however, discussed my approach and information I obtained from the interviews to ensure the quality of interviews.

[6] I decided on data gathering and analysis techniques. For my study, the research team and I decided on the group of populations that we were aiming to target and divided into 2 different age groups into 18-34 years old and 35 years and over. I decided to use thematic analysis by utilising NIVO software. I will discuss further in Chapter 5. [7] I used purposive after due consideration of the advantages as well as disadvantages of purposive sampling.

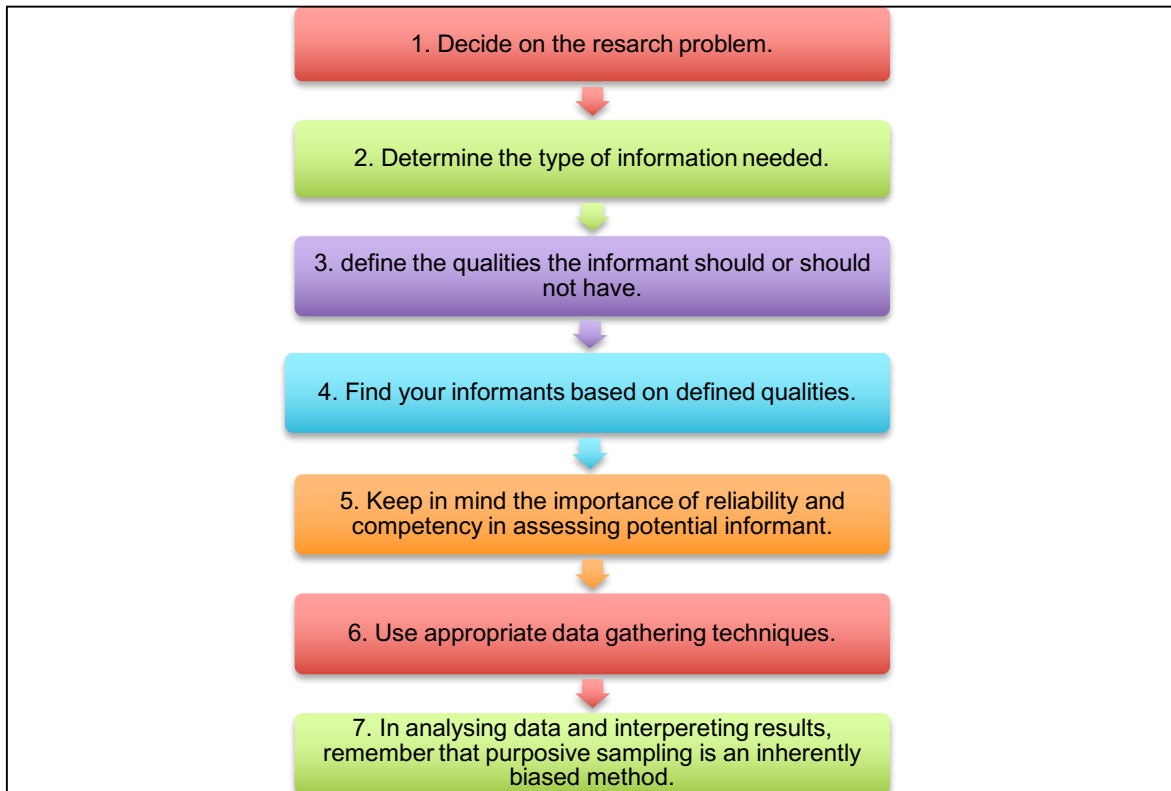


Figure 5: Diagram showing 7 steps of purposive sampling¹²⁴

4.5. Sample Size: sampling to saturation in qualitative work

As discussed in 4.4, in a quantitative study, the sample sizes are calculated to minimise the risk of random sampling errors and ensure that there is enough power and statistical significance to the results.¹²¹ With statistical sampling, a hypothesis is tested, and results are interpreted with numbers.¹¹⁴

There is no standard or rules for selecting a sample size in qualitative research.¹²²

Traditionally, a sample size for qualitative research is small to enable one to extract information rich data, but doing so, the researcher needs to make sure that results reach saturation.¹²³

Moreover, a sample size in qualitative research can be determined during the study. If you gain data which are information rich and relevant to the study questions, the smaller sample size may be required for the study. This concept is called “information power” and can enable a researcher to do a detailed research with just a few participants.¹²⁵ This is different from “theoretical saturation” of qualitative data. Information power are determined by 5 factors suggested by Malterud and colleagues.¹²⁵

- 1) The aim of the study
- 2) Sample specificity
- 3) Use of established theory
- 4) Quality of dialogue
- 5) Analysis strategy

On the other hand, theoretical saturation of the data is achieved when participants are not adding new information and themes are reoccurring in the study. In the qualitative studies, reaching saturation is important to ensure the integrity and validity of the study. There are many factors such as the study design and data collection method that can influence the sample size and the point of saturation.¹²⁶

For my study, I have consider these 5 factors. Broader aims and objectives require larger samples to achieve the information power.¹²⁵ In my study, the aims and objectives of my study are specific (To understand the present situation, the perceptions, and the views of parents and professionals who look after high-risk infants discharged from the NICU in relation to neurodevelopmental follow-up). I

decided to use in-depth approach for the interviews which consisted of open-ended questions. By doing so, the research questions are answered easily hence the sample size for the study is not required to be large. I utilised purposive sampling techniques where I targeted a population with certain features and characteristics (sample specificity). This requires a less extensive sample size in comparison to other sampling techniques. My study has not been conducted before therefore, my target population is holding their experiences and views which are not previously explored and described by other studies. This can enhance information power. Established rapport between the researcher and interviewee in a “strong and clear conversation” (good quality dialogue) can help with the quality of the interviews.

In the case of my study, since I had never conducted qualitative research, a few pilot studies were required to practise my interviewing techniques. I have been trained to take histories and establish rapport (as a medical student) with patients and multidisciplinary professionals, these skills came in useful when establishing rapport with interviewees.

Finally, I am using thematic analysis (analysis strategy) which requires a fewer participants compared with an exploratory analysis or cross-case analysis which require more variation than thematic analysis. Considering these five factors I have produced a sampling matrix to enable me to sample for my study (See Chapter 5).

Before I conclude this section, I need to understand the factors that would limit the sample size in qualitative research. Moor says that the sample sizes tend not to reach saturation and produce incomplete and undetailed data when recruitment

processes are facilitated by hospital staff.¹¹⁴ This may be because staff may recruit people when it is convenient for them.¹²⁴ The researcher is also likely to sample when participants are identified by knowledgeable staff. Tongco¹²⁴ and Harry¹²⁷ describe this situation a type of bias called inherent bias. Inherent bias occurs due to an systematic error of a researcher due to the nature of study environment and it can be a problem as sampling in this way may limit the depth of findings.^{128,129} I tried to minimise this risk by asking several different staff who are involved in different follow-up cares, wards and clinics so that I can ensure the variety of patients and families background (age, sex, and geographical area).

4.6. Topic guides and their purpose

In qualitative work, a topic guide is useful in planning a study. It provides a loose structure of what the researcher wants to cover during the interview.

Generally, a topic guide is more often used in a semi-structured interview than an in-depth interview.¹⁰⁸ In in-depth interviews, a general interview guide will allow interviewers to probe and to make sure answers are kept within the parameter of the aims and objectives of the study.¹³⁰

A topic guide is a list of a small number of open-ended questions with a few prompts which facilitate an interviewer to ask about the topic in detail and allows further discussions between an interviewer and interviewees.¹¹¹

The development of topic guide is an important process in qualitative research and careful preparation is needed to build a topic guide that asks the “right questions”,

but still keeps flexibility in phrasing questions and allows interviewee to lead the conversation.¹¹¹

I developed a topic guide with help from my supervisory team who from their previous experience, had different perspectives, interest, and experiences. I kept this topic guide open ended by using questions such as, “Tell me....” The topic guide was adapted with piloting as some areas worked well and some did not enable enough discussion. My topic guide is shown in Appendix E.

4.7. Recoding and transcription

Writing observational notes, making charts and audiorecording are all types of data collection methods used in qualitative research. Notes can be made during or after the interview but making notes during interviews can interfere with building rapport with participants, disrupt the process of interviewing and may miss body language that participants might show during interviews. Some participants may find it difficult to speak in front of a recorder. Yet, most people agree that audiorecording is the best way of recording interviews and group interviews as it will make sure that the researcher will not miss any information and it will help a researcher analyse verbatim data afterwards.¹¹⁶

For my interviews, I used Dictaphone to record interviews. I also made observational notes and a research diary where I recorded participants’ body language, mood and behaviour and also wrote down my own interpretation of participants perspectives,

views and experiences as I believed this would help me analyse data and write the discussion.

Transcription of interviews help making data accessible.¹¹¹ Although it has been known that this method is very time and resource consuming, all interviews for my study were transcribed verbatim. Transcribing was done by myself, (26 interviews), as well as Faye Moody from Liverpool tropical School of Medicine (3 interviews).

4.8. Methods of Analysing Data

I conducted in-depth (one-to-one) interviews to enable me to answer the research questions and study objectives that I need to for this study. To utilise this data in the best way, I needed to choose an appropriate data analysis method to make my data presentable and ensure that I could answer the research questions.

One analysis method that has risen for use in qualitative research is thematic content analysis. This is one of the most commonly used qualitative analytic methods in health research and is a foundational method of analysis in the qualitative field.^{111,131,132} There are two approaches to generate themes: deductive and inductive.¹¹¹ The deductive approach, it is also referred to theoretical thematic analysis, is used when you are working towards pre-existing framework or preconceptions of the researchers.¹³² An inductive approach on the other hand works oppositely. It starts off from collecting, coding and analysing data and generate themes and theories.¹³² Therefore, it is sometimes possible that themes and theories generated from the data may not answer the research questions fully.

Themes evolve by identifying common patterns that are reoccurring in the interviews and themes are made to ensure that they capture the important data in relation to the research question.¹³² There is no clear standard or agreement as to how the data should be analysed hence, the analysis process is flexible and is dependent on the study.^{132,133}

4.9. Quality assurance: trustworthiness

There are several frameworks or methods which can help to support the trustworthiness of qualitative research.¹³⁴ One model produced by Guba (Table 2) describes 4 criteria which evaluate the trustworthiness of a qualitative study. Since 1990, these criteria have become standard checklists to check the trustworthiness of qualitative studies.¹¹⁴ Here I review 4 criteria for my study.

Quantitative research	Qualitative research
Internal validity	Creditability (True value)
External validity	Transferability (applicability)
Reliability	Dependability (consistency)
Objectivity	Confirmability (neutrality)

Table 4: Guba's constructs describes 4 criteria to evaluate the quality of qualitative research¹³⁴⁻¹³⁷

Creditability

Creditability is also known as “true value”. This assesses how much the researcher is confident about the truthfulness of their studies. Sandelowski said that the study is

credible when for example, people who share the same experiences recognise each other's experiences.¹³⁶

Use of peer debriefing and reviewing can also make a study credible.¹³⁷ For my study, all documents (study proposal, information sheets, consent forms, and topic guides) were per reviewed by the research team, sponsorship committee and some post graduate students. Moreover, information sheets and topic guides for parents were reviewed by the mother who oversees Liverpool Women's Facebook group for parents of premature babies and the Bliss champion who works at Liverpool Women's Hospital. Peer reviewing allowed our work to be reviewed by people with different backgrounds and demographics as well as different cultural perspectives. Secondly, for my study we purposefully selected a variety of individuals in our sample for the one-to-one interviews.

To show "true value" of my study, I selected parents and professionals with wide range of backgrounds which enabled a range of ideas from those who have had some similar experiences (all having had high risk infants born at the LWH). All interviews and discussion were transcribed word for word, which enables truth and accuracy of results. I have only used direct quote from interviews which shows the "true data" rather than any amalgamation of the message.

Triangulation is a way to supplement qualitative research in a way to make it credible, reliable and valid.¹³⁷ Triangulation occurs when multiple methods and multiple

sources of evidence are used to test and compare the results to enable convergence and identification of limitations and weakness of the study.^{108,123}

For my study, I used one-to-one interviews as well as questionnaires and observational notes. For my study, interviews and questionnaires came from 34 people (see table 6 and 7) which helped me to compare different perspectives and ensured the accuracy and creditability of the study.

Transferability

Transferability, also known as applicability, is a method which ensures that the findings are applicable and generalizable in different settings.¹³⁶

Strategies for enabling transferability includes providing a thick or detailed description of methodology and samplings.¹²³ A “thick description” refers to the detailed information and evidence that allow researchers to evaluate patterns and relationships of information and findings which are transferrable to different settings with different people.¹³⁸

I believe this study is transferable and generalizable since the study settings and the inclusion criteria for participants can be found in many secondary or tertiary centres.

Dependability

A study is dependable if the study methods and findings can be replicated with similar population or settings.¹³⁶ The criteria to ensure dependability includes detailed description of the research methods, triangulation, and peer examinations and reviews^{134,136} Through this Chapter and Chapter 5, I describe the research methods

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including; a plan of study, study population, methods of data collection and analysis in order to ensure that someone else in a similar settings could conduct my study accordingly to my study methods.

As with triangulation, different data collection methods ensured triangulation of the study. The study was constantly monitored and reviewed by the supervisory team who gave me constant feedback on my study.

Confirmability

Confirmability refers to the degree to which the results could be confirmed by others and refers to the extent of objectivity of the study. In order for a study to have good confirmability, the results should reflect the participants' perspectives rather than researchers' preference.¹³⁴

Triangulation, practice flexibility, and a detailed description of research methods can ensure the quality of confirmability.¹³⁴ It is hoped that my study is confirmable by providing a detailed description of methods in this chapter as well as Chapter 5. Although I have written topic guides and questionnaires for my study, I kept an open mind when using it and when it felt appropriate, it was altered somewhat. For example, with the professionals that I recruited from Liverpool Women's Hospital and Alder Hey Children's Hospital have different follow-up systems, I adapted questions for those settings. I also found that I needed to probe, ask or promote a topic in a different way depending on the caregiver that I was interviewing. This came with my ability to sense what and where they might go with something and to provide pointers to go in the direction that might give me some answers.

4.10. The role of the researcher

Any study results can be affected by how interviewer sampled the population, interviewed and interpreted data. Objectivity is very important in qualitative research to ensure trustworthiness of the study.

It is important for me to reflect on my role as a researcher in understating this study and the results of this study.

I am originally from Japan and have been studying in the U.K. since year 10 of school. Although I have been living in the U.K for a long time, my ethnicity and cultural background might play a significant role in the study. In comparison to people who have born and raised here, I might have less similarity to the participants in the way that they have grown up, been taught and educated. There might be cultural differences as to how participants interpret certain issues in comparison to the way I do.

As I am from a Japanese culture, the way I ask questions or interact with people might be considered polite but also seen as “too laid back”. This is a very crucial element in qualitative research as you need good rapport to enable participants to answer the research questions in the most useful way.

In order to minimise these affects, topic guides were made and discussed with the supervisory team which includes 3 paediatricians who are raised and trained in the U.K. Moreover, my first pilot interviews were reviewed and discussed in order to enable me to reflect on the way I might engage or ask questions.

I had no experience in qualitative research despite conducting 4 different studies throughout medical school. To being with this may have led to me being fixated to what I had planned to do and may have led to a lack in flexibility. To avoid this, interviews and transcriptions were discussed in detail with the supervisory team who then supported me in feeling confident in how I was conducting interviews. This provided me with confidence and an ability to feel I could become more flexible in how I approached participants as the study continued.

In my study, participants are asked to discuss neonatal and neurodevelopmental follow-ups. Having an interviewer who is from the health care system may prevent participants from feeling relaxed and free to speak and say what they would like to say. However, as I am an intercalating medical student who is not necessarily wedded or attached to one or another of these hospitals, I kept my position neutral. I hope this enabled participant to feel more comfortable to disclose and share positive as well as negative experiences and views about the current follow-up systems.

Chapter Five: Study Methodology

Summary of qualitative methodology

In Chapter 4, I outlined the qualitative methodological approaches to my study including; advantages of its use, an overview of different qualitative methodologies, sampling frameworks and quality reassurance.

For my study, I utilised pre-interview questionnaires and in-depth interviews to enable me to obtain data that would answer my research question. Pre-interview questionnaires were used to gain information on the child's and his/her parents' basic demographics. In-depth interviews were chosen as it enabled me to explore in depth, the participants' perspectives of the current follow-up situation for these families. It also enabled me to explore in more depth, what, how and when parents were told about the long-term prognosis of the child. This study is one of the few studies that purely concentrates on parents' as well as professionals' perspectives in the context of their neurodevelopmental follow-up. Using these approaches, I aimed to keep the interviews as open and flexible as possible.

In this chapter, I will outline the recruitment process, leaflets and forms that I use in the study and the process of interviews.

5.1. Study design

A qualitative study design investigates the present situation, the perceptions and the views of parents and professionals who look after high risk children at Liverpool Women's Hospital and Alder Hey Children's Hospital.

5.2. Sponsorship and Ethical Approval

This study was sponsored by the University of Liverpool. The study and all documents used in the study were approved by the National Research Ethics Service (NRES) Committee West Midlands (IRAS Project ID: 217848, REC reference 17/WM/0016). The protocol, participants' information sheets and consent forms were amended accordingly to the suggestion made by the sponsorship and NRES Committee. Human Research Authority approval was obtained from Ms Gemma Oaks on 17th February 2017.

I also obtained a research passport from the two base hospitals, Liverpool Women's and Alder Hey Children's Hospital which allowed me to conduct my study.

5.3. Recruitment Setting

The study took place in the Liverpool and Sefton areas of Merseyside. Merseyside has a population of 1,391,113. Liverpool has the highest population with 478,580 in the region, and Sefton has a population of 273,707.¹³⁹ (2015 data)

The LWH is a tertiary centre for Obstetrics and Gynaecology which takes care of up to 1,000 neonates every year in their NICU.⁷⁷ The AHCH is also a tertiary centre for

paediatrics which treats over 270,000 children every year.¹⁴⁰ Detailed descriptions of these two hospitals are discussed in 2.5.1.

5.3.1. Recruitment

Recruitment was undertaken at both base hospitals:

I recruited parents for my study from the two base hospitals - Liverpool Women's Hospital (LWH) and the community paediatric and neurodevelopmental follow-up clinics which are linked to Alder Hey Children's Hospital (AHCH).

Liverpool Women's Hospital:

Nurses provided participants who were coming to neonatal follow-up clinic with an information leaflet and provided them with a brief description of the study. LWH Community nurses who were also visiting parents at home provided them with a leaflet and a description of the study. If parents were interested in taking part in the study, they were then contacted me to provide them more information about the study, to answer any questions and to make a time for them to meet with me.

Alder Hey Community clinics:

Community physiotherapists from the AHCH neurodevelopmental follow-up services were provided with information leaflets which they used to introduce the study to parents. Physiotherapists are often referred children who have been born high risk from the LWH to review and support. These were children with some concern about

their development. Participants who provided verbal consent to the physiotherapists for me to contact, I then arranged to meet for an interview.

Professionals

My study was introduced to professionals including doctors, nurses, physiotherapists and occupational therapists, through ward meetings, by leaving posters in the LWH staff room and through emails to all professionals who worked in the NICU as well as in community child health (e.g. neurodisability consultants, oxygen nurses and physiotherapists). Those who were interested, then provided consent to participate and I arranged to contact with them and organised a time and a place for an interview.

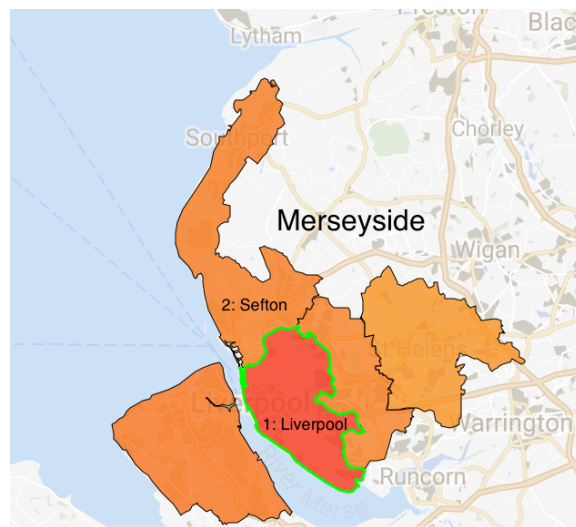


Figure 6: Map of Merseyside. 1: Liverpool; 2: Sefton¹³⁹

5.3.2. Participant information sheets

For this study, I produced two information sheets for both parents and professionals having one-to-one interviews. The participant information sheets outlined the background, purpose and methods of the study and discussed the risks and benefits

of participating in the study. I also provided information regarding the Patient Advisory and Liaison Service (PALS) as a point of call to voice their concerns about the study.

Participants were given more than 24 hours before they consented to the study. Participant information sheets are found in Appendix A.

5.3.3. Posters

I created posters which briefly described the purpose and methods of the study and provided the research team's contact details.

They were displayed in the staff room on the neonatal ward for neonatal nurses and neonatologists to see as well as on the Liverpool Women's Hospital closed premature babies Facebook group.

Posters are found in Appendix B.

5.3.4. Social Media

A mother who oversees the closed Facebook group for parents who have had premature babies born at the LWH and the Bliss champion helped me introduced the study through a group chat on the social media using a poster.

5.3.5. Study population

We recruited two groups of participants for this study:

[1] mothers and fathers of babies who were born prematurely (less than 37 weeks) and babies who have and hypoxic ischaemic encephalopathy.

[2] multidisciplinary professionals including doctors, nurses, allied health professionals who have been involved in follow-up of at risk infants in the Merseyside region.

The decision was made to focus on parents who have children between the ages of 0 and 3 within the Merseyside region, to reflect the current system in this area. We felt that parents of older children might have a different experience of a different system and their reflections might not be suitable for this study.

In order to understand the parents' perspective in depth without having difficulties in communicating, I interviewed only fluent English speakers. I did not include any participants below the age of 18 as they may not be able to consent to the study with full capacity.

The table 3 shows the inclusion, exclusion and withdrawal criteria for the study.

Inclusion criteria

Parents

1. Mothers and fathers who are over 18-years old
2. Mothers and fathers of preterm infants born before 37 weeks
3. Parents of babies who had HIE (total body cooling)
4. Parents of babies who spent time in the NICU
5. Parents of babies living in Merseyside
6. Parents of babies aged between 0 to 3-years old

Healthcare professionals

- Qualified healthcare professionals involved in follow-up of high-risk babies in Merseyside

Exclusion criteria

Parents

1. Parents who cannot speak English fluently
2. Parents of babies who are not at high risk (meaning <37 weeks or with a previous history of HIE)
3. Parents of babies who had congenital malformation
4. Parents unable to consent including those under the age of 18 years

Healthcare professionals

- Participants who cannot speak English fluently
- Participants unable to give consent

Withdrawal criteria

- Participants will be informed that taking part in the study is voluntary and that they can withdraw at any time. Should parents feel uncomfortable for any reason during the interview ~~or focus group~~ and if they do not want to continue or cannot continue, they are able to withdraw from the study. They will be informed that withdrawing from the study will not affect care for their children in any way.
- Professionals will be informed that taking part in the study is voluntary and that they are free to withdraw at any point. It will also be made clear that withdrawing from the study will in no way affect their employment.

Table 5: Inclusion, exclusion, and withdrawal criteria of this study

5.3.6. Sampling

I used a purposive sampling method as outlined in section 4.4 Chapter 4.

In-depth Interview Sample size

The sample size was carefully considered and decided on so that the numbers we aimed to recruit were realistic and sufficient, in other words, to enable the data to be significant, representative, and generalizable, for the study.

Most importantly the sample size was considered to ensure that it reached a point of saturation where participants were not adding new information and that themes were

not reoccurring in the study. In a qualitative study, reaching saturation is important to ensure the integrity and validity of the study. We were aware that the number needed to reach saturation depends on the study design and data collection method.¹²⁶ No formal statistical sampling method was used but we also intuitively, through transcribing and analysing as we went along, decided when saturation was met as the study continued.

We decided to group the cohort into two age groups: 18-35 and over 35. These two age groups were chosen as they may differ in maturity and the younger parents may have different worries and perspectives in comparison to older parents.

Babies mothers' age	18-35		36+		Total
	Mother	Father	Mother	Father	
0-6m	3	1	3	1	8
7-12m	3	1	3	1	8
13m-3yrs	3	1	3	1	8
Total	9	3	9	3	24

Table 6: One-to-one parents interview sampling matrix

Professionals	Hospital where they are based		community (including 3 sites)	Total
	LWH	AH		
Neonatologists	2			2
Neurodisability consultants		2		2

Other healthcare professionals (physiotherapists, occupational therapists, speech and language therapists, neonatal nurses, health visitors and community midwives)	2	2	2	6
Total	4	4	2	10

Table 7: One-to-one professionals interview sampling matrix

5.3.6. Topic guide

Two topic guides, one for parents and one for parents were made for the study to facilitate the interviewer.

[1] Topic guide for parents interviews

The interview questions were divided into three different stages of the follow-up pathway: at the time of discharge, after discharge and the current serveries, either neonatal or neurodevelopmental follow-ups. I aimed to explore their perspectives on current follow-up systems and how and when they received information about neurodevelopment or milestones.

I kept my questions as open as possible. For example, I asked “Can you tell me about the information regarding development (e.g. milestones/ steps for growth) that you were given around the time of discharge?”. Prompts and probes were also used in interviews to make sure interviews covers essential topics to answer the research questions.

Topic guides are attached in Appendix E.

[2] Topic guide for professionals

I asked a total of 13 questions to professionals to explore their perspectives on current neonatal and neurodevelopmental follow-up high-risk babies. I also aimed to understand their views on other follow-up systems in the rest of the country or worldwide that they would like to implement in Liverpool. I also discussed their perspectives on a new follow-up system in the Liverpool and the new NICE guideline on follow-up of premature infants.

As per parents' interviews, I aimed to formulate as many open questions as possible.

For example, "Can you tell me about follow-up of children who are high-risk who have left the Liverpool Women's Hospital?"

Topic guides are attached in Appendix E.

5.4. Interview Settings

The venue of the interviews was carefully selected from two hospitals and community clinics that belong to the hospitals.

Most parents' interviews took place at participants' house where the privacy was guaranteed and where it was quiet and comfortable. We also offered paid Ofsted-inspected nursery nurses or play leaders to be available at either Alder Hey Children's Hospital or the Liverpool Women's Hospital. However, no one asked for this service for this study.

All professionals' interviews took place at participants based hospitals either at the LWH and the AHCH. Professionals chose places for the interviews including their offices and clinic rooms.

All interviews were recorded using the audiorecorder without personal identifiable information such as names and addresses.

5.5. Informed Consent

The participant information leaflets were provided as described above. Every participant was given more than 24 hours before they consented to take part in the study.

Every participant signed three consent forms including; a copy for the institute file, a copy for the case notes and a copy for parents themselves. I ensured that all participants had read and understood the information sheet fully and that they were taking part in the study voluntarily.

5.6. Data analysis

Every interview was recorded on the Dictaphone. I transcribed as I went along with the interviews and began using NVIVO (version 10) whilst interviews were still ongoing. This process allowed me to reflect on my interviewing skills and alter some questions in the topic guide to ensure I could lead participants in the best way possible.

A stepwise approach to thematic content analysis introduced by Braun et al from the University of West England¹³² was used. Here I outline how I analysed the data in each step.

Step 1: familiarizing myself with data

This step includes taking research notes and transcribing.¹³² I started writing a research diary from the time I commenced the interviews to reflect on what kind of questions that I would like to ask further, cues from the interviews and my own interpretations of the interviewee's views and opinions.

Transcribing is an essential process of making verbal information into a written format to enable thematic content analysis.¹³² Most interviews were transcribed by myself however the last 3 in-depth interviews were transcribed by a professional from the Liverpool School of Tropical Medicine due to my personal time constraints.

Step 2: generating initial codes

Transcribed data were then entered to NVIVO and analysed. I then assigned codes for every interview. For example, when the parents or professionals were talking about the follow-up systems that they would want in Liverpool, I coded the sentence as "ideal follow-up". For this study, I did not use any priori coding.

Step 3: searching for themes

To start identifying themes, all data was be collected and coded.¹³² As Braun et al suggested, I wrote down all the codes on papers to visualize clearly which codes

could merge or form groups. This process also allowed me to think about the relationships between themes or codes. There were some codes that did not seem to belong any specific themes.

Step 4: reviewing themes

First, I formed 5 themes: [1] amount of information, [2] referral and management, [3] support systems and the use of social media, [4] capacity of health and related services, and [5] ideas for systems-and support. Some themes were overlapping, and some did not have enough data from parents or professionals to understand or frame. Some key issues were not addressed well with these 5 themes. I then revised the themes 3 times before I decided on the final 5 themes and the subthemes that I provide as results in this study.

Step 5: defining and naming themes

At this point, I needed to be confident and satisfied that the themes are presentable and should be able to be clearly defined in a few sentences.¹³²

During analysis, I came to a list of the most commonly identified themes which related to my original aims and objectives. I then felt that the major themes was answering one of the following final themes and therefore placed them into themes as follows; What, how, who, when and capacity of the health care system. This was for clarity as there was a lot of information and because the data seemed to be answering these five questions.

I was confident that my themes were now presentable. I have been given an opportunity to present my study findings in front of peer review groups and professionals which enabled me to triangulate and also let me feel confident that I could understand and explain each theme well. The final themes emerged from the interviews are: [1] what, [2] how, [3] who, [4] when and [5] capacity of the health care system.

Step6: producing the report

This phase involves final analysis and writing a report with finalized themes.¹³²

Diagrams were also completed to show the relationships between themes.

5.6. Pilot study

Five pilot interviews were conducted to test the recruitment process, topic guide and settings for interviews. Three patients were recruited from the neonatal follow-up clinic at the Liverpool Women's Hospital (LWH). I recruited through the neonatal nurses. I interviewed them after their consultations with the neonatologist. These practices enabled me to make sure that the recruiting process worked efficiently.

Two patients also then agreed to participate from the NICU ward.

This experience was very valuable as I could practise asking questions and I could also ask for feedback on the topic guide and the information sheet. The Bliss Champion also advised me to change a few words on the topic guide as parents may find them difficult to interpret. For example, neurodevelopment or milestones can be a jargon for some parents. Therefore, I used milestones or growth steps instead.

5.7. Ethical considerations

The Chief Investigator obtained approval for this study from the Research Ethics Committee and Health Research Authority (HRA). The study was submitted to each proposed research site for Confirmation of Capacity and Capability. The study was conducted in accordance with the recommendations to physicians involved in research on human subjects adopted by the 18th World Medical Assembly, Helsinki, 1964 and later revisions.

Throughout the study, I made sure I kept autonomy, justice, non-maleficence and beneficence. To respect autonomy, we only interviewed people who signed the consent forms voluntarily. We did not consent those who felt uncomfortable taking part or who did not understand the purpose of the study.

For the study, I made sure that all participants satisfied the inclusion criteria and had the same chance of being selected in the sample and that they were all given the same information.

We also considered the specific risks and ethical issues with qualitative research. Interviewing can include talking about embarrassing or upsetting issues. To minimise these risks, we provided a full explanation about the study and provided information leaflets to parents and professionals about our study. All participants were told that they were free to withdraw from the study at any time. They were also told that they did not need to disclose any information that they did not want to us. We also arranged to have the support of a specialist psychologist who also worked with

parents in the NICU in case there were any parents who needed to talk to someone or who felt distressed after our interviews.

5.8. Data Protection

I preserved the confidentiality of all participants taking part in the study and abided by the Data Protection Act.

I stored the recording of the interviews in a locked cabinet under the care of the Institute of Child Health. All information were also stored and kept in a securely password locked M Drive under the computing service from the University of Liverpool. The information could only be accessed by the chief investigator and the research team. For analysis purposes, any personally identifiable information such as names and address were anonymised immediately at the time of the study hence the participants were not identifiable.

Personal information of participants will not be disclosed to any third party.

To anonymise all participant data, every interview was coded. For example, a code FDNIDI 1 was used for FounDatioN STUDY In-Depth Interview, a code FDNIDIP for FounDatioN STUDY In-Depth Interview for professionals. This also enabled me to quickly identify different participants when analysing the data.

Chapter Six: Results

6.1. Introduction

In this chapter, I will outline the demographics of the study population. I will then present the results within the large themes that have emerged from my data. The themes have fallen to 5 different categories: what, how, who, when, and the capacity of health care system.

6.2. Study period

Data collection was conducted over 4 months with the first day of recruitment beginning the 13th March 2017. All interviews were completed by June 2017.

6.3. In-depth Interviews

A total of 23 parents were recruited from neonatal follow-up clinics, community neonatal nurses and physiotherapists. One father contacted us to take part in the study through a Facebook post.

I interviewed 11 professionals which included community paediatricians, neurodisability consultants, neonatologists, physiotherapists, neonatal nurses and occupational therapists. I could not recruit professionals from community settings such as health visitors, community midwives, and community neonatal nurses due to constraints on NHS Research and Development with the upheaval of Liverpool Community Health at the present time and the time scale of organising recruitment through the Community trust was very challenging in the time I had to complete this degree.

6.4.1. Parents basic demographic information

Table 7 below outlines parents' demographic information.

Baby's age	Babies mothers' age				Total
	18-35		36+		
	Mothers	Fathers	Mothers	Fathers	
0-6m	3	1	2	1	7
7-12m	2	1	0	0	3
13m-3yrs	7	2	4	0	13
Total	12	4	6	1	23

Table 8: Sampling Framework for one-to-one interview with parents

Code	Area	Professionals involved	GA	Age of child at interview	Diagnosis
FDNIDIPREM1 FDNIDIPREF1	L	Neonatologist, GP, and Health visitors	31w	14 weeks	Prematurity
FDNIDIPREM2	S	Respiratory consultant, Health visitors, and Neurodisability team	27w	21 months	Prematurity, Chronic lung disease, CP-possibly, Seizure -waiting for an EEG
FDNIDIPREM3	S	Health visitor, and Neurodisability team	31w	2 Years and half	Prematurity , CP- diagnosed Jan 2017
FDNIDIPREM4	L	Neonatologist, Health visitors, Orthopaedic and Trauma consultant, Audiology, Care coordinator, and Neurodisability team	27w	3 years old	Twin 1- CP, spastic diplegic and prematurity, Twin 2- CP + axial hypotonia and prematurity
FDNIDIPREM5 FDNIDIPREF2	S	Neonatologist, Respiratory team Health visitor, Neurodisability team	29w	14months	Prematurity and Pulmonary sequestration
FDNIDIPREM6	L	Neonatologist, Cardiology, Ophthalmology, Neurodisability team	25w	11 months	Prematurity, Grade 4 IVH, Spontaneous perforation of the bowel- surgical fixed at the AH and nystagmus
FDNIDIPREM7 FDNIDIPREF3	S	Neonatal nurses, Health visitors, Neurodisability team	32w	15 months	Prematurity
FDNIDIPREM8	L	Respiratory consultant , Health visitors, Neurodisability team	28w	2 years 9months	Prematurity, Developmental delay - without diagnosis ?Autism

FDNIDIPREF4	L	Neonatologist, Ophthalmology, Nephrology, Dieticians, Neurodisability team	23w	3 years old	Twin 1- died Twin 2- global developmental delay and sensory function disorder
FDNIDIPREM9	L	Respiratory team Neurosurgeon, Community neonatal nurse, Ophthalmologist Community, Midwife, Health visitors, Neurodisability team	26w	3 years old	Twin 1- prematurity, cerebral palsy Twin 2- prematurity. No other diagnosis
FDNIDIPREM10	L	Community neonatal nurse, Community midwife, Health visitor, Respiratory team, Orthopaedic	31w	11 weeks	Prematurity, Came home with oxygen- Chronic lung disease
FDNIDIPREM11	S	Neonatologist Neurodisability team	26w	17 months	Prematurity.
FDNIDIHIM1 FDNIDIHIF1	L	Neonatologist, Gastroenterologist, Dietician , Respiratory consultant, Ophthalmologist, Audiology, Neurodisability team	38w	22 months	Hypoxic Ischaemic Encephalopathy Spastic quad CP and Global developmental delay
FDNIDIPREM12	S	Neonatologist, Neurosurgical team, Dietician-hospital and community, Ophthalmologist, Health visitor, respiratory team, Neurodisability team, Had surgery before- gastro but no follow up	24w	11 months (almost 12)	Prematurity Suspected CP Morbidity issue- R leg VP shunt
FDNIDIPREM13	L	Community neonatal nurse	30w	11 weeks	Prematurity

FDNIDIPREF5					
FDNIDIPREM14	L	Neonatologist, Cardiologist, Health visitor, Urology-surgery Neurodisability team	28w	2 years old	Twin 1-Prematurity, cerebral, Hernia repair Twin 2- Prematurity
FDNIDIPREM15	L	Health visitor , Community neonatal nurses, Community midwife	33w	6 weeks	Prematurity
FDNIDIPREM16	S	Health Visitor , Community neonatal nurses	28w	11 weeks	Prematurity

Table 9: Parents Basic Demographic Information on parents and their children recruited to the study

(L=Liverpool, S=Sefton, W=weeks, GA=Gestational Age, Neurodisability team- children who had input from community or neurodisability pediatrician, and/or physiotherapists, and/or occupational therapists, and/or speech and language therapists)

Characteristics	Number of participants	Notes
Gender		
Female	17	
Male	6	
Relationship to child		
Mother	17	
Father	6	
Number of children at home		(total number of families in the interview =18)
1	8	
2	8	
3	1	
>4	1	
Total number of children	22 (4 sets of twins)	One diseased
With Diagnosis	13	
No diagnosis	9	
Cerebral Palsy	8	
Other	5 (1 deceased)	

Table 10: Summary of parent's demographic information

Code	Occupation	Site
FDNIDIPDCN1	Neurodevelopmental paediatrics	AHCH
FDNIDIPDCN2	Neurodevelopmental paediatrics	AHCH
FDNIDIPN1	Neonatal nurse	LWH
FDNIDIPN2	Neonatal nurse	LWH
FDNIDIPDN1	Neonatologist	LWH
FDNIDIPDN2	Neonatologist	LWH

FDNIDIPPT1	Physiotherapist	AHCH
FDNIDIPPT2	Physiotherapist	AHCH
FDNIDIPPT3	Physiotherapist	AHCH
FDNIDIPPT4	Physiotherapist	AHCH
FDNIDIPOT1	Occupational therapist	AHCH

Table 11: Professional basic demographic information

6.5. Themes and findings

5 major themes have emerged from the analysis of transcripts from the interviews with parents and professionals. I outline these major themes and the subthemes in Table 11 below:

Major theme	Subthemes
What	<ul style="list-style-type: none"> [1] Focus on Health [2] The Future [3] Information on Support for neurodevelopmental follow-up [4] Reassurance
How	<ul style="list-style-type: none"> [1] Written information [2] Verbal information [3] DVD [4] Parents' education [5] Internet and social media [6] Discharge and clinic letters
Who	<ul style="list-style-type: none"> [1] Who is consistently there and gives quality information [2] Follow-up Clinic Professional services for follow up – who are the most effective or supportive [3] My lead professional

	[4] Who provided me with support
When	[1] In NICU [2] At the time of discharge [3] At Follow-up [4] Around the time of diagnosis
Capacity of health care system	[1] Barriers in capacity of neonatal follow-up clinics [2] Smooth transition to the neurodisability specialist services [3] Other possible systems which could be implemented in Liverpool [4] Capacity in NHS

Table 12: A table outlining the themes and subthemes which emerged from in-depth interviews with parents and professionals on their views on the current neonatal and neurodevelopmental follow-up services in Liverpool

6.6.1. Theme 1- WHAT

In this theme, I outline what kind of information and support children and parents received from the hospitals as well as in the unit and how they perceived them. This theme was merged as participants told me about the contents of information given during NICU stay and follow-ups and different kinds of support services. The theme “WHAT” deemed appropriate to gather the content of each information and service that parents received and professionals offered.

I will present in the order of:

[1] Focus on Health

[2] The Future

[3] Information on Support: Knowing about the Availability of Support

[4] Reassurance

[1] Focus on Health

Although it was not the primary focus of the study (the main focus being to explore what information regarding development parents received), many parents explained to me that much of the information and support they received was regarding general health issues. In this subtheme, I will discuss how parents highlighted to me how they received information and support regarding 3 main health issues: acute illnesses, breathing and feeding. These were commonly brought up by parents and professionals and deemed important as well as difficult for them to deal with. Many parents were very eager to share their experience with me.

A. Focus on the acute illness

Upon discharge, many parents reported that they were told what to do in an emergency (e.g. when to go to the GP, when to call the LWH and when to call for an ambulance).

According to parents, they were not provided with much other information.

Most parents explained that seeing knowledgeable health care professionals in A&E was reassuring. Although waiting times might be very long, one mother described how efficient it was to get examinations and investigations done all at once.

*“we prefer A and E because we get things done quickly in A and E than in the normal ward and they do that check-up and they call someone from the neuro team and they investigate her and send her home. I like A and E because you get things done quickly believe it or not.” FDNIDIPREM12
(mother)*

Parents were not satisfied when professionals did not provide them with an explanation of their management. Parents of a child who had HIE shared their frustration with me in that some professionals only focussed on their child's cerebral palsy rather than the present problem for their child.

"...that one was a big one for me. I always got annoyed when they automatically jumped on that. Brain damage, cerebral palsy, bang bang and bang. He does have that ... you know... there's draw back to that but in this occasion, it is no that. He is not well...he's PEG fed, HIE, he's got cerebral palsy. they just look at that. They don't look at the reason"
FDNIDIHIF1 (father)

B. Breathing

Chronic lung disease is one of the common complications for infants born preterm. I interviewed some parents who had babies who were discharged home with oxygen. All these families described how the education sessions delivered by the oxygen nurse on the ward at the LWH, the follow-up visits and the support from an oxygen nurse from the AHCH were reassuring.

On the other hand, these specific children, had a much less straightforward follow up pathway. Considering the fact that these children are also at high-risk of neurodevelopmental difficulties, infants with CLD are followed-up by respiratory paediatricians at the AHCH rather than the neonatal team at the LWH. Some parents described to me how they felt as though the LWH had cut short their relationship and how they felt almost isolated until the day of respiratory follow-up at the AHCH.

“it wasn’t like we weren’t supported but it was just like the person came once (from the LWH) and we were just sort of left in the community. I know we had the oxygen nurse and stuff for support but I just feel like a bit like that once wasn’t it? And that was it. because how early he was, he was dying, erm... so we just thought they would’ve continued a bit longer rather than just once visit. I know they’ve got other people to see and stuff.” FDNIDIPREM5 (mother)

These parents made it clear that they wanted at least some transitional care between discharge from the LWH and their follow up at the AHCH. Moreover, parents reported that follow-up visits by the oxygen nurse were infrequent and insufficient. A few parents described how they felt left-alone with their infant when they had concerns about breathing and feeding.

C. Feeding

One mother described how she was expressing 10 times a day on the unit because she felt that it was the only job that she could do for her twins. She described that she was worked-up emotionally and physically and she described herself as “obsessed” with expressing breastmilk. She described how supportive the breastfeeding team at the LWH was.

“The midwife... massaged my breast for 45 minutes. And then she’s got health care assistant to come and massaged another one... they were fantastic.” FDNIDIPREM9 (mother)

Some parents described how they found specific issues with weaning difficult and that the information they were given was confusing and not consistent between professionals;

“... To be honest, we didn’t feel well supported because he was so early and he was so behind. We were sort of learning as we went along. Probably meant to be telling us thing. For example, we were advised to wean at 4 and half months old and he was about this big and flopping everywhere and so he would have been putting off food then. We just decided to go against that advice. We just decided with our own prospective, being mum and dad.” FDNIPREMF2 (father)

[2] The Future

This subtheme presents the information discussed between parents and professionals in regards to long-term prognosis and what to expect in terms of child’s neurodevelopment in the future.

A. Parents’ understanding of the long-term prognosis

Some parents described how they felt depressed and unhelpful when they were told that their child may not be able to walk or talk. Some parents on the other hand, explained how being provided with information could prepare them for the worst circumstances. One parent described to me the difficulties in being provided with a poor prognosis from quite early on. He described how negative this was and how little this provided for the family in terms of looking at the strengths that their child had.

“it is hard of course, you are told he probably wouldn’t walk, wouldn’t talk, probably wouldn’t it. Even if you are just faced with that bang bang bang... all at once, you would just fall apart. But if we come down the line 2 years of X, he isn’t walking, he is not talking and he

doesn't eat but he smiles and he laughs and he doesn't stop smiling and laughing so interactive and he tries his best with everything. He is dead sociable. I think if we were told more along that side. Just the grey... you are not just given well they could do this not ... not the case of probably they wouldn't do that." FDNIDIHIM1 (father)

It was clear from my interviews, that what parents understood in terms of the risks and future prognosis for their babies varied considerably. It also seemed to depend upon the severity of babies' condition. For example, parents who had a baby who had suffered from an intraventricular haemorrhage were told about future prognosis by the consultant on the unit.

"he (neonatologist) gave us a very open ended long term scope for X. But had to be open ended, based on the fact that her age, based on the fact that they never know brain bleeds, that was like our formal chat." FDNIDIPREM6 (mother)

Most parents, on the other hand, told me that they were not aware of what the long-term outlook was for their baby. They also did not recall having a conversation about milestones and neurodevelopment with professionals.

Many parents described that they were concerned when they faced in knowing where their child was with their development. A particular worry was knowing whether the child was not meeting the milestones because of developmental delay or disabilities or due to the fact that he/she was born early and still "catching up".

"Because we were worried that he had disability, the reason he is not rolling over or because he has disability, I don't know it could be developmental or learning or what we weren't prepared for the slow

development in anyway.” FDNIDIPREM5 (mother)

One mother told me that her child was having a delay in his speech but that she had not been aware as to what the normal milestones were and that she had not noticed the delay.

“...to be honest I didn’t know he need it when he wasn’t talking. No... I don’t know whether it sounds stupid but to me, it did. I didn’t know.”

FDNIDIPREM8 (mother)

Another mother described to me how her previous knowledge had helped her. She had had her first child born prematurely. From her previous experience, she described how she was able to understand her baby’s development and take care of her baby more easily. She also suggested that professionals should discuss milestones and long-term prognoses more.

“Obviously being the second time premy mum it was little bit easier ...I don’t think you were fully prepared for developmental delay... I am obviously second time around experience in it. But I think that should be an area that should be discussed a little bit more. And just gone in to a little bit more because this I think all babies are different and some babies hit their milestones like normal full term babies but they are a lot of them who aren’t going to sit up at the right time or be ready to be weaned at the right time, crawl, walk, smile, laugh...In that more information with regard to that, just through neonatal stay really, would be beneficial and stop a lot of anxiety when you get home.”

FDNIDIPREM10(mother)

B. Realistic approach by professionals

Some parents who had antenatal complications such as premature rupture of membranes, told me that they were given opportunities to go around the unit and speak to NICU staff to familiarise themselves with the NICU environment and prepare themselves. Parents reported how helpful it was to be told in advance what to expect in terms of the future for their baby.

“when they brought a DVD over to the mat base to me, and I was explained about the NICU before I had them. erm... even the person came over early and went through everything from blindness, deafness and lung problems, everything he went through. Which was good. Obviously scary and worrying but he did go through everything. I need steroids, if they were born at this gestation, and this gestation we get to pass this one. You know it is better to go through like that. It was good.” FDNIDIPREM14 (mother)

Parents appreciated this realistic and honest approach so that they could prepare themselves.

“... he did tell us what we should know but he was negative and I didn't want to see him again. Whereas other doctors would be probably overly positive. Not giving me the full understanding... it will be fine, it will be fine... whereas Dr X came out, he said he is not fine because of this, this is cerebral palsy. that brain damage leads to this...” FDNIDIHIF1 (father)

“SPOT team for not so long and they've given us so much feedback and they kept it real. They said this is either going to happen or this isn't going to happen but I'm prepared and it helps so much” FDNIDIPREM12 (mother)

One professional described the balance that has to be played by professionals who are providing this information;

“...I think it is a fine balance that I think if they continue what they are looking, they feel like they need tick boxes and that can impact on their enjoyment of their child...” FDNIDIPDN2 (professional)

The balance between enabling parents to enjoy a baby that they have waited for so long, and providing them with the stark reality of what might or might not be to come, is hard. For some, the focus on those precious first moments together rather than worries about future prognosis may be important. Clearly, any referrals or interventions done at these very early stages need to consider this very carefully.

C. Keeping Hopes

The balance for both parents and professionals to be both hopeful and realistic in some very difficult situations can be difficult. They want to have a hope yet, both parents and professionals were aware that they both need to communicate the reality of the child's development.

A father described:

“you don't want to give false hope it is really hard, isn't it? You need to be realistic but you've got to have some hope.” FDNIDIPREM4 (father)

One of the mothers described how the fact that her child survived was such a miracle, that she could only continue to hope for the best.

“Because throughout my pregnancy, I was told that he had 1% survival.

So, it's so I think now, I don't really like, I just hope for the best really. You know what I mean. That way. I hope for the best outcome. I'm trying not to get myself worried too much. Trying to enjoy everything up to now."

FDNIDIPREM2 (mother)

For some parents, keeping hopes might have helped them to get more engaged with follow-ups and physiotherapies and also helped with maternal health in a way that they could keep being positive in a course of challenging journey.

D. False hope

It emerged from my interviews that some parents feel frustrated when they are told that their children are ok at the time of discharge but then later their child develops problems such as cerebral palsy. Some parents described how they would have rather been told about the possibility of encountering developmental problems "at the time of discharge" rather than having to wait for a confirmation scan or an assessment. Parents often trust professionals as they believe that professionals are experts in caring at-risk children. However, some parents reflected that some information have been too hopeful (e.g. being told that the child will be ok). Thinking retrospectively, they think that they were given a false hope. They would have wanted to know a realistic prognosis so that they did not need to hope for the future outcomes that may not come true. These events have made parents not to trust professionals.

"Don't tear me up for it is going to be amazing and he is going to be absolutely fine when we don't know at that point. So, it was misleading and ashamed really... it does, I felt like our experience when we were discharged was so, so positive." FDNIDIPREM3 (mother)

E. Uncertainty

Although parents reported that they were told much information regarding breathing, feeding and handling and that they were given admission and discharge information leaflet packs, many parents told me that they still had uncertainty, worries and questions as to what to do at home. My interviews included a few parents who were health care professionals. Those mothers' experiences highlighted the fact that professionals should not overestimate how much parents know even if they are healthcare professionals.

“Because she was premature erm and so actually even after coming home, we still had some uncertainty and I guess that’s even though I have got limited paediatric experience that’s me as a doctor not being sure what to do with her if she has a temperature and so...”

FDNIDIPREM15 (mother)

Many parents reported that they expected professionals to know and predict everything that may happen in the future. Signs and symptoms of a child can keep changing which makes it difficult to make a diagnosis at an early stage.

“I just feel very much they (professionals) just don’t know as much as we don’t know.” FDNIDIHIM1 (father)

[3] Experience of Support: Knowing about the Availability of Support

This subtheme describes the barriers and facilitators to gaining information and support on neurodevelopment and what kind of support services were offered to parents by the hospitals and in the community.

A. Information about Support

One parent told me that she did not know how to seek help from professionals and that little information had been offered routinely from the NICU or from the GP about what to do if she had concerns. She felt that she had suffered alone with her child with global developmental delay. She did not know that she could call the GP to organise a visit by the health visitors.

“if I had known that... that was there were all these different people who could help me I would have done... I would have been glad... I would have tried to ring them... but because I didn't know there is anything like that, I was trying to do it on my own” FDNIDIPREM8

She also suggested that:

“yeah... just... let mums know that there is help available. If they do need it... that they know they could phone him... and go to this person and go to kind of... because I felt like I was completely alone. It is not out there. Let me know... let me know... I could... could... could ask for help and there was people out there that could help me. I didn't know... I didn't have a clue” FDNIDIPREM8 (mother)

B. What Kind of Support Did Parents Get or Did Not Get?

Parents often described the neonatal nurses as providing valuable support. They were described as “approachable, kind and professional”, taking time to answer any questions, talking to parents and giving hugs when necessary. It emerged that parents felt well supported by them whilst in the NICU. Community neonatal follow-up continued until 6 weeks post discharge. Some parents described how having these nurses coming out in the community from day one after discharge was

very reassuring. Some parents said that they wished it could have continued for longer.

“FDNIDIPREM13: ...We were supported and most people we came across were very approachable. (mother)

FDNIDIPREF5: like if we had any issues whilst we were at the hospital we felt that we could easily approach you know the sister there or anybody (father)

FDNIDIPREM13: the matron

FDNIDIPREF5: the matron or anybody. We felt that that network is good you know. In terms of being able to review or problems we had, someone would always do their best to try and answer your questions as soon as they could. You don't feel like you were dismissed.”

Having a baby is a joyful moment, yet very challenging for many parents especially when their child is born prematurely or born with complications.

Many parents described the journey in the NICU as an emotional roller-coaster. They explained that many professionals did not focus on the well-being of parents. Many mothers said that they had sought counselling and had been referred to counselling through a number of different avenues including; fertility services at the LWH, GPs and health visitors. Many agreed that it would have been nice to be offered counselling automatically or some time to talk to someone in private about themselves whilst they were with their baby on the ward.

“I ended up being referred for counselling... Because I think it is quite traumatic... it is possibly a too bigger word but it is a shock. You know... you are not expecting. We had him via IVF. The IVF clinic

offered counselling. So, it was so surprised that it was not offered here...” FDNIDIPREM1 (mother)

One of the mothers told me how useful the “what’s app” group that her and her friends on the unit had created was. The mother described how this enabled an exchange of information regarding growth, feeding and even nurseries for their babies.

*“We met when we were expressing milk. So we just go in there and we just have a cry and we just have a laugh and talk about everything that was happening and everything happening this morning and that happened to my baby last week and this is what they did and it was just amazing support. As much as your friends and family support you and love you and be there for you, they don’t know, they don’t know what’s going on day to day. Whereas these mums knew what the beep sound on the machines and the cares and the routines and apnoea and desats and all that. We knew about all the machines...”
FDNIDIPREM9 (mother)*

Some parents were interested in community support groups for parents of children born premature. However, parents felt that these community support groups mainly based in children centres tended to focus on term-babies where parents have completely different experiences and issues.

One physiotherapist described how important regular input from specific community support groups could be and how it could fill in gaps between appointments by the professionals.

“... I know again through experience if there was something support group sat up, even for couple of weeks or couple of months to give you just a chance like dropping in session where you could go back. Not necessarily to the women’s but all meet somewhere and it is just a

chance for you to meet with other mums and there's different support groups tons of support groups from the community. But a lot of the time, can't go because he is on oxygen because it is for full term babies and there's a risk for infection picking things up. To be around other prem baby mums from the community that would be very beneficial and that support would be... just would be very valuable really." FDNIDIPREM10 (mother)

[4] Reassurance

Hearing reassuring words from professionals at follow-up visits was perceived as very important and reassuring for many parents. Most parents wanted to get reassurance on the growth and neurodevelopment of their baby e.g. whether their baby was smiling, walking and talking. Ultimately, parents wanted to gain confirmation that the child was ok and that they were doing the right thing. Some parents expressed an uncertainty as to whether their child was meeting milestones particularly when they looked after their child every day and therefore sometimes it was more difficult for them to see changes.

A few parents told me that they sought reassurance from online sources such as the parents' forum or the Facebook group.

"I was always reading up in terms of his development because he was premature and I wanted to do everything that sort of also reassured myself that everything he was doing was normal." FDNIDIPREM6 (mother)

6.6.2. Theme 2- HOW

Parents described different ways of gaining information regarding development, growth and early stimulations. There were also many ways in which professionals utilised to communicate important information with parents and their child. The theme “HOW” gathered different tools that have been used by both parents and professionals.

I will present in the order of:

[1] Written information

[2] Verbal information

[3] DVDs

[4] Parental education programmes

[5] Internet and social media

[1] Written information

Sometimes written information was a preferred way of providing or receiving information. Most parents told me that they found written information helpful as they could read it in their own time, take it back home and refer to it if they had any questions.

“Having them in the leaflet form that we could take home and we can go back to it as reference guide for when you were at home. Because there were so many things happening at home. It’s good to have that information.” FDNIDIPREM10 (mother)

Every parent was given an admission pack and discharge pack which covered essential information such as breastfeeding, safe sleeping and meningitis. However, there was no information regarding milestones, long-term development or future prognosis. Not knowing about the future left some parents uncertain and worried. They expressed that it would have been beneficial to receive more information about development prior to discharge. They also said that it would not have frightened them but may have enabled them to be more ready to accept the slow development of their child. Some suggested that teaching sessions regarding child development and what to look out for would have been useful.

“FDNIDIPREF2 (father): we’ve got a lot of leaflets but

FDNIDIPREM5 (mother): but this is our first baby and having a premature baby, it is a bit like we didn’t know like... why he wasn’t rolling, why he hasn’t been rolling over, and if we had been prepared, we wouldn’t have been this upset by these slow progresses. But we did like the resuscitation, oxygen and they showed how to do vitamins.”

It seemed that professionals tried to cover everything by providing many leaflets, but equally, this was perceived as excessive by some parents. What they wanted is information that was tailored to their individual need which then was supported by leaflets.

“And it is still in the box haha... so I think... I think the written stuff is always helpful but equally... It has a tendency to give too much”

FDNIDIPREM1 (mother)

[2] Verbal Information

Most parents told me that they had discussed their child's condition, scan results and signs of acute illness with a neonatologist, verbally on the ward as well as in follow-up care.

Parents reported that they preferred face-to-face communication because they felt they could take in the information better when it was explained in person.

On the other hand, many parents found it difficult to retain information when they were communicated to verbally without any leaflets.

"... I would have liked someone sit down and tell me. But then at least for leaflets... It's always there. If I have ever... like I still have them all now. If I ever need to go back to them I can always go read them. I have them with all the hospital reports when he left. So, it's always there. So, it is good to have them..." FDNIDIPREM2(mother)

Professionals were also cautious about how much information was communicated in one setting.

"I think it is a lot to be said about verbal communication but backed up something written, and a lot of times..." FDNIDIPDN2 (professional)

"I do both. So, I would give them verbal information on the home visits. Sometimes I send the families some information and tell them have you tried this bath for example a little booklet on bath. If the child is very much using their extension, we need to promote flexion I would suggest things like that. And I would then perhaps send them information by email or erm... post information, it is parental preference." FDNIDIPOT1 (professional)

One of the professionals working in the community mentioned that some parents had gone home from a doctor's follow-up appointment confused as the doctor had used new terminologies that they were not familiar with.

"We often find that the family will come back to us we went to this appointment and they told me this but we didn't understand what that meant. Because they don't understand that terminology at all. So, we do a lot of explaining for them" FDNIDIPPT4 (professional)

[3] DVDs

Cardiopulmonary resuscitation (CRP) training is mandatory before parents leave the NICU at the LWH. This session is delivered by trained neonatal nurses or through a DVD that parents can watch on their own. Most parents reported that they found it useful to learn CPR. Parents who only got taught by a DVD wished that they could also have had a teaching session from the nurses and did not feel it was fair to just be taught by a DVD.

[4] Parental education programmes

Health care professionals and charities such as Tommy's organise various antenatal classes at hospitals and children centres. Some parents mentioned in the interviews that they could only go to a few classes as their labour started earlier than expected. They suggested that antenatal classes should start earlier in the so that parents could have better understanding of what to expect when they experience the signs of labour (e.g. membrane rupture).

Being taught how to clean, dress, feed and handle their own baby by the neonatal nurses on the unit reduced parents' anxiety. Parents told me they felt more confident in caring their babies and more included in the babies' care on the unit.

"I think they were focused on making us confident enough to take him home." FDNIDIPREM1 (mother)

Children's centres offer many parents' education/ training sessions including baby massage, breastfeeding and weaning, however many parents found it difficult to find any sessions focused on premature babies.

Many parents expressed the desire for education on child development. It emerged that they would prefer receiving this type of information from professionals. Some suggested that these education sessions could be held while babies are still inpatients or after discharge.

"even just during parents' education, just like an information sheet, erm... all around neonatal loads and loads of information that tells you like what baby should be doing, if they were born between 26 and 28 weeks it tells you what you can expect up to full term. If baby was born between 32 and 34 weeks what can you expect and things like that. In terms of actual development even just like during the parents' education towards discharge..." FDNIDIPREM10 (mother)

[5] Internet and social media

A. Internet

Almost every parent I spoke to had had an experience of searching online. Many parents wanted to avoid untrustworthy and frightening information and many used

websites such as “NHS choice, Tommy’s and BLISS” which they found useful, informative and reliable.

Some parents told me that they had had some terrifying experiences online; *“Google tells you the worst thing”* FDNIDIPREM2 (mother). Some parents used more specific sites if they had the knowledge. For example, one father (who by profession is a researcher), even utilised PubMed;

“as supposed to let’s say the use of Wikipedia to diagnose something it is bit more like I would use things like PubMed if I wanted to look for something specific, so certainly in terms of PDA and treatment for that that was pretty much it. Erm... the NHS have their own webpage about all these things a lot of them are very good starting point but if I want to go deeper I would go into the literatures.” FDNIDIPREF4 (father)

Some parents specifically described how they used Google to search for conditions or to look for information. Parents were often quite negative about the internet describing how “anyone could put information on the internet” but how much of this might not be reliable. Sometimes this could interfere with their own hopes.

“Because a lot of the other websites were just, just not the parents want to see. Yeah... yeah... when you are trying to have a hope. Maybe a formal, this is the potentials possibly, possibly something that would stop me from googling. Maybe I googled anyway, I don’t know.” FDNIDIPREM6 (mother)

As much as parents wanted to avoid searching online, sometimes insufficient information was communicated during consultations. One parent told me that the

term “cerebral palsy” had been mentioned to them but that no leaflets or further information had been given. These parents could not help but search online for information to support their concerns.

“no we only done that by looking up online (to gain information regarding development) ... Just NHS websites and forums that mums write on. They didn’t give much information really.” FDNIDIPREM11 (mother)

B. Social media

Many parents were members of different Facebook groups. A Facebook group for premature babies was frequently mentioned by parents throughout the interviews, but other groups mentioned included those specific for children with; hemiplegia, HIE, and periventricular leukomalacia.

Some parents found it really helpful to read about other parent’s experiences as they could relate easily and felt reassured.

“... car seat with X, because of his reflux and stiffness in his hips, he just screamed and screamed for the first year. I couldn’t put him in the pram until he was about 1 because he would just have screamed in the pram. You literally couldn’t put him down. So literally we went on the Facebook group and yeah... that happened to us. You can swear by it would stop at one day that screaming every evening that would stop when he got to 6 months and having that reassurance you know, it would get better, it would get easier. Erm... so yeah...” FDNIDIHIM1(mother)

For many, this kind of media enabled parents to share experiences and situations.

“there is one mum posted who’s child got the same condition as X and

it was actually overwhelming because when you are in the situation, you feel like you are the only ones with that situation and that's quite nice to know that there is someone out there with the baby with the same problems and we are not the only ones" FDNIDIPREM12 (mother)

Some parents found it useful to use Facebook however many wished they could get same amount of information from professionals.

"Everything. Everything I know, I've got it through there. Everything. It's just amazing... But, should you really be getting that information from private group? It should come from medical experts..." FDNIDIPREM4 (mother)

Views on using social media and online resources were varied. Some people did not want to know about the "worst case scenarios" that they might find online for other children with the same condition.

"I didn't read the blogs on brain bleeds because I just found it very scary so I did not read the blogs just everything just seems to be worst case scenario. So, I just stopped because it wasn't doing many favours" FDNIDIPREM6 (mother)

[6] Discharge and Clinic Letters

It was clear from my interviews that the discharge and clinic letters can be used as important communication tools between professionals as well as parents. There are both facilitators and barriers to using these as a good source of information. On one hand, information was not helpful if sent to the wrong place. One parent told me how the discharge letter on her child was sent to the previously registered GP. Therefore, FOUNDATION Study. Ayuko Komoriyama

when the child fell ill, the GP was not aware of the child's background. Despite this, even when letters are sent appropriately to the right place, one parent complained that the GP did not read the discharge letter, so the family was required to repeat the history at every single visit.

One mother complained how some information in discharge letters were never discussed and that she had spotted a few errors.

"I think there were things that...we didn't get told because when we got the discharge letter...we went home with it but hadn't read it before we left and actually when I read through it there were things in it we haven't talked about prior to discharge so there was about an examination that something had been picked up on her examination that has required her to have an appointment at Alder Hey in a few weeks' time. But that wasn't mentioned, explained before we left."

FDNIDIPREM15 (mother)

A mother mentioned how useful it was in other hospitals where a professional went through the discharge summary so that parents could ask questions or make corrections when necessary. Being copied in to clinic letters meant that parents could be able to read through them which could be useful and reassuring. Parents reported that they liked the way that some clinic letters provided the whole assessment in the letter. Parents could then review the assessment that was conducted during and also look at the plans (e.g. referrals) provided in this written format. Some parents complained however, that this information could take about 6 to 8 weeks for letters to arrive.

Many parents described to me that they found it helpful to have both written and verbal information when professionals describe about the general health issues (e.g. feeding), risks, and short and long-term outcomes. This combination of information allowed them to consolidate and remember the information. Having a written information in hand helped many parents to provide source that they could refer back to. It was seen in the interview that parents wanted to get detailed information. When they were explained in detail, they were more likely to be satisfied with the information and the care provided by the professionals. Similarly, when they were not explained in-depth, they were dissatisfied with the quality of information and the clinic time. A few physiotherapists mentioned that some parents needed to clarify the information from the doctors with physiotherapists to understand fully. Many parents shared their negative experiences with having to communicate the same things (e.g. child's background and current situations)

consistency of information (discussed further in theme "WHO"), and constant update and discussion, that affected how parents and professionals perceived the quality of information as good. This is represented in the diagram below (figure 8).

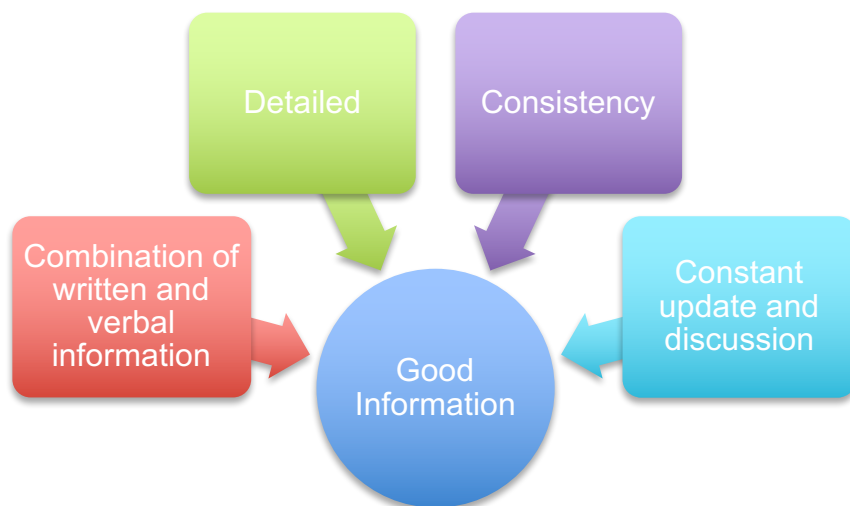


Figure 7: Diagram showing factors that make information a "good information".

6.6.3. Theme 3- WHO

Both parents and professionals identified different specialists who were actively involved with follow-up and support services. The theme "WHO" explores how different professionals were involved in these situations and describes the facilitators and barriers of who provided parents with information and support in the hospital and community.

I will present in the order of:

- [1] Who is consistently there and gives quality information
- [2] Follow-up Clinic Professional services for follow up – who are the most effective or supportive
- [3] My lead professional
- [4] Who provided me with support

[1] Who is consistently there and gives quality information:

In this subtheme, I describe the enablers to who provide good support and information on subjects pertinent to the neurodevelopmental follow up of children, such as; feeding, neurodevelopment and physiotherapy. Interwoven into this theme I will explore the importance of the quality and consistency of this information. I will also discuss the issues which emerged relating to referral pathways for parents and professionals. Having no standardised referral pathways resulted in inconsistency of referral and screening processes. This was one of the major barrier for supporting high-risk children.

Almost every parent told me that their child had had follow-up visits from health visitors. Many parents described how they found these visits really beneficial as health visitors provided a lot of information regarding feeding, sleeping and health issues like reflux. Parents told me that they also felt well-supported when health visitors provided parents with their phone numbers. Parents could ask questions whenever and health visitors made extra follow-up appointments when they felt it was necessary.

“Health visitor has seen me and she continued to see me and she’s very lovely when I asked her she gave a lot of stuff. Can I have some information on weaning and she gave me the government guideline packs, can I have information, because we went to bottle feeding, and she gave me that. She was very good when I asked. Can I have something formal, she has given me loads of stuff. She has been very good.” FDNIDIPREM6 (mother)

On the other hand, some parents felt that their health visitor was not knowledgeable about the specifics of babies born prematurely. Hence, they could not

provide information at the level required by parents or answer parents' questions or concerns appropriately (discussed in WHAT).

According to a number of parents who had children with some difficulties, physiotherapists were the main sources of information regarding other therapies such as sensory classes or hydrotherapy.

".. introduced to us through physios... and they would point us through to the direction to hydrotherapy... they would obviously have wanted to tell us about the rebound therapy as well... little taster trial thing... as I said knowing that it's there ...physio has told us about it. It always has been very much you decide you know they can give us all the information about it... and the benefits have fallen and things like that. If we want to do it, it was very easy for us to get arrange it... to get him into classes" FDNIDIPREF4 (father)

Physiotherapists were also seen as very knowledgeable about support services, nurseries and schools in the community. They also were reported as providing information about support groups and Facebook groups for mothers who were unaware of those groups or reluctant to make connections with other parents.

"I have recently joined a Facebook group erm with mums with Alder Hey that was because Physiotherapist and Health visitor pushed me to do it. Because I tend not to venture out with people and babies so it has been I don't know how to put it without sounding better in our situation but it made me realise that she could have been a lot worse than she is already and the situation could be a lot worse going by other families." FDNIDIPREM12 (mother)

Consistency between Professionals

Consistency of information is very important to parents. Parents told me that one of the barriers to them gaining information was the rotation of doctors on the NICU. It meant that it was harder to form a relationship with one doctor and therefore to feel the confidence to ask questions. One mother told me that being under the same breastfeeding consultant at the LWH was incredibly helpful in enabling consistency enabling her to build up a good relationship and not need to explain things over and over.

Some mothers were frustrated, upset and disappointed by the quality of handover and consistency of the care.

“...every day we went in and the message was changing and things were changing...” FDNIDIPREM15 (mother)

In terms of follow up care in the community, many parents explained how they had benefited immensely from the consistent support of multidisciplinary teams. At these clinics, parents see the same professionals who work closely with the families at home and within the nursery environments until the child is 3 years old. This allows a strong relationship and a place for parents to ask questions or raise concerns. Visits by professionals to nursery nurses was also enunciated as important to support the child appropriately for his needs (e.g. how he needs to sit on the floor for his spasticity in his legs) in this environment.

It was clear from the interviews with parents and professionals that unclear referral pathways and inconsistency in screening processes was a major barrier for supporting high-risk children. In some cases, high-risk children first developed worrying signs and symptoms before they were referred to community paediatrics by GPs, health visitors or neonatologists. Sometimes referral pathways came through physiotherapy. Some professionals mentioned that some children might not be referred until they were 18 to 24 months and that this might depend on the threshold for referral by different practitioners.

“I had a child who was two who obviously had a cerebral palsy but he wasn’t referred until the age of 2” FDNIDIPPT1 (professional)

[2] Follow-up Clinic Professional services for follow up – who are the most effective or supportive

In this subtheme, I will describe the facilitators and barriers relating to the support that present professionals involved in follow up in a range of settings provide.

A. Community Follow-up (Community midwives, community neonatal nurses and Health visitors)

Community midwives were seen to provide good support to many of the mothers I interviewed, particularly with breastfeeding. Many mothers told me that they had had regular follow-up for the first few weeks. However, some parents felt that midwives were not very knowledgeable about premature babies and they had limited

understanding of the difficulties faced by mothers of premature babies in breastfeeding.

For many parents, the first encounter that parents had with receiving information on developmental milestones was when the community neonatal nurses visited for the first time after discharge. They provided parents information of how premature babies' milestones can be different from term-babies. However, within my sample, this service seemed to be inconsistent within Liverpool and Sefton. A few parents had no awareness of the community neonatal nurses.

“I thought it was really good especially the community paediatric nurse coming to discharge and knowing that when we came home that somebody would be coming out the following day made me feel like much less anxious about that transition” FDNIDIPREM15 (mother)

Most parents had positive views on the follow-up by health visitors. They were described by some as being “by parents’ sides” whenever parents needed help (e.g. get a referral to a counsellor). Out of the mothers who mentioned health visitors, most were satisfied with the frequency of visits and felt comfortable calling them whenever they needed advice or had worries about their child’s health. Parents were specifically pleased with routine vaccinations being provided by health visitors at the house as it meant that they could avoid taking the baby to the GP where they were at risk of catching infections.

B. Neonatal Follow-up Clinics:

Most parents found the neonatal follow-up clinics reassuring and felt “listened to”. Parents felt that neonatologists understood the course of their journey and parents found that comforting.

“The clinic I like the clinic because it has given me reassurance...”

FDNIDIPREM5 (mother)

As it has been mentioned above, some neonatologists gave false reassurance and false hope to many parents. Some of the parents of children who had ended up having a neurodisability were less satisfied in retrospect with the neonatal follow-up clinic. Some enunciated that they felt as though the neonatologists neglected signs of developmental delay and withheld treatments that could have been provided earlier.

“It was just after care I am annoyed with. Obviously leaving Y for 16 months, 14-16 months I think it was, not knowing that he might have cerebral palsy, I think it is disgusting.” FDNIDIPREM14 (mother)

There was also a lack of awareness of the purposes and reasons for neonatal follow-up clinic between parents. Follow-up information was not provided before discharge or in the invitation letter to the clinic.

“Some of the parents come in say, I don’t even know why they are coming in...” FDNIDIPN1 (professional)

C. Specialist Respiratory Follow-up at AHCH

A respiratory consultant-led team at AHCH follows up all children who went home with oxygen. These children no longer have a neonatal follow up appointment. A

community oxygen nurse visits these children regularly to check these children's respiratory function.

Many parents described to me that the respiratory follow-up at the hospital was "brilliant" but that at the same time, they felt that the community oxygen nurse follow-up was stopped abruptly when oxygen was no longer required. Parents wanted further follow-up for reassurance.

D. Community/ Neurodisability team follow-up

Most children who present with developmental delay are referred to a community paediatric doctor. Many parents described this referral process and shift to services through the children's hospital as a hurdle in their follow-up pathway. Parents describe variable waiting times depending on the pathway that children started on – sometimes waiting as long as 9 months. Furthermore, parents complained of the lack of consistency of doctors that they saw which was distressing because they needed to explain their traumatic and challenging experiences repeatedly. Some parents found the lack of multidisciplinary team working really difficult.

"He saw him twice now. And he asked me whether he has seen any speech and language. And he has never had an appointment. And he said he apologise because he should have been referred..."

FDNIDIPREM8 (mother)

Community paediatricians assessed neurodevelopment as well as general health. Parents were reassured by having appointments with these paediatricians as they felt as if the child was getting a "full MOT". Some parents found community paediatric

appointments overwhelming as they conducted a very thorough developmental assessment and sometimes mentioned potential diagnoses without warning.

“paediatricians scared me because I didn’t know. When ... I was just watching me weirdly ... The doctors and last month, the paediatrician said we are looking out for autism. I stood... I just ... no one told me that... I have never heard it and it was just shock to the system ... Because you don’t get told things as well... like I have always been told he will be fine, by the time he starts school. If anyone could have told me that he could have autism I could get my head around that and dealt with that. It was only last month that I found that out. I was like looking at him look he is doing this ...he’s so clever... look at him doing this and no...” FDNIDIPREM8 (mother)

Some specialist neurodisability doctors made it clear that referring earlier to their services might prevent complications in the longer term. They felt that they were in a better place for following-up high-risk children particularly due to their close working with support systems in the community.

*“there is no criticism to anyone but its more about you pick them up quite late and some of them have already developed changes with their posture tone and they have not been seen by physios, so that like you already missed six to nine months of care for this child”
FDNIDIPDCN2 (professional)*

[3] My Lead Professional

Many parents felt that having one person with which they felt was leading their child’s care was incredibly helpful. Too many leaders felt confusing. Some parents identified their neonatologists as the lead professional. As neonatologists started the journey

with parents together from birth, parents were pleased to see these familiar faces at follow-up clinics. Some parents felt that this good relationship we built up on the unit meant that the neonatologists were able to understand parents' needs and enabled that really important continuity of care.

"I like (neonatologist) sort of has a helicopter view and able to then access physio, ophthalmology and community paediatricians. I like that she's seen in the clinic." FDNIDIPREM6 (mother)

Other parents identified their physiotherapists as their lead professional as they were often the most proactive person in the team. Many parents also mentioned that the physiotherapists provided a realistic and holistic approach to a child's care who also provided sufficient information on developmental delay and cerebral palsy. Moreover, they also have helped parents to get appointments at the AHCH and have played a role as a bridge of communication between the community paediatric team and parents.

[4] Who provided me with support

This subtheme describes who provided support to parents and who acted as a key person in supporting in the different settings (e.g. on the ward, during follow-ups and on social media).

A. NICU ward team

Every parent spends considerable amount of time worrying and thinking about their children's progress. Many parents relished the fact that they were able to see their child anytime in the NICU. Most parents had good relationships with neonatal nurses

who played crucial roles in providing information, updating on progression, and educating parents about bathing, changing and handling. Many parents respected these nurses who were always welcoming, approachable and considerate especially when parents were going through very difficult situations. Some parents have also taken back their children to NICU ward to see the professionals who cared for them.

B. Professionals in the Community

Parents told me that they saw neonatal nurses, midwives, and health visitors all in the community. Parents felt that professionals varied in their awareness of the management of infants born premature with some GPs being very empathetic (fitting in appointments as an emergency as needed) but others were more resistant to prescribing specifics for premature infants such as ready-made formula milk. A few parents reported that some health visitors, GPs and practice nurses were not used to or trained to take care of premature children. This made parents anxious as they were not sure who else they could ask if the professionals did not know.

“it is a bit worrying when you know the medical practice, they are asking you the question... you look to them for reassurance and advise. Not to be unsure. Not for them to ask you question.”

FDNIDIPREM13 (mother)

C. Support groups

There are many support groups and charity groups. As discussed above, many mothers of premature babies felt that support groups in the community were focused

only on term-babies. Parents of infants born with hypoxic ischaemic encephalopathy (HIE) however, had a different opinion that there was a lot of support and awareness of prematurity at the hospital as well as in the community but there was a lack of support specifically for HIE.

“With HIE mums always say to me. It is all for premmy, everything is focused on premature babies. It’s like they were kind of forgotten about... not unwelcome but like we were out of place ...Things like that. I don’t think there is a lot of awareness anywhere. Erm... for instance, last year, it was very first year, we did HIE awareness month.”

FDNIDIHIM1(mother)

Figure 9 describes the factors that deemed very important for parents to maintain a good relationship with professionals. When parents received detailed information (e.g. feeding, what to expect in the future, how parents should do physiotherapy at home) at appropriate time, parents were more likely to be satisfied with information and follow-ups. Many parents were very satisfied with the care by the community physiotherapy team as there kept the continuity of care. Both a child and a family were able to build up a good relationship with their physiotherapist and they could to discuss parents’ concerns (e.g. hospital appointments) and questions (e.g. nurseries) apart from physiotherapy. On the other hand, some parents were very disappointed when there was no continuity of care especially between different group of professionals or ward. Some professionals rotate every day and some have different management pathways and parents were the victims of receiving inconsistent information. Parents seemed to have a good relationship with those professional that provided parents with sufficient support both physically and

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mentally. As described above, parents appreciated an honest and realistic approach in communicating short-term and long-term prognosis. It deemed to have affected how parents perceived the quality of care and how much parents trusted and bonded with professionals at the hospitals and in the community.



Figure 7: Diagram showing the factors that affect parent-professional relationship

5.6.4. Theme 4- WHEN

Within a journey of follow-up, a child and family experience difficulties and pleasures at different times. Through interviews, I identified 4 key periods when important events happened to the family or the professional. This theme also describes the facilitators and barriers perceived by parents and professionals as to when professionals discussed future prognosis and when they provided support to parents.

I will present the results in the order of:

[1] In NICU

[2] Around the time of discharge

[3] Around the time of diagnosis

[1] In the NICU

A. Isolation

Many parents described how they experienced a lonely and isolating time at the NICU from time to time. There were times, parents told me, when they preferred to be alone to think and digest what they had been told by the professionals. It emerged from my interviews that the time in NICU was tougher and more isolating for single parents. Clearly, support from friends and family have a huge impact on parental mental health.

“I would come in and I would see the mum and dad around everyone all the babies’ incubators and I would be there on my own and I would go and sit in the toilet and go and cry to myself” FDNIDIPREM16 (mother)

Most parents had a close relationship with their parents and received a lot of support from them during NICU stay and after discharge. However, some family members hesitated to come into the unit. Some parents also prevented many friends and relatives visiting as they were cautious about the infection risks. In these situations, nurses provided massive support to parents who needed a cry and a chat.

“when I was upset the nurses... always be like are you alright can I do anything” FDNIDIPREM16 (mother)

Many parents told me about the loneliness they experienced when they went home from the unit. Many parents had got used to having people around all the time so parenting alone during the day once home, was a shock. Trying to deal with problems and anxiety alone made some parents have panic attacks. Some parents

told me that they did not receive follow-up for the first 6 weeks. This was perceived very isolating.

“it wasn’t like we weren’t supported but it was just like the person came once and we were just sort of left in the community.”
FDNIDIPREM5 (mother)

B. Psychological support

Most mothers (by the fact that they had had a premature infant) had pregnancies which had come to closure unexpectedly early. A few mothers told me that they had suffered from post-traumatic stress disorders, panic attack and anxiety as a result.

“I nearly lost a baby then I had to go.. I had to go and see.. a group for anxiety and everything because apparently I had PTSD. Well... I don’t know. I just felt like I don’t know... everything...my head fell off kind of, don’t know how to explain it kind of things.” FDNIDIPREM8 (mother)

Some mothers told me that at the 8-week check, only sometimes was their mental health asked about. Often mothers reported that they were still suffering from anxiety, post-natal depression or post-traumatic stress disorder unchecked. Some mothers told me that mental health problems were not something that went away a few months after discharge, but that often they were still having difficulties a long time after this. Often by this time, follow-up, hospital appointments and many of the child’s health issues had calmed down and some mothers told me, they finally had time to themselves to reflect on what they had gone through. At present, there is no specific service that focusses on maternal mental health for this group of parents, particularly after the initial six weeks.

“about 8 months old, I started to get really upset about thing, things have calm down with the boys and Y was weaning off the oxygen and things were getting bit easier and some more settled and coping well with the boys and I think just started to have bit of time to reflect on what we have been through.” FDNIDIPREM8 (mother)

[2] Around the time of discharge

Many of the doctors' goals and aims were to make babies stronger and healthier for discharge. They particularly focused on establishing feeds and therefore, the weights of the babies. Parents described discharge processes as ad hoc. Professionals provided leaflets and asked parents to sign forms around the time of discharge, but some parents felt that there was no formalised discharge process. Many parents were so thankful for what the professionals had done to save their children and they were also so happy to be going home, that they did not question this in any way. The admission and discharge information packs given to every single parent from NICU at LWH were reported by parents to be very informative although when specifically asked, it was clear that they did not contain any information on neurodevelopment. There were a few babies that transferred to the AHCH for further interventions (e.g. ventriculo-peritoneal shunts). Parents of these infants did not go through standard discharge processes and received no discharge information from the unit. Parents found this inadequate and voiced the fact that they had wanted to get more information and support at the time of discharge.

“I know some people go home with oxygen. May be X needed the hands on supports like that like I just said the community nurse will visit me after a few days and that was it. I think little bit more support I

just the nurses themselves said we don't usually send babies home from here. They usual go back to the women's. Maybe that's why I had slightly different experience as well. I don't really know what support I would have wanted I think it was ok, bye bye now. Maybe a little bit of transition possibly. Especially first time being parents. Being first time parents of the baby who's sick possibly little bit more"
FDNIDIPREM6 (mother)

[3] Around the time of diagnosis

A. Before the time of diagnosis

As it has already been discussed above, parents were worried when they noticed developmental delays or differences in movements such as tightness in the leg.

Some parents needed to wait up to 2 years to get their child's diagnosis.

Many parents of children who later were given a diagnosis of a neurodevelopmental condition said that they wished that they had been told about the possibility of developing these conditions and about the specific conditions much earlier on.

"I do also think, if you are given too much information, at the time when actually nobody knows what is going to plan out. It could potentially spoil your enjoyments of the baby and you would be looking for something that aren't there... you would be paranoid and worried, stressed about so I felt like one side I thought that was a problem that was stressful enough so at least I had a few months of enjoyment." FDNIDIPREM3 (mother)

B. Getting a diagnosis

Parental satisfaction of how the diagnosis and prognosis were communicated seemed to be associated with the certainty of the diagnosis when provided to parents. Moreover, when professionals talked in an empathetic and supportive manner or when parents and professionals had built a good relationship, parents seemed to have received the information better and felt comfortable raising concerns. On the other hand, parents were dissatisfied how the information were given when paediatricians were not empathetic or presumed that the problem has already been communicated other professionals.

It is hard to know the family background fully and what happens in parents' life every day, professionals assess parents' state of mind before communicate serious issues.

“And he said to me like... when he explained to me... because I didn't get upset...he said “I don't think you are taking all in...understanding what I'm saying?” I lost my step-dad 2 days before I had X.”
FDNIDIPREM2 (mother)

A mother described that she was very shocked when her child was diagnosed with cerebral palsy. She told me that she then found it difficult when her child was compared with other children and it was explained that her child was not so severe as others.

“Physiotherapist X at the time said, you know, I think she was trying to say “compared to some of the children that she is dealing with its nothing”. But to us is everything at the moment and I kind of head off in the appointment and I said don't say it's nothing because it's something to us, this is huge we are never really expecting it. And so almost like although I expected all the way through that ... something in me that

hoped that it is going to be fine. And it wasn't I was a bit ok... so... don't try to say it is nothing. For us its nothing. For us is still major. It will still impact his life. So erm...yeah... it's emotions run high it's the thing really." FDNIDIPREM3 (mother)

It is clear that sometimes the diagnosis is not easy to make and that this can be confusing both for parents and for professionals.

"I think there are two ways of looking at that. Sometimes children might be getting the label of cerebral palsy when they haven't got cerebral palsy. you know when others may have cerebral palsy and the doctors haven't said...that they have because they are not sure." FDNIDIPPT1 (professional)

A mother described her experience when she received her son's diagnosis.

"whole getting the diagnosis, it took away the pressure. And having cerebral palsy isn't something to be ashamed of." FDNIDIPREM4 (mother)

Most parents worried about the possibility of their child having a condition. Being uncertain about the causes of certain movement difficulties or delays in neurodevelopment can cause significant stress to parents. Therefore, getting a diagnosis can sometimes relieve the pressure off parents and it helps focus on the management (e.g. physiotherapy to prevent a child from suffering complications such as contractures or postural abnormalities).

C. Predicting diagnosis and prognosis

Cerebral ultrasound scans are done from very early on in the NICU and due to the fact that they sometimes can be helpful in prognosis and diagnosis, were quite FOUNDATION Study. Ayuko Komoriyama

emotive to some families. This is particularly the case when considering that sensitivity and specificity of these cerebral USS can be limited. This is not always clear for parents. Some mothers told me that they were told that their child's cerebral ultrasound scan was clear but that this false reassurance was distressing when a child then later ended up with a diagnosis (e.g. cerebral palsy). MRI scans are often not done in the U.K. until a child reaches the age of 2 years due to better clarity on myelination patterns on the scan at this age. This, again, means that parents have to wait and can lead to distress.

“yeah I think they should have really checked his brain scan. Well they did brain scans so because they told me when I was in neonatal unit they did so. I want to know why it wasn't picked up. If he has got cyst on it, on his brain, like the doctor said, I know nothing can be done with it but why wasn't cyst picked up on scans earlier on. He could have been having physio from day 1.” FDNIDIPREM14 (mother)

One mother told me about the difficulties that she faced in not getting a diagnosis until the age of 2. Many parents of children who actually had had a diagnosis of cerebral palsy or autism expressed their anger at the process of diagnosis. They told me of their regret in not having had an earlier diagnosis or at least a discussion about these conditions by the professionals. A mother conducted her own research and compared the system between the U.K. and the U.S.

“I know probably one hospital in the U.K. but in America, while the children and baby is in neonatal, young age, they do MRI scans to see if there is any brain damage or if there is PVL. If it would've been done when boys were still in there we would have got the PVL diagnosis. We had to wait until 2 to get that diagnosis or 2 and half. That means

first 2 and half years of their life kept worrying, when they walk, when they walk... is it cerebral palsy? or is it not cerebral palsy? is it developmental delay? Or is it not developmental delay? Because we didn't, we didn't know. It would have just changed a lot for us we would have been prepared. We wouldn't have spent first two years of life constantly worrying what is going wrong" FDNIDIPREM4 (mother)

Professionals, on the other hand, expressed the lack of clarity that comes with investigations particularly when investigations such as MRI are done before the age of 2 when the brain is still developing. Some argued that parents' expectations of the scan results tended to be high particularly when the pros and cons of investigations had not been fully explained to parents.

"at this point if you can explain why we have to do it at 2 years that will be the way to go" FDNIDIPDCN2 (professional)

It seemed that scan results were also important for physiotherapists to enable them to plan the most appropriate programmes.

"So, they haven't got any scans and it makes it very difficult from that point of view... what we can continue to do we know it is the best ... sometimes they have been told something wrong..." FDNIDIPPT3 (professional)

Diagram below (figure 10) summarises the parents' perspectives of information and support given at different stages of follow-ups that emerged from the interviews. The bubbles above describe what made parents satisfied with the information and follow-ups and bubbles below describe what made parents frustrated and disappointed about the care they received at the hospitals and in the community.

Upon discharge, most parents received a discharge pack which included some information regarding acute illness (e.g. meningitis) and some were told where to call in acute settings (e.g ward 6, A and E or 999). Parents found these information useful and helpful however, they were not fully satisfied as they did not received much information regarding neurodevelopment and milestones in high-risk children. A lack of or inappropriately hopeful information were perceived as “bad experience” by many parents.

Infants who stayed in NICU were all followed-up by the community nurses until the age of 6 weeks and who satisfied the criteria are followed-up by neonatologist at the LWH and parents were found these clinics reassuring.

From whilst infants were in patient in the NICU, some parents were actively involved in peer support groups on social medias where parents can read someone else’s experiences and gained information (e.g. growth, early stimulations, and support groups). Although, some parents described that reading someone else’s post was somewhat disturbing and worrying, some found it very useful and informative.

Most parents appreciated consistent care by the community team such as health visitors and physiotherapists whereas a lack of consistency was perceived negatively by most parents and this seemed to have affected anytime in their developmental follow-up journey.

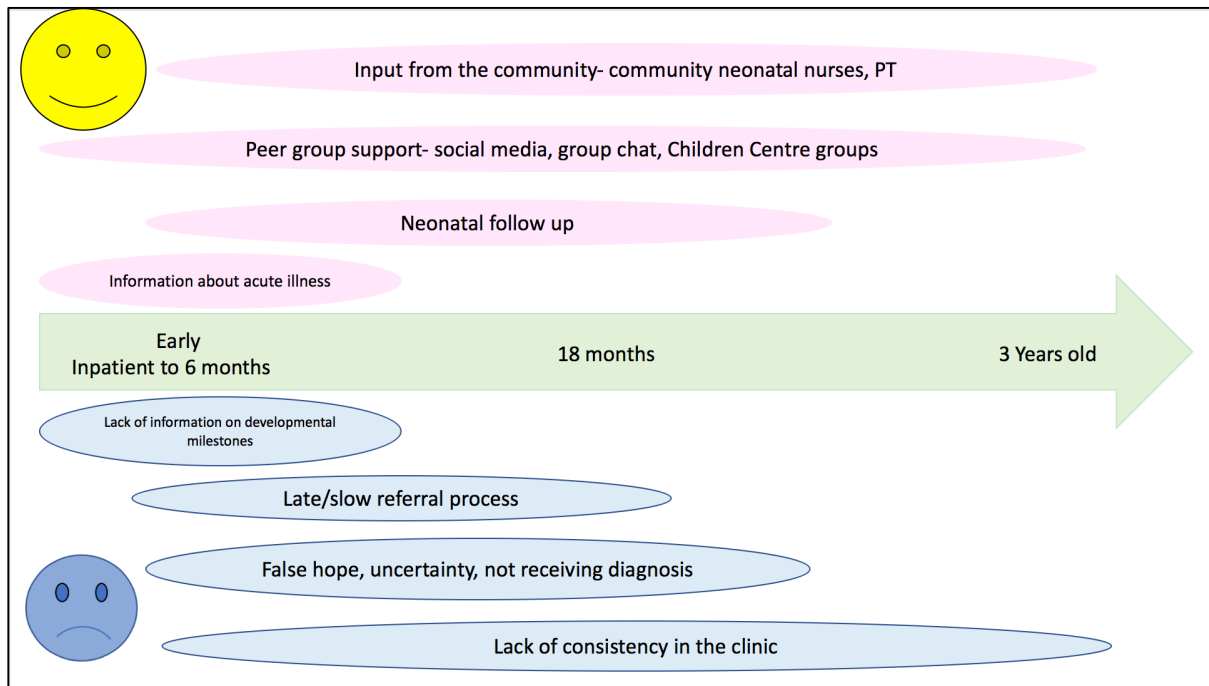


Figure 8: A diagram shows the summary of parents' perspectives- what made them satisfied or happy with the care and what made them unsatisfied with the care.

6.6.5. Theme 5- Capacity and its effect on neurodevelopmental follow up

Many parents and professionals described how waiting time, the availability of the resources such as time and money, and accessibility of follow-up and support services affected their experiences of current follow-up and support service negatively. This theme describes parents' and professionals' perspectives on the capacity of individual hospital and the NHS to support good neurodevelopmental follow up of high risk children.

I will present the results in the order of:

- [1] Barriers in capacity of neonatal follow-up clinics
- [2] Capacity of the neurodisability specialist services
- [3] Other possible systems which could be implemented in Liverpool
- [4] Capacity in NHS

Figure 11 describes 5 factors perceived to have acted as barriers in making improvement in the current neonatal and neurodevelopmental follow-ups which as a result, affected the quality of follow-up services in Liverpool.

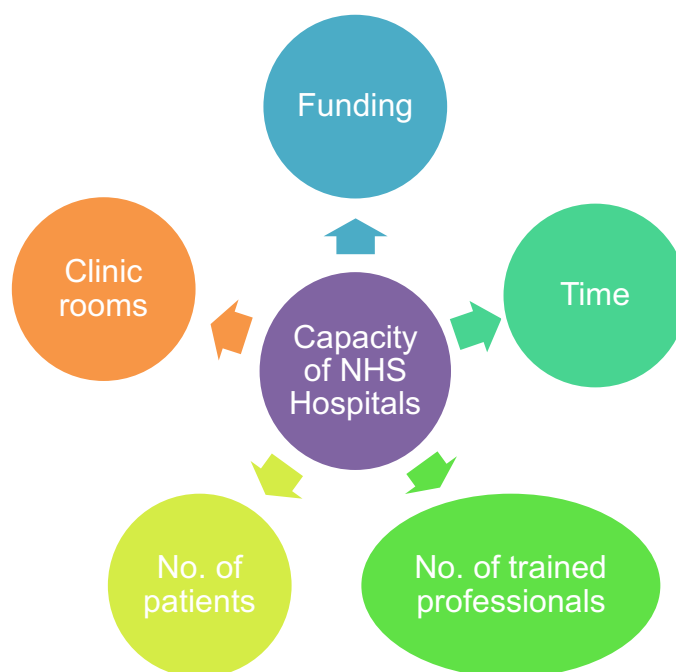


Figure 9: Diagram summarising factors risen from the interviews that affect the capacity of follow-up services.

[1] Barriers in capacity of neonatal follow-up clinics

It emerged from the interviews with parents and professionals that no formal developmental assessment tool was used during neonatologist-led follow-up clinics.

Neonatologists explained the reason as follow:

“I don’t think we have enough clinic now to do formal developmental assessment in the follow-up.” FDNIDIPDN1 (professional)

As mentioned above, there were many professionals and parents who had concerns about the delay in referrals.

Normally, neonatologist need to check general health of a child and assess development in a 10-minutes consultation. Therefore, they do not have enough time to use standardised assessment tools to assess child's neurodevelopment. Moreover, neonatologist may be satisfied with how they have been assessing high-risk children currently and they do not see a point of using the assessment tool if they have not been missed any at-risk children who needed specialists input early. It may also be that they feel responsible for caring high-risk children who spend a lot of time with them in the NICU.

"it may not add much to the management of your child as such, do we miss any of those milder categories, it is hard to say... we might do. Because we are not doing the formal assessment, I think... I would like to think that we don't miss any significant developmental delay. Mild ones we might miss but even if we detect those milder ones, what would we do with them, I'm not entirely sure." FDNIDIPDN1 (Professional)

Some neonatologist described that they are not confident that neurodisability or community paediatrics team will be able to meet patients need as they are experiencing huge demand the waiting lists are very long. Therefore, they are concerned what happens to those identified high-risk children while they are waiting for an appointment.

"... I am just aware that those resources are quite limited I want to have quite reason to refer them not just passing on the problem. I just hope there is something to offer. The one I found most difficult is the speech therapy. Because understanding when the best time to intervene is..." FDNIDIPDN2 (Professional)

[2] Capacity of the neurodisability specialist service

Clearly the parents felt that long waiting times were detrimental to young infants. A week may mean more to an infant than to an adult in a way that in a week, infant may be able to grow heavier and taller, learn new skills, and become more sociable (smile, bubble, talk and interact with others). If these infants were to miss these crucial developmental windows, professionals also miss the window to support neurodevelopment of a child by stimulating movements or correcting postures.

“...I think with little babies, especially with premature babies, like a window of development time, for the waiting list in that window, it’s just frustrating as a parent, they’ve got a little window for the development. 3 months is a long time in babies’ development. FDNIDIPREM6 (professional)

One professional felt that community paediatricians (who also have better links to speech and language therapy) were more equipped to manage neurodevelopmental follow up, and if linkages or follow up were possible from early on, parents would have better support.

“it is children that I was concerned in terms of whether they have got competent swallow? A lot of parents have concerns that their child is aspirating. Erm... and ... it’s very concerning that they haven’t got a paediatrician... waiting long time for a paediatrician ... probably end up coming into the A and E for chest infections but we haven’t got a clear pathway to refer those children. We have those concerns that. I have tried referring them directly to the speech therapists but they don’t accept our referrals.” FDNIDIPOT1 (professional)

As discussed already, many interviewees felt that there was no uniformity in the referral pathways from neonatal follow-up systems. The neurodisability consultants felt that they would like to receive referrals earlier but partially blamed the financial limitations (which then limit clinic time and resource) for preventing better pathways.

“... I think with the current scenario and with the lack of resources I don't think that's feasible what would, ideally what I would want is on the discharge planning meeting that's when we should be involved and get to know the kid and then we do a joint clinic with the neonatologists and then we see that it is a smooth transition and also for the parents there is a person who they have known for some time”
FDNIDIPDC2 (professional)

If hospitals or the NHS realise the importance of following-up high-risk children, they may be able to provide more money which may serve the needs of parents and children. As mentioned above, the new NICE guideline will be published in August 2017 and this may help professionals from receiving more money to hold more clinics and longer clinics.

“...to the local commissionable who holds the pots of money, and say this is what NICE says but this is what you need to do so they have much more stronger case to demand what children need.”
FDNIDIPDN2 (professional)

[3] Other systems

A few professionals wished they had a Child Development Centre (CDC) in Liverpool. They explained to me how a CDC would change the current management pathways

for high-risk children and for those with disabilities. Some felt that a multidisciplinary team who could work in the same building would avoid some of the current problems.

“I think Liverpool is unusual. I worked in different areas. I have worked in London, I worked in Birmingham and Liverpool is unusual... because we have got tertiary centre, we have got women’s hospital which is separate and I have not got a child developmental centre as a whole professional working... I think some sort of hub that all the paediatricians, speech therapists and OT, physio as minimum. I think key workers as well I think is very important but I think some people bought into the children centre model whereas other people didn’t... and ended up with this fragmented model where families are in the middle.” FDNIDIPOT1 (professional)

[4] Capacity of NHS

From the interviews, it was evident that not every family were able to see the neonatal nurses and community midwives which also means that they received less support and information than other parents who have had input from those professionals. Although the NHS supposed to be equal and fair, participants perceived that there are local funding and commissioning issues which prevent this. One of the neonatologists summed this up.

“No, but I think it is the nature of the NHS. It is very much like a postcode lottery and different commissioners fund differently so I wish I could provide all the babies with same care but it’s not something that within our grasp.” FDNIDIPDN2 (professional)

6.6.6. Conclusion

In this chapter I have summarised my results which I have extracted into 5 main themes which include; 1) What information and support was found useful, helpful and necessary, 2) what facilitates How parents receive information, support and follow up, 3) Who best provides this information and 4) When it is best provided. Finally, 5) the capacity of services within the NHS was intimately related to many of the issues discussed but was placed in its own separate theme.

First theme, WHAT described how the focus of neonatologist and parents were about the health issues in the short-term, how information regarding future prognosis were not communicated, what kind of information regarding support for follow-ups were given to parents and finally, what kind of information and support were perceived reassuring to parents.

Second theme, HOW outlined how information regarding acute and long-term prognosis and support and follow-up services were given. There were 5 ways to provide and receive information: written information leaflets, verbal communication, DVDs, through the education programmes and the internet and social media.

Third theme WHO explored who consistently gave information and support to parents, who parents through was the professionals leading their child's follow-up care.

Fourth theme WHEN described what kind of information and support were given and what information and support were available for parents and children at which time frame of the NICU stay, after discharge and during follow-ups.

Lastly, Capacity and its effect on neurodevelopmental follow-up explored what was acting as a barrier in the capacity of the current neonatal and neurodevelopmental follow-ups. It also explored how capacity affected the quality of the current systems and how capacity of health care was important factor to consider when implementing new follow-up systems.

These Interviews have enabled me to explore what information and support were found useful, helpful and necessary by parents. I have also been able to discuss the current and new follow-up systems with parents and professionals. When I was analysing and exploring themes, I found some themes overlapping. For example, the results of how parents received information was the same as who provided the information. Every theme was somewhat affected by the capacity of resources such as time, funding, and availability of trained professionals.

Chapter Seven: Discussion and Conclusion

7. Discussion

In this final chapter, I will summarise the findings from Chapter 6 and discuss what this study supports and adds to recent literature. I will also discuss the limitations of my study and future clinical implications. I will conclude this chapter by making suggestions for future research.

7.1. Summary of findings

My study aimed to understand: the present situation; the perceptions and the views of parents and professionals who look after high risk infants discharged from a tertiary NICU. I aimed to understand at the views of parents and professionals on the support provided during neurodevelopmental and neonatal follow-up; as well as the ways in which parents and professionals felt the follow-up system could be improved. I also aimed to understand the views of parents and professionals on the facilitators and barriers to where, how and who provided information regarding the neurodevelopment of children at high risk.

My study consisted of qualitative interviews with 23 parents and 11 professionals to gain in depth information on the present situation from the voices of parents and professionals. 5 themes and 24 subthemes were identified from the data.

Support and information provided on the NICU

Most parents viewed that the support they received while their baby was in the NICU was good and that the NICU staff were approachable and understanding. Parents in

this study generally felt that they were provided with enough information during the NICU stay. There were however, differing opinions with regards to the quality and quantity of information provided depending on the situation and condition of their child.

Although a lot of support and information is provided, much of this concentrates on the short-term prognosis and care for the child in hospital and on early discharge. Parents did not perceive that the support with regards to information on the neurodevelopment of their child was provided in the same way. It was often felt that this was inadequate or in some cases, completely lacking. On the other hand, neonatologists demonstrated to me an enthusiasm in trying to introduce this information from the early stages of the NICU journey.

How information was communicated

Our results also showed that parents were better at understanding information if it was given both verbally and in written form. Many parents were not happy with how prognoses were communicated by consultants. They described that sometimes information was misleading and too hopeful. Although parents were upset at the time, they preferred a more honest and realistic approach even if it was to tell them things that they might not want to know such as that their child may not be able to walk. The honest and realistic information enabled parents and relatives to prepare for the worst situation and to support each other. Moreover, the parents-professional

relationship was perceived as being better when professionals provided detailed and thorough information and constant support to parents.

Quality of information

Consistency of information emerged as vital for parents. Inconsistent information was perceived to be caused by disorganised communication between professionals. Information provided by health visitors and GPs was perceived as inconsistent due to lack of training in supporting and managing high risk neonates.

Many families were concerned and frustrated that their child could not have an MRI or definitive diagnosis of cerebral palsy before the age of two. They expressed a desire for an earlier diagnosis so their child could receive early physiotherapy. This anger and concern arose from a lack of communication from professionals regarding an explanation for why the diagnosis could not be made before the age of two.

Ideal follow-up pathways

A new system is being introduced at the LWH through which neurodisability specialists and physiotherapists run joint clinics with neonatologists at neonatal follow-up once a month. All professionals have a positive view of this system. However, the capacity and the sustainability remains unclear from the interviews.

7.2. Discussion of findings

This study has provided some unique and interesting insights into parents' and professionals' perspectives of neurodevelopmental follow-up.

In this section, I will discuss my findings in relation to the present literature.

7.2.1. Health

Despite my research focusing on the parents' and professionals' perspectives on the current neonatal and neurodevelopmental follow-up and what, how and when the information regarding neurodevelopment were given, many parents mentioned their child's health problems and their experience with breastfeeding. It seemed that the time that they breastfed their child was the time they needed more support from professionals and other organisations like breast feeding peer supporters such as Babies & Mums Breastfeeding Information and Support (BAMBIS). From the interviews, it was clear that many parents came across difficulties or challenges around 5 main topics regarding health. These were: acute illness, breathing difficulties, feeding, swallowing difficulties, and weight gain. Of those 5 topics, acute illness and feeding were the most common topics to be discussed with most parents. Here I will discuss these 2 topics in more detail.

[1] Acute illness

Some parents suggested that it would have been very useful to get a list of problems that their child may encounter as a premature baby and what to do in that situation planning would help make a smooth transition period for the family. For example,

confirm the address of the GP with parents before they are discharged, go through the contents of the letter before and make a heading saying, “high-risk children” on the letter.

Some GPs in a study in Newcastle¹⁴¹ used a priority heading to ensure that everyone knew that the child has additional needs. This kind of support and consideration may be very valuable for parents and it may prevent delayed consultations with GPs.

[2] Feeding

It was apparent from the interviews that most parents had concerns about breastfeeding and weaning.

Studies show that a difficult breastfeeding experience can have a negative impact on mothers’ well-being.⁹³ From my interviews, it was clear that parents needed more guidance and support on certain areas of breastfeeding in hospital as well as in the community. This is consistent with other studies.¹⁴²

Of course, we know that adequate information, support and follow-up should be provided to all breastfeeding mothers.¹⁴²

This is doubly the case for parents of high risk infants. It is clear that the opportunity for parents in this group to meet and talk with breastfeeding support services trained to support high risk mothers would help mothers and their babies immensely. Issues particularly raised were; the frequency of pumping, breast massage and the facilitation of producing an adequate amounts of breast milk. These support services

may also provide opportunities for fathers to learn how they can contribute in feeding or weaning babies who stayed in NICU.

7.2.2. Factors affecting Perspectives of Information given at NICU and Neonatal Follow-up

From my interviews, I identified three factors that affected parents' perspectives of neonatal follow-up services.

[1] Information and Communication

A study described that parents are often described as “passive recipient for information” especially around the time of discharge.¹⁰² Although many parents in this study described that they received a large amount of information at NICU and after discharge, they perceived that they received an inadequate amount of information on long-term prognosis and conditions that are more common in premature babies such as, developmental delay, cerebral palsy and autism. Giving insufficient information may increase the risk of neglecting developmental concerns that arise in a child born at risk.

In contrast, at least one professional in my study thought that they tried to introduce information on future developmental outcomes from an early stage of the NICU journey. These conflicting views may portray issues with a lack of good enough communication between professionals and parents (the use of written information or repeated opportunities to provide this information). Many parents may be busy

concentrating on their baby's daily progress, making future prognosis less important during that time and setting.

Many parents mentioned that they would have liked receiving written information from professionals to take home so that they could stop searching online which was perceived as "scary" and "the worst thing" by many parents. This is consistent with consistent with findings from a multiplicity of studies.^{22,143}

It emerged that the quality and quantity of information about development might not have been as extensive as other information which parents remembered being told (e.g. feeding, the diagnosis and the results of scans). These pieces of information may have been more memorable, shocking and distressing at the time for parents. Other study¹⁰² show similar findings and have similarly demonstrated that professionals are more likely to report that they have discussed the risks of developmental problems than that which parents report.¹⁰² Several factors have been identified as perceived barriers for taking in information on a NICU.¹⁰² These include: stress, being told information whilst transported to NICU and the effect of maternal delivery complications on parental ability to take in information.¹⁰²

It is important that information guidelines are in place to ensure parents receive the same information in an equal and fair way.¹⁰² Timing of information giving is crucial and if it is not chosen appropriately, it is the same as not being communicated at all and therefore will not help in decision-making.²² Some parents reported that the

professionals were reluctant to give detailed information about the future when they were asked because the future is one of the uncertain things.

Neonatologists felt that giving too much information might take the joy away from the family and some mothers had similar opinions. Although it was perceived as heart-breaking and parents were not happy to be told negative information, parents appreciated an honest and realistic approach by neonatologists. This has been previously suggested in other studies.¹⁰² Having knowledge about premature birth can also help to cope with the stressful situation of having a premature baby.⁸²

[2] Support

Most parents felt they were well-supported by the neonatal nurses on the ward particularly when things came to a head. However, some parents felt that nurses were always busy handling and caring for the babies and had little time for counselling. For that reason, many parents suggested the introduction of counselling services during NICU admission and after discharge. Having external support on the ward would help open parents' feelings and discuss their worries. A psychologist has started visiting the unit however, no one mentioned in the interviews. This showed that the service is not sufficient and not meeting parents' needs. The resources and capacity are too limited for professionals on the ward to be able to spend time with parents in a sit-down approach like a counsellor. Therefore, extensive counselling service would benefit both parents and professionals.

Parents in my study found the community neonatal nurses a valuable source of information and support for many mothers. This has been found in other studies from the US by Brazy *et al.*¹⁴³ Parents found these neonatal nurses to be the main support post-discharge however the quality of this neonatal community care may vary enormously¹⁴⁴

Only a few people mentioned how different input from professionals affected the parent-infant relationship. They said that outcomes from NICU, good or bad care, and in other cases “nothing”, affected their relationship. This finding was not extensively explored in my study hence a conclusion cannot be drawn from the limited number of participants, however this finding disagreed with findings of a few previous studies. Previous studies describe how stressful experiences in NICU and the protracted separation from infants can negatively impact on the parent-infant relationship.¹⁴² Taking this into account is important when supporting parents both during their stay in NICU and afterwards on discharge.

The Korean study¹⁹ described in Chapter 3 found that mothers and fathers had different experiences in how professionals treated them in the NICU. Mothers were more likely to get involved in the NICU care, however, fathers felt ignored and neglected. In my study, I could not identify any major differences between mothers’ and fathers’ experiences and their opinions on the current follow-up and support system. This might have been because I did not have equal number of mothers and

fathers. In the future i would like to interview more fathers to see whether the finding that was observed in Korea was observed in my cohort

[3] Developmental Assessment and Referral

The parents in my study, on the whole, were reassured by the consultant neonatologist at neonatal follow-up clinics at the LWH. However, often parents were not aware of the importance of follow-up clinics and the fact that their children were considered “high risk”. This was especially the case with those who had a relatively smooth journey at NICU. The importance of explaining to parents when, how, and why their babies should be followed-up and the possible developmental implications in the future emerged as a feature in my study.²² This has been shown to be helpful for parents of children with disabilities who are followed-up by the neurodisability specialists. Parents wanted to be told the purpose of the follow-up and whether the appointment could be conducted over the phone instead.¹⁴¹ Knowing the purpose and reason for follow-up is likely to reduce the “Do Not Attend” (DNA) rate and improve the use of resources in regards to professionals, hospitals and the NHS.

As explained in Chapter 2 and 6, neonatologists identify developmentally delayed children and refer them to physiotherapists and community or neurodisability paediatric teams. Many parents described to me that they were not satisfied with the timing of referral, some occurring as late as 2 years of age. It emerged through my interviews, both with parents and professionals, that professionals at the LWH were often the barrier to referring for physiotherapy and other early intervention programmes. This finding was very similar to a finding by Tang *et al*⁴⁷ who found that

high-risk children were not appropriately referred to an early intervention services. On the other hand, neonatologists argued that mild developmental delay at an early age could be monitored under them as they were aware of the limited resources at the AHCH. Hence, they were reluctant to refer to neurodevelopment specialists early. This argument has emerged in other research and continues to be a big dilemma for professionals.¹⁴⁵

Interestingly, my research did not on the whole show that parents disliked having information and referrals earlier. It may be that this is reassuring even if their children turn out to have less difficulties than imagined.

Here, I would like to discuss whether an established diagnosis is necessary to refer a child to early intervention programmes. In an American study, Silverstein *et al*¹⁴⁶ found that more than two-thirds of general paediatricians thought that an established diagnosis was important when making a referral to early intervention (EI), hence the referral rate was lower than those thought diagnosis were not important. This finding was different from the perceptions of neurodisability professionals (EI team) who wanted to receive referrals as soon as a child developed signs.¹⁴⁶ This was because they could identify and refer further for more detailed assessment and investigation.¹⁴⁶ Silverstein *et al*¹⁴⁶ concluded that the perceptions of what makes an appropriate referral differed often due to lack of standard criteria for EI referral. This may be one issue but the other is the continued concern by professionals in being able to make suitable predictive judgements as to which children will or will not go on to have more major difficulties in the future. This is where tools such as the Prechtl's

or the HINE or even more specific and sensitive developmental assessment measures may be helpful in providing this prediction.

Other studies have also pinpointed this lack of confidence by professionals in making a definitive diagnosis coupled with the fear of misdiagnosing children too early.¹⁴⁷

Some studies also suggested that a lack of coordination in the referral system might have caused the delayed presentation to the early intervention team.¹⁴⁵ This finding might explain what has been happening in the current follow-up systems of the LWH and the AHCH where no standardised guideline for follow up is used. Personal judgements of professionals should not affect how and when a child is referred to specialists and may lead to parental anxieties. My interviews demonstrated that professionals may underestimate how beneficial follow-up by neurodevelopment professionals is for high-risk children.¹⁴⁷

On the other hand, some physiotherapists in my study were concerned that doctors sometimes gave a diagnosis too early when it was uncertain, damaging the relationship between parents and doctors. After initially being given incorrect information, it later becomes difficult for parents to have faith in professionals. To avoid this, early referral to neurodevelopmental specialists who are trained to accurately assess and diagnose the condition should be done prior to a neonatologist making the diagnosis. This would also help maintain a good relationship between parent and neonatologists.

Increased parental awareness and knowledge of signs of developmental delay many also support this processes parents can monitor their children over time whereas professionals often only see a snapshot of the child's development.

7.2.2. Factors affecting Perspectives of neurodevelopmental follow-ups

Some parents in my study were under the care of physiotherapist and a community paediatrics or neurodevelopmental consultant from the tertiary specialised hospital. Here, I will discuss what the views of parents' and professionals' who area already immersed in more specialist neurodevelopmental follow-up services.

[1] Information

Many children that I interviewed were receiving physiotherapy for delayed development or cerebral palsy.

Early stimulation has been shown to benefit both physical and mental well-being of the child, enhance parent-child relationship and it can take place as early as the child is in the incubator.¹⁴⁸ This includes skin-to-skin⁹¹ as well as general developmental stimulation.^{148,149} In my study was no mention of early developmental stimulation interventions in the NICU or straight after discharge. Those that at-risk of developing developmental complications should be identified and could receive early interventions to enhance their development if capacity was there.

Only a few parents recognised the term “early interventions” or “early stimulation” in my study although many parents described to me that they were told how to

encourage the child to move to prevent secondary complications of developmental delay or spasticity. The finding was supported by literature.^{148,149} Knowing how to stimulate the child is very important but it is also important to know what it is called to enable themselves to search for more information or ask professionals for further guidance. It would be interesting to see how different early interventions have benefited the child and children and families' views and thought about these interventions in Merseyside.

Information-giving was reported to vary depending on which physiotherapist was involved and what area parents lived in. This variability in practice is common and described in large multicentre studies.³² In order to avoid inequality between areas, the same information materials could use across an area by all physiotherapists. This may enable some consistency in what information is shared

In my study, I noted that single and younger mothers voiced the fact that they had limited support as well as limited sources of information to me. It emerged from my transcripts that mothers who were older and had other children tended to be more prepared for developmental problems by reading information from appropriate sources. Moreover, this group tended to be more assertive in their language and ask more questions. As a result, they are more likely to receive more information and equipment and help from community. This is a common finding.^{150,151} Clearly, support systems should specifically target young and single mothers. This could include community or peer support groups and even social media. In my study, there

seemed to be a very variable provision of information giving, support and physiotherapy between parents and children depending on the area that they lived. It was unclear why this was the case but it was clear that these postcode inequities are not fair and are difficult to equate. It may be that some parents and children who are most at risk should be provided with the most services no matter where they live.

[2] Parent-professional relationship

Some professionals in the neurodevelopmental teams also mentioned the importance of “building a relationship” over a long time. Physiotherapists stressed the importance of getting to know every parents and child in order to build up the rapport with the patient and have an effective session. It is also crucial to have a consistent support from the same professionals and follow-up services at the same place from day one of follow-up services.

[3] Assessment tools

From the interviews, it is apparent that there is no standardised guideline as to which developmental assessment tools should be used to support identification of high risk children who may have developmental delay. The debate here may lie in how much value professionals place on the use of these types of tools and how much time professionals have to use them. Some professionals describe using “crude milestones” and “their experience”. Some professionals may also not be appropriately trained to perform certain assessments. Although I did not have a chance to conduct interviews with health visitors, we do know that all health visitors should be conducting

the Ages and Stages parent report developmental screener with all children. This should act as a universal system of identifying children with developmental delay. If this system is working then you would hope many children would be identified through this. This does not mean that it is not useful for highly trained professionals (neonatologists and community paediatricians) to at least have some consistency in what they use in their clinics and to at least use something that is consistent to guide them every time they see patients. Clearly there are some specific assessment tools that can be used in certain situations and it may depend on parental concerns and the presenting problems of children in determining which assessment tools should be used.²² When assessments are used, professionals should be familiar with the tool to yield results that are clinically relevant and helpful in organizing early interventions.²² The tools which can be used to assess and provide more information on the neurodevelopmental status of neonates do not necessarily require a certain professional to do the assessment (e.g. it does not need to be a physiotherapist or a consultant neurodevelopmental paediatrician). As long as professionals are adequately trained, a number of different persons can conduct these assessments including nurses or physiotherapy technicians. This could in future take the workload of doing this off some of the most expensive and limited staff.

A neurodevelopment consultant mentioned that she was considering using a tool called Health, Functioning and Wellbeing Summary (HFWS), produced by Karen Horridge,¹⁵² in neurodevelopmental follow-up clinics. It uses a set of questions which have a traffic light system to grade parental concern about child development.¹⁵²

Implementing this tool would aid professionals to elicit parental concern more easily and reduce consultation time. The tool allows parents to write down their concerns and questions freely, reducing the issues caused by parental forgetfulness

As up to 40% (2012 data)¹⁵³ people who have mobile phones use smartphones, it may even be worth considering this tool as an App. Parents could then take pictures or videos to monitor child growth or capture moments when the child behaved differently. This may also be more practical as phones are widely used readily accessible (e.g. patient can write in the app on the sofa, in the bed or while they are waiting for appointments).

The app can be made to send reminders if the form has not been completed before the appointment. When the form has been completed, parents can send it to the hospital network like a log book. This way, professionals can also keep a record of appointments and identify the trend and progression of child development.

Some apps (e.g. BabySparks- Development activities and Milestones) have been developed that can help parents monitor child development. Tommy's launched a free app for parents to record and write down thoughts about development, record weight and feeding routine, as well as sharing data with family and friends via Facebook.¹⁵⁴ This app is made for parents of premature babies.¹⁵⁴ To the best of my knowledge, there is currently no app that serves as a traffic light system for developmentally delayed children with the purpose of summarizing a child's Functioning and Wellbeing so an enabling this might be really helpful. The use of modern technologies like apps has been studied in various health care settings. An Australian study¹⁵⁵ explored how pregnant women or mothers who have recently

given birth used apps. They found that apps were perceived as helpful for obtaining information and monitoring child growth. In these studies, parents were reassured by the information provided.

One case study¹⁵³ even demonstrated how a father was able to realise his child's head circumference was 2 standard deviations higher than the mean by recording his growth on an app. Similarly a mother reported how a breastfeeding app helped her realise her child had reduced the frequency and duration of breastfeeding. It turned out that the child was suffering from an infection..¹⁵³

With the use of an app, parents may be able to recognise a difference in development or other signs of disease early or difference early and professionals may be able to support parents better and facilitate monitoring of neurodevelopment more closely. Further research is required to explore parents' and professionals' views on the use of apps to monitor development and to ensure confidentiality of data.

7.2.4. Care and support in other settings

Community

As discussed in 7.2.2, most parents were supported by the community neonatal team as likely also by a health visitor in the community. Some parents reported that health visitors visited the family every week to weigh the baby and to and provide information and support. Some acted as a bridge between the family and the hospitals and helped parents or children be referred for counselling or physiotherapy but this reportedly varied with area.

A study also identified regional variations in community services.¹⁴⁴ The community neonatal nurses were seen as incredibly helpful by parents. In some settings (Cambridge), neonatal community nurses share a job with nursery nurses which increases the number of nurses in the community and improves the cost effectiveness.¹⁵⁶ This may be something which could be implemented elsewhere.

The importance of health visitors has been emphasized recently. The healthy Child Programme highlighted that the health visitor plays an important role in identifying families who need extra support and coordinating multidisciplinary approach.⁵⁷ England has been investing to increase the number of health visitors by 50% over a 3 years.¹⁵⁷ Hopefully the number of health visitors will increased in England with time and this will allow increased frequency and length of visits. This does not necessarily mean a quality service will be achieved. Parents have obviously found this input very helpful however my study did demonstrate that some parents found the knowledge and experience of some community staff limited with regard to the high-risk neonate. It may be important therefore to think further about training for the new population of health visitors or to consider linking this service more with the specialist community neonatal nurses.

Physiotherapists in my study have formulated education sessions with health visitors to raise awareness of the importance of conducting a comprehensive growth assessment to detect developmental problems in these high-risk children. It will be interesting to see how effective these teaching sessions are in identifying high-risk children earlier.

7.2.5. Capacity in Health Care system

When to follow-up and catching up with children that may only have mild problems

It is difficult to estimate how long high-risk children should be followed up by professionals. For some children, problems may only begin to surface in school. Some consider that follow-up of these high-risk children who have already been discharged should happen once more before the child starts primary school.²² Sadly the capacity of professionals and hospitals is limited and it is difficult to say how feasible and sustainable this might be. This may be something that a well-trained community nurse or health visitor should or could be able to screen for in a pre-school check.

The U.K. government has been trying to improve the care of children with disability by promoting multidisciplinary approach and emphasizing the importance of social care.¹⁵⁸ Some professionals from AHCH mentioned the importance of sustaining a multidisciplinary team approach and they expressed their wish to have a Child Development Centre (CDC). For high risk neonatal follow up, having all children who are at risk plugged in and linked in to a centre like this may make referrals much easier. The linked professionals (paediatricians, physiotherapists, speech and language therapists, occupational therapists, clinical psychologists, audiologists, play therapists and hospital social workers) at a CDC can help children reach their developmental potential by intervening from an early age. Linking a service like this much more closely with the neonatal community nurses and health visitors would mean that children could more seamlessly be referred.

Services such as this can also be really helpful in the expertise they have in managing children with neurodevelopmental delays but also in supporting families by helping children develop confidence and overcome challenges.

The new NICE guidelines for follow-up of premature babies will be published in the summer 2017. In my study, professionals discussed how this may help the current situation. Of course it is likely that having a national guideline will help standardise care, however it will be important to tailor it to the local level particularly when funding is so limited at present.¹⁵⁸

7.3. Strengths and limitations of this study

Strengths

This study aimed to understand the perspectives of parents who have had children born at high risk and professionals who work with them. It is the first qualitative study that has been conducted specifically focussing on neurodevelopmental follow up using in-depth interviews. Utilising qualitative methods has enabled me to gain in-depth knowledge of the views and ideas of parents and professionals who manage high risk infants. This study has been extensive and has provided many different perspectives on the views of both parents and professionals. My study has included many interviews with parents from different locations, with different ages of children and with parents who both have a child who has now been discovered to have a problem and those who have a child with no difficulties or known problems. Having sampled purposively like this has enabled me to clearly get differing opinions

and an overall viewpoint and focus to some of the specific and complex areas within this topic. Having worked both with community and hospital teams and gaining ethical approval in two locations means that I have had unique insight into the views and perspectives of both, albeit that the community services I worked with were maybe at more of a secondary or tertiary level.

This study was conducted over a year and although it was not as extensive as some studies could have been, this time to devote purely to this study has enabled me to ensure that I conducted the best interviews possible through piloting and revising my topic guide multiple times and by making sure that I was able to recruit a wide range of participants through regular communication with all professionals involved in neonatal follow up.

Being a medical student rather than a more senior professional has given me a different perspective and wider insight into this subject. Being in this position made it easier for me to form a relationship with both parents and professionals where my role in terms of power, was less of an issue. I was able to maintain an independent position in an area where some researchers may have already had more of a professional perspective. This may have made families being interviewed feel that they were able to talk to me more freely and feel less pressured to give positive feedback since I have not been involved in their care.

My study was conducted a few months before a new neonatal follow-up system is going to be implemented. This study was able to catch an important period of transition. The study included high-risk children discharged from NICU at LWH, who were 0 to 3 years of age and lived Liverpool and Sefton. The study population was the same as the target population for the new system. Understanding what parents thought about the current system and what kind of support professionals might need in supporting high-risk children well has been very beneficial. The results of this study can be hopefully be reflected in the new follow-ups system.

The study quality including creditability, transferability, dependability, and confirmability was ensured through my careful methodological consideration which is discussed in Chapter 4 in detail.

Limitations

I am an undergraduate medical student with limited research experience. This was my first experience in conducting a qualitative study hence, the quality of the study methods and interviews were not perfect particularly at the start. As I did more interviews, I learned quickly how to get more detailed and in depth data.

One limitation of my study was the fact that I was unable to conduct a focus group within the time frame. It was much more difficult to arrange this than I had imagined and sadly, was not possible to do. The addition of a focus group would have enabled participants to discuss and have debate over some of the issues in my study. My

sample size was therefore slightly smaller than expected. However, I was satisfied that I reached saturation with the data through my interviews.

The process of recruitment may have caused some bias in my study. As mentioned in Chapter 4 and 5, I have attempted to recruit participants through neonatal follow-up clinics, neurodevelopmental follow-up clinics and through a parent's Facebook page. It was hard recruiting parents of children who were born high-risk and had no problem (which I hoped would happen through Facebook) and only a few contacted me after receiving the information sheet from the clinic and seeing a Facebook post. Participants were therefore predominately recruited by community neonatal nurses and community physiotherapists and may have had more problems than those who were not recruited. This needs to be taken into account when considering the perspectives of parents in my study. Moreover, as community physiotherapists took part in first, they identified and talked to patients before the community neonatal nurses did. Therefore, more than half of my participants have already developed conditions such as a global developmental delay and cerebral palsy. This might have affected how parents reflected their neonatal and neurodevelopmental follow-ups. They tended to be more negative about the neonatal follow-up and the quality and quantity of information regarding development that they were given on the unit.

Another major limitation of my study with regards to recruitment was that I was not able to recruit GPs, health visitors, community midwives and community neonatal

nurses due to the limited study period that I had. I would like to continue this research if possible in the next academic year to explore their perspectives and views of current follow-up systems, their opinions on the hospital professionals or the referral systems and what it is like to follow-up high-risk children in the community. This would mean getting further dispensation to work with some staff not employed by either the LWH or AHCH. This would add an added layer onto my study.

The study is a qualitative study which asks parents and professionals to look retrospectively at their situation. Hence, this may mean that participants have recall bias. Parents might have not remembered correctly what exactly happened and may reflect on their experience in a more biased way. Moreover, if they had good or bad experience, the memory might have been transfigured. Conducting a study following parents from early on through their journey in time would add much to the literature and I would like to do that in the future.

Gender bias might have occurred. As mentioned above, since I am female, I may have attracted more mothers than fathers. Furthermore, it was more common that mothers brought their children to clinics and follow ups than fathers; hence, most people who were interviewed were more likely to be female than male. Moreover, like other qualitative studies¹⁰², this female bias will lead to a perspective that needs to be taken into account much more from a female point of view than a male point of view. Fathers might have been able to provide different experiences and perspectives of the follow up and support system. My study would have benefited from having equal

numbers of mothers and fathers to understand whether this was different however this was difficult to achieve in my study.

7.4. Implications for Clinical Practice

There are very limited studies which focus on the parents' and professionals' perspectives of neonatal neurodevelopmental follow-up. The results of my study have highlighted some important issues that I will discuss further. This includes ways where we could change our approach to meet the needs of parents of high-risk infants. Moreover, I will discuss some of the ways we may be able to implement change according to the professionals I interviewed.

NICU Stay

As discussed above, neonatologists may often not choose to provide information regarding future prognosis and neurodevelopmental outcomes within the NICU. My study suggests that professionals could take a step-wise approach to slowly introduce information about development and future outcomes within NICU and that many parents would appreciate this. It is always important to understand how much information parents want to receive and how much in-depth that they want to know however it is clear that help retention and understanding, information could also be given in written form so that parents could go over on their own time. A leaflet about growth and development and how this may be different in the high-risk neonate from children born at term or from healthy babies could be provided in a sensitive and thoughtful way to all parents of high risk infants in the NICU.

Information regarding peer support groups might be useful for parents who were not aware of the groups or who were scared of joining groups. The peer support groups will also help parents long after babies are discharged from hospital and enable exchange of information about their child's development, early intervention programmes, nurseries and schools. This may also help parents to ask for more specific information and support from professionals as they can compare with their peers.

The community physiotherapy team in Liverpool has their own website and has information for making a self-referral. Some mothers in the study realized signs of developmental issues before the professionals and this information should have been provided to parents as part of the discharge information.

Some parents liked the idea of having a parental education session on the ward about development. They also were keen to come back for teaching sessions at the LWH as they could have opportunities to ask questions to professionals who are experts in this field. A drop-in teaching session such as this could happen around the same time as the follow-up clinic and may reduce DNAs in both clinics and teaching sessions.

Neonatal follow-up clinics

The neurodevelopmental neonatal follow-up system is changing from summer 2017, around the same time as the new guideline will be published. Referral issues that were raised by parents and professionals from the LWH to the AHCH may be able to be solved through this new system I will disseminate my results to professionals who will be conducting follow-up clinics to reflect the parents' in my study's opinions on the present system for neonatal follow-up.

The follow-up invitation letter only contains dates, time and the name of the consultant. The letter should also include the purposes of follow-up and what will be done in the follow-up appointment. If parents know that the consultant would check the child's general health as well as development parents might respect the appointments more.

Neurodevelopmental Follow-up clinics

As reviewed in discussion, the use of the "Health, Functioning And Wellbeing Summary" would be useful tool for summarising what is going well and what worries the parents with regards to the progress of their high-risk neonate.

This form should also be utilized in the neonatal follow-up clinics. Although the majority of patients in neonatal follow-ups are well, the record may make it easier to show whether problem is new, recurrent or ongoing. The form also provides a place for parents to write their concerns. This would reduce the time taken by parents to remember and talk about their concerns in the clinic and prevent them from going home forgetting to ask questions.

Support and counselling

My results demonstrated that a more comprehensive system of support is needed for children born at high risk and their families. Talking to someone was seen as vital in coping with stressful situation in the NICU. It may be useful for the LWH neonatal unit to consider offering counselling service which is opened to everyone on the unit. This will meet a lot of parents' needs and help parents cope with depressing and stressful situations better. It may be helpful if these could be extended to parents who have then also left the NICU but who have had severely unwell neonates. A system where at-risk families (e.g. single, young, and unemployed parent) are referred on to specifically identified support services and community workers such as health visitors and disability social workers would be helpful. At present, there seems to be no specific system to do this and therefore parents get referred (if they do) to generic services who may or may not support families.

Summary of recommendations

- Counselling services where parents can talk to professionals (e.g. clinical psychologist) one-to-one should be provided during hospital stay and after discharge.
- Make an information sheet which explains about developmental milestones for those stayed in NICU. It may be beneficial for parents to attend a class or workshop to go through milestones and development with professionals.
- Neonatal Unit should produce a list of support groups (e.g. local peer support groups) and information regarding workshops at hospitals and children centres.
- Professionals should explain thoroughly why some diagnosis or referrals cannot be made earlier. For example, MRI brain scan may not be able to take place before a child reaches 2 years old and earlier scans may give a false result as the brain is still growing.
- Formal discharge pathway should be established. For example, discharge summary should be discussed with parents to ensure that the information is correct and provide chance to ask questions before they are discharged.
- Discharge from AHCH should be revised. Neonatologists should be present at the time of discharge to ensure the quality of discharge process from AHCH.
- Funding source for the new follow-up should be clearer

7.5. Directions for Future Research

Here I suggest recommendations for future research.

When I was conducting my research, I came across very limited number of qualitative studies conducted in neurodevelopmental settings for high-risk infants.

Qualitative studies can be very time-consuming however, a study such as this one gains in-depth perspectives of participants and can explore further depending on

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what participants disclose. Neurodevelopmental paediatrics is still a new area of paediatrics and qualitative studies in relation to services have not yet been conducted in many settings and situations. As it is a relatively new field, more research is needed to determine the parents expressed needs. It would be interesting to see results of a similar study but in other setting which may have a different system. For example, places where CDC is available or where more early screening occurs.

Whether the disclosure of future prognosis would remove the joy from the families was a topic not explored in-depth enough and therefore this study cannot draw any conclusion.

In this study, I excluded non-fluent English-speakers. Being an international student myself, I understand that how foreigners can go through challenging and difficult times adjusting to a different environment. They might be facing more barriers that are different from the parents I interviewed in this study. I would love to understand the experiences of non-fluent English speakers or immigrants in getting information that they need having both language and cultural barriers. It would be important to find out if the professional-parent and parent-infant relationship would be any different from the population I studied, and whether it is affected by cultural, spiritual, and religious backgrounds.

Qualitative research into fathers' perspectives and experiences of follow-up and support system may be useful. I had fewer fathers participated than mothers in my study and it was hard to draw a conclusion in my study with regards to the views of fathers. It would also be interesting to see how they felt about leaving the partner at home with the child on oxygen, medications, and in need of one-to-one care and what the perceived barriers were to taking part in the child's care.

It would be interesting to measure the effectiveness of the neonatal neurodevelopmental follow-up in identifying children early by conducting a quantitative research. The outcomes of the children identified at follow-ups should be measured to see if early involvement by neurodevelopmental specialists would make any difference in outcomes of children and perspectives of families with high-risk children.

7.6. Conclusion

Based on existing literature, it is clear that definitions of high-risk infants vary between countries and studies. The long-term outcomes of early interventions are unclear, however short-term neurodevelopmental outcomes appear to be promising. Children meeting neonatal follow-up criteria are seen by different professionals depending on their needs in an inconsistent manner. Timing of referral to services can be very variable possibly due to ineffective teamwork and communication between the neonatologists and the neurodevelopmental specialists. At present, there is a lack of a standardised guidelines surrounding the neurodevelopmental

follow-up system for high-risk children in England. It is likely that these guidelines will improve and focus more standardised care.

Neonatology outpatient appointments tend to focus on the short-term with a reluctance from professionals to discuss longer-term issues. This emphasis avoids placing a negative impact on the initial joy and happiness experienced by parents following the birth of their baby. Despite this, parents do have concerns from early on and felt they would benefit from one-to-one long-term parental emotional support through counselling services from the hospital or community. An honest and realistic approach is appreciated by parents of high-risk infants. Consistency of follow-up services, information provided and referral pathways were variable and this impacted significantly on parent satisfaction with follow-up.

It clearly may be beneficial to discuss future prognosis and signs of developmental delay for high-risk babies in an informed, sensitive and understanding manner. Furthermore, parents will benefit from being provided information regarding multi-disciplinary teams, support services, and, breastfeeding support both in written and verbal formats. In particular, information regarding future prognosis should be provided early from professionals on the ward to raise awareness for the possible outcomes and avoid making themselves unnecessarily worried by searching information online. Continuous support and information are required after discharge from the follow-ups at the hospitals and in the community. Once reviewed by neurodevelopmental specialists, more explanations around the minimum age of diagnoses and the pros and cons of certain investigations would be helpful.

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Appendix

Appendix A: Participants' information sheet

FOUNDATION Study

Alder Hey Children's 
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Liverpool Women's 
NHS Foundation Trust

Parent interview information sheet

Project Title:

Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care?"

Research team: Ayuko Komoriyama (MPhil Student), Melissa Gladstone (neurodisability consultant),
Fauzia Paize (Consultant neonatologist), Christopher Dewhurst (Consultant neonatologist)

Introduction

We would like to invite you to take part in a one-to-one interview to share your experience and views of follow-up for your baby. We are interested in what kind of information you were given when you left the hospital with your baby, particularly relating to the developmental follow up of your child and how and where to get that information from. We would also like you to tell us about your baby's follow-up by the doctors, health visitors, or other healthcare professionals such as physiotherapists. Before you decide to take part in this study, we would like to let you know why and how this study is conducted and why it is important us to know about this topic.

Please take time to read the following information carefully and discuss it with your family and friends.

If you have any questions or uncertainty, please do not hesitate to contact Ayuko or Melissa from the research team (details below).

What is the purpose of the project?

Around 1 in 10 babies are born too early and 7 in 100 babies are born too small every year around the world.

Many parents describe having babies as exciting, amazing and life changing experience yet some parents also experience chaotic, uncertain and sad moments when their babies stay in the Neonatal Intensive Care Unit (NICU).

It is very important that those babies born too small or too early or with other conditions get followed up by doctors in hospitals or in the community so that they are checked to make sure they are doing what they should do in terms of their development. There are no agreed standard procedures and schedules as to exactly how and where these babies should be followed up and what will be most effective for parents and their infants. Parents have never been asked their views and opinions before either.

Our aim is to improve our follow up so that is appropriate and meets families' needs.

Parents interview information sheet. FOUNDATION study. IRAS 217848. Version 2. 13.1.17

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Therefore, by doing this study, we would like to see what kind of support and services mothers and fathers were offered and how the babies have been followed-up in Liverpool so that we can provide parents and babies with the right support to ensure the babies developmental goals are achieved.

Why me?

We are contacting you because you and your baby have experienced a stay in the NICU and are being followed up by consultant neonatologists or community paediatricians and you and your baby are in Liverpool.

How much of a time commitment will this be for me?

We would like to conduct a one to one interview which may take up to an hour. Before we start, we will again go over the study and make sure you are happy to give consent. We are planning to conduct interviews at hospital or other clinics including those at the Liverpool Women's hospital, Alder Hey Hospital and clinics in the community such as those in Garston, Childwall, May Logan, Netherton and Knowsley. You can choose the venue and a time that would suit you the best.

How will the information be recorded?

With your permission, we will also be recording our interviews. This enables us to revisit our conversation to analyse and compare your views and opinions with other people. However, everything will be anonymised and your personal information will not be recorded.

Do I have to take part?

No. It is entirely up to you whether or not you take part in this study. If you do not wish to take part in the study, please ignore this information sheet. If you initially agree to take part in the study but want to withdraw your application, you are allowed to withdraw yourself from the study at any point before we interview you.

What will happen to me if I decide to take part in the project?

You will need to agree to sign the consent form and submit to one of the staff or the researcher. We will contact you later to give you further information about the study and discuss the venue and time of the interview.

How long do I have to express an interest in taking part?

You can consent after your clinic appointment today or you can take this leaflet back to your home to discuss with your family and friends. You can take up to 6 weeks to decide and you can always come back to the clinic to submit the consent form.

Will I get travelling expenses?

We are unable to provide travel expenses for this study as it is a student project. We will make sure that the location for the interview is close to your home to make it easier for you to meet us.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks from taking part in the study. However, we will be asking you come to one of the venues (Liverpool Women's Hospital, Alder Hey Children's Hospital, community clinics) and the interview will take up to an hour of your time. Therefore, you might find that more commitment is needed than you expected.

What if something goes wrong and I want to make a complaint?

All our studies are covered through sponsorship by the University of Liverpool. If you want to make a complaint you can get in touch with sponsor@liverpool.ac.uk

If you wish to make a complaint or seek advice about taking part in the study, you can also contact Patient Advice and Liaison Service (PALS) at either Liverpool Women's Hospital or Alder Hey Children's Hospital. Please see the details below.

Liverpool Women's Hospital: Call 0151 702 4353, Write to PALS, Liverpool Women's NHS Foundation Trust, Crown Street, Liverpool, L8 7SS.

Alder Hey Children's Hospital: Email pals@alderhey.nhs.uk, Call 0151 252 5374 or 0151 252 5161, Write to PALS, Alder Hey Children's NHS Foundation Trust, Eaton Road, Liverpool L12 2AP.

Is everything confidential?

Any information we discussed will be kept strictly confidential. We will not mention any personally identifiable information including you and your baby's name, address, and phone number.

What will happen to the results of the research study?

The result of the study will be shared between healthcare professionals from Alder Hey hospital, Liverpool women's hospital and community neurodevelopmental follow-up clinics. We will provide you with a newsletter to report our findings.

Will I know the result?

The result of the study will be shared between healthcare professionals from Alder Hey hospital, Liverpool women's hospital and community neurodevelopmental follow-up clinics. We will provide you with a newsletter to report our findings.

Who can I contact for further information?

Parents interview information sheet. FOUNDATION study. IRAS 217848. Version 2. 13.1.17

FOUNDATION Study

If you want to know more about the study or have questions, please do not hesitate to contact:

Ayuko Komoriyama: hakomor@liv.ac.uk

Melissa Gladstone: 0151 252 5139 (M.J.Gladstone@liverpool.ac.uk)

Project Title:

Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care?"

Research team: Ayuko Komoriyama (MPhil Student), Melissa Gladstone (neurodisability consultant),
Fauzia Paize (Consultant neonatologist), Christopher Dewhurst (Consultant neonatologist)

Introduction

Babies who are born and admitted to a neonatal unit are more likely to have difficulties with their development than babies who are not admitted. This is particularly the case for babies born early (premature) or those who have had a serious illness whilst in the neonatal unit. Following up the development of these babies is really important to allow us to see how babies are doing and to identify which babies may need extra support. At present, it is not very clear what the best processes are for providing information to families about neurodevelopment of high risk infants. It is important to identify babies having developmental delay or disability early and so that we provide the information and support for parents at early stage. There are some studies which look at this but very few have looked at the views of parents and other professionals who work with parents.

We would like to invite you to take part in a one to one interview to share your experience and views of organising and conducting follow-ups for high-risk babies. We are interested in how you think children should be followed up and identified if they have problems, where you think parents should get their information from, what information you give in your role, what care package you offer, and how you provide this to parents.

Before you decide to take part in this study, we want to make sure you know what the purpose of this study is and why we think this is an important topic for us to study.

Please take time to read the following information carefully. If you have any questions, please contact Ayuko Komoriyama or Melissa Gladstone from the research team (details below).

What is the purpose of the project?

It is very important that at risk babies are followed-up by healthcare professionals from hospitals or community settings to identify babies at risk and to support those who need it to reach their potential developmental goals. At present, there are no standard guidelines or protocols to guide healthcare professionals as to the best follow-up systems and schedules. Moreover, there have been no studies which have attempted to understand what parents and professionals feel would work best for a follow up system to be effective in identifying infants early and supporting those parents and children in the way that they would like.

FOUNDATION Study

Our aim as healthcare professionals is to improve and develop a healthcare system that is appropriate, accessible and sufficient for patients.

By undertaking this study, we would like to see what kind of support and services mothers and fathers are offered and how babies are followed-up in Liverpool.

How much of a time commitment will this be for me?

We would like to conduct one to one interview which may take up to an hour. Before we start, we will again go over the study and make sure you are happy to give consent. We are planning to conduct interviews at hospital or other clinics including those at the Liverpool Women's hospital, Alder Hey Hospital and clinics in the community such as those in Garston, Childwall, May Logan, Netherton and Knowsley. You could choose the venue and a time that would suit you the best.

How will the information be recorded?

With your permission, we will also be recording our interviews. This enables us to revisit our conversation to analyse and compare your views and opinions with other people. However, everything will be anonymised and your personal information will not be recorded.

Do I have to take part?

It is entirely up to you whether or not you take part in this study. If you do not wish to take part in the study, please ignore this information sheet. If you initially agree to take part in the study but want to withdraw from the study, you are perfectly entitled to withdraw from the study at any point even during the interview.

What will happen to me if I decide to take part in the project?

If you are interested in taking part in the study, please let one of the clinic team know and we can then come and see you and organise a time and date for you to come back to have an interview. You can also contact us by calling us or sending us an email. We can then meet with you, go over the information sheet again with you and if you are still happy, we will ask you to sign a consent form.

How long do I have to express an interest in taking part?

We are conducting the study any time between December 2016 and June 2017. You can let us know at any time if you are interested in taking part in the study.

Will I get travelling expenses?

We are unable to provide travel expenses for this study as it is a student project. We will make sure that the location for the interview is close to your home to make it easier for you to meet us.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks from taking part in the study. However, we will be asking you come into one of the venues (Liverpool Women's Hospital, Alder Hey Children's Hospital, community clinics) and the interview will take up to an hour of your time. Therefore, you might find that more commitment is needed than you expected.

What if something goes wrong and I want to make a complaint?

All our studies are covered through sponsorship by the University of Liverpool. If you want to make a complaint you can get in touch with sponsor@liverpool.ac.uk

If you wish to make a complaint or seek advice about taking part in the study, you can also contact Patient Advice and Liaison Service (PALS) at either Liverpool Women's Hospital or Alder Hey Children's Hospital. Please see the details below.

Liverpool Women's Hospital: Call 0151 702 4353, Write to PALS, Liverpool Women's NHS Foundation Trust, Crown Street, Liverpool, L8 7SS.

Alder Hey Children's Hospital: Email pals@alderhey.nhs.uk, Call 0151 252 5374 or 0151 252 5161, Write to PALS, Alder Hey Children's NHS Foundation Trust, Eaton Road, Liverpool L12 2AP.

Is everything confidential?

Any information we discussed will be kept strictly confidential. The audio recording device will be carefully stored in a locked cabinet at Alder Hey Hospital. Your name and details will not be recorded on the audiorecorder and you will only be given a number which will be identifiable on the audiorecorder. None of your personally identifiable information will be associated with any of the data that we publish in the future.

What will happen to the results of the research study? Will I know the result?

The results of the study will be shared with both parent forums as well as healthcare professionals from Alder Hey hospital and the Liverpool Women's Hospital. The results will also be presented in a thesis submitted to the University of Liverpool. Presentations, posters and publications which may be shared with other national and international organisations who are interested in this subject. We will provide you with a newsletter to report our findings.

Who can I contact for further information?

If you want to know more about the study or have questions, please do not hesitate to contact:

Ayuko Komoriyama: hakomor@liv.ac.uk

Melissa Gladstone: 0151 252 5139 (M.J.Gladstone@liverpool.ac.uk)

FOUNDATION Study

Professional interview information sheet. FOUNDATION study. IRAS 217848. Version 2. 13.1.17

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Dear professionals,
Do you have any opinions and ideas about how we might best follow up and support parents of babies discharged in terms of their neurodevelopment?

Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care"

Would you like to be a research participant?

We need participants to take part in a one-to-one interview!

What is it? This is a MPhil student project at University of Liverpool, which is studying the views and opinions of parents, carers and professionals in relation to the current neurodevelopmental follow up system and support system after leaving the NICU at the Liverpool Women's Hospital in Liverpool.

Who? We are open to many professionals who work in neonatal and neurodevelopmental follow up clinics.

Where? Hospitals: Liverpool Women's Hospital, Alder Hey Hospital
Community clinics: Garston, Childwall, May Logan, Netherton and Knowsley

How long will it take? 60-90 minutes

Interested?
Find out more in information on leaflet on the wards and clinics
Or contact Ayuko Komoriyama hakomor@liv.ac.uk or
Melissa Gladstone M.J.Gladstone@liverpool.ac.uk

 UNIVERSITY OF LIVERPOOL

 Liverpool Women's NHS Foundation Trust

 Alder Hey Children's NHS Foundation Trust

Dear mothers, fathers and carers,

Do you have any opinions and ideas about how we might best follow up and support parents of babies discharged in terms of their neurodevelopment?

Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care"

Would you like to be a research participant?

We need participants to take part in a one-to-one interview!

What is it? This is a student project at the University of Liverpool is studying the views and opinions of parents, carers and professionals in relation to the current neurodevelopmental follow up system and support system after leaving the NICU at the Liverpool Women's Hospital in Liverpool.

Who? Parents of babies who are now 0-3 years old, who were born before 37 weeks, had hypoxiaemic ischaemic encephalopathy (with whole body cooling), or stayed in NICU after birth.

Where? Hospitals: Liverpool Women's Hospital, Alder Hey Hospital
Community clinics: Garston, Childwall, May Logan, Netherton and Knowsley

How long will it take? 60-90 minutes


Interested?

Find out more in information on leaflet on the wards and clinics


Or contact Ayuko Komoriyama hakomor@liv.ac.uk or
Melissa Gladstone M.J.Gladstone@liverpool.ac.uk




Appendix C: Consent forms



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Alder Hey Children's 
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Parent Consent Form

Participant identification Number of this study:

**Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care"**

Research team: Ayuko Komoriyama (MPhil Student), Melissa Gladstone (Neurodisability Consultant),
Fauzia Paize (Consultant Neonatologist), Christopher Dewhurst (Consultant Neonatologist)

Please initial box

1. I confirm that I have read the interview information sheet dated 13.01.2017 (version 2)/ focus group information sheet 13.01.2017 (version2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3. I understand that my data will be anonymised after the interview / focus group. Therefore, I will not be able to withdraw my data once it has been anonymized.

4. I understand that an audio recorder will be used during the interview/ focus group and it will be anonymised. I give permission for my interview/ focus group discussion to be recorded and kept it for analysis purposes.

5. I understand that relevant sections of my medical notes and data collected during the study, may be looked at by individuals from Liverpool Women's NHS Foundation Trust, Alder Hey Children's NHS Foundation Trust, the University of Liverpool, from regulatory authorities where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records.

6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.

Parents' consent form. FOUNDATION study. IRAS 217848. Version 2. 13.1.16

7. I agree to take part in the above study, as part of a one to one interview

8. I agree to take part in the above study, as part of a focus group discussion

Name of Participant Date Signature

Name of Person taking consent Date Signature

Principal investigator:

Name Dr. Melissa Gladstone
Work address Alder Hey NHS Children's Foundation Trust
 East Prescott Rd, West Derby, Liverpool L14 5AB
Work telephone 01512525250
Work Email M.J. Gladstone@Liverpool.ac.uk

Student researcher:

Name Ayuko Komoriyama
Work Email hlakomor@liv.ac.uk

Professional Consent Form

Participant Identification number for this study:

**Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care"**

Research team: Ayuko Komoriyama (MPhil Student), Melissa Gladstone (Neurodisability Consultant),
Fauzia Paize (Consultant Neonatologist), Christopher Dewhurst (Consultant Neonatologist)

Please initial box

1. I confirm that I have read the information sheet dated 13.01.2016 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
3. I understand that an audio recorder will be used during the interview and it will be anonymised. I give permission for my interview discussion to be recorded and kept it for analysis purposes.
4. I understand that my data will be anonymised after the interview. Therefore, I will not be able to withdraw my data once it has been anonymised.
5. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers.
6. I agree to take part in the above study, as part of a one to one interview

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

Principal investigator:

Name Dr. Melissa Gladstone
Work address Alder Hey NHS Children's Foundation Trust
East Prescott Rd, West Derby, Liverpool L14 5AB
Work telephone 01512525250
Work Email M.J. Gladstone@Liverpool.ac.uk

Student researcher:

Name Ayuko Komoriyama
Work Email hlakomor@liv.ac.uk

Appendix D: Patient Pre-interview Questionnaire

FOUNDATION study



Alder Hey Children's 
NHS Foundation Trust

Liverpool Women's 
NHS Foundation Trust

Patient Pre interview Questionnaire

Project Title:

Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care"

Research team: Ayuko Komoriyama (MPhil Student), Melissa Gladstone (neurodisability consultant), Fauzia Paize (Consultant neonatologist), Christopher Dewhurst (Consultant neonatologist)

The questions below will be filled out from the case file by the primary researcher (Ayuko Komoriyama).

Date of the interview: _____

Are they live in- Liverpool, Sefton, Knowsley

Age of the child today _____

Gestational age of the child at birth _____

Birth weight _____

Mother's age when the child was born _____ **Her current age** _____

Did the child stay in NICU/HDU/SCBU? YES NO

If yes, which hospital was it? _____

Any diagnosis that child has

FOUNDATION study

Number of children _____

These questions will be asked at the beginning of the interview and filled in by the primary researcher (Ayuko Komoriyama).

Did you other children stay in NICU/HDU/SCBU?

If so, why?

Who is at home with you and your child?

Can I just ask- are you working at present? YES NO

What do you do? _____

Does your child go to nursery? YES NO

Do you feel well supported in looking after your baby? YES NO

Which professionals have you seen and where?

Appendix E: Topic guides

FOUNDATION Study

Topic guide for parents and carer

Project Title:

Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care"

Research team: Ayuko Komoriyama (MPhil Student), Melissa Gladstone (neurodisability consultant), Fauzia Paize (Consultant neonatologist), Christopher Dewhurst (Consultant neonatologist)

Thank you very much for coming today to attend this session. Today, we want to talk you about your child and how we monitor your child's development. We also want to know what kind of information you get during the time you are in the NICU and where and how you get that information and advice after you left hospital- we want to explore what you find useful and what you did not like about the follow-up system we provide particularly relating to your child's development.

Discharge

1. Can you tell me about the information regarding development (e.g. milestones/ steps for growth) that you were given around the time of discharge?
2. Did you have a good understanding of the long-term outlook for your baby?

Prompt

- What kind of information regarding child development did you receive whilst your baby was in NICU?
- What did you think about the amount of information you were given?
- How was your baby's condition and growth explained to you?
- How prepared were you when you were discharged?
- Can you tell me the story of what happened after the discharge?
- Where did you get the information about the follow-up?
- Who did you get it from?
- What could be improved about the support system at discharge?

After the discharge

3. Can you tell me what happened after you were discharged from the hospital?
 - How did you prepare for any future acute illness? What kind of information

FOUNDATION study. Patient topic guide. IRAS 217848. Version 1. 31/10/16

1

FOUNDATION Study

were you provided when you were discharged?

- Can you tell me the problems that you have encountered since your child left the hospital?

Current service

4. Can you tell me about your child's developmental follow up?
5. Can you tell me your opinions and views of your child's developmental follow up and the support system you received from the hospitals or the communities?
6. Who would you identify as being the lead professional for your developmental follow up?

Prompt

- Can you tell me how your child has been monitored by different health care professionals? (who, where, how often)
 - How is it benefiting you and your child?
 - How easy is it to ask for help or raise your concerns to the professionals you see?
 - How do you feel about the current follow-up system and support you could get from the professionals?
 - Can you tell me about the things that stop you from being able to ask questions or voice concerns?
 - Would you like to see other healthcare professionals? Why?
 - Was there anything about the follow-up service and support that you particularly liked?
 - How satisfied are you with current follow-up system/ scheduled follow-up clinics?
 - What could be improved about the follow-up system?
 - How would you want to change the system if you can?
 - How likely are you to recommend this follow-up system if your friends or family go through a similar situation?
7. How much did you know or understand about the milestones e.g. when to introduce solids, what to look out for?
 - Can you tell me about what you had heard or knew about play and early developmental stimulation and if so, where did you hear this from?

FOUNDATION Study

8. Have you used social media or support groups to share your experience with other families?

(What do you think about it?)

➤ If yes: how did you feel about it?, If no: what stopped you from joining the group?

9. Do you have any concerns?

10. Do you have any questions?

Topic guide for professionals

Project Title:

Neurodevelopmental follow-up for high-risk babies in Liverpool; A qualitative study
FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care"

Research team: Ayuko Komoriyama (MPhil Student), Melissa Gladstone (neurodisability consultant),
Fauzia Paize (Consultant neonatologist), Christopher Dewhurst (Consultant neonatologist)

1. Can you tell me about follow-up of children who are at high-risk who have left the Liverpool Women's Hospital?
2. Can you tell me who you follow-up and how you identify the high-risk patients?
3. Are there standardised procedures in place? /What are the systems that are in place just now? Tell me about them?
4. Can you tell me about the care package that parents can get when they leave the hospital?
5. Are you using any particular neurodevelopmental assessment tools? Can you tell me the tools that you use while you are assessing the patient?
6. Can you tell me about what you think that parents think of these follow-up?
7. Can you tell me how you communicate between different healthcare professionals working in the follow-up clinics?
8. Do you think there is a good teamwork between different healthcare professionals, hospitals and communities?
Why? Why not?
9. Can you tell me about a different follow-up system or assessment tool that you have encountered before that you would like to use here?
10. Can you tell me about the things you would like patients to do before coming into the clinics?
11. What do you think is the most important system in follow-up system?
12. How would you like to change the current system?
13. What do you think we can do to improve the service?
14. If the developmental system to be changed, will there be any difficulties?
15. In August 2017 the NICE guidance for neurodevelopmental follow-up of high risk infants will be published. How do you think this will help you in the future?
16. Is there anything else that you would like to tell me or discuss?
17. Do you have any concerns?
18. Do you have any questions?

Appendix F: Ethical Approval by the Health Research Authority



Health Research Authority

Dr Melissa Gladstone
Department of Women and Children's Health
Institute of Translational Medicine
University of Liverpool
Alder Hey Children's NHS Foundation Trust
Eaton Road
Liverpool
L12 2AP
M.J.Gladstone@liverpool.ac.uk

Email: hra.approval@nhs.net

17 February 2017

Dear Dr Gladstone,

Letter of HRA Approval

Study title:	Neurodevelopmental follow-up for high-risk babies in Liverpool: qualitative study. FOUNDATION study "Follow-Up for NeuroDevelopmentally AT risk Infants Of Neonatal care"
IRAS project ID:	217848
Protocol number:	UoL001259
REC reference:	17/WM/0016
Sponsor	University of Liverpool

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.

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- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](http://www.hra.nhs.uk), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](http://www.hra.nhs.uk).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

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If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

Your IRAS project ID is **217848**. Please quote this on all correspondence.

Yours sincerely

Gemma Oakes
Assessor

Email: hra.approval@nhs.net

Copy to: *Mr Alex Astor, University of Liverpool [Sponsor Contact]*
 sponsor@liv.ac.uk
 Miss Lucy Cooper, Alder Hey Children's NHS Foundation Trust [Lead NHS R&D
 Contact]
 Lucy.Cooper@alderhey.nhs.uk
 Miss Ayuko Komoriyama, University of Liverpool [Student]
 hakomor@liv.ac.uk

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Appendix A - List of Documents

The final document set assessed and approved by HRA Approval is listed below.

<i>Document</i>	<i>Version</i>	<i>Date</i>
Contract/Study Agreement [Statement of Activities]	1	09 February 2017
Contract/Study Agreement [Schedule of Events]	1	09 February 2017
Interview schedules or topic guides for participants [FOUNDATION Study. Parent topic guide 31.10.16]	1	31 October 2016
Interview schedules or topic guides for participants [FOUNDATION Study. Parent topic guide 31.10.16]	1	31 October 2016
Interview schedules or topic guides for participants [Parents topic guide for focus groups]	Version 1	27 December 2016
IRAS Application Form [IRAS_Form_20122016]		20 December 2016
IRAS Application Form XML file [IRAS_Form_20122016]		20 December 2016
IRAS Checklist XML [Checklist_23012017]		23 January 2017
Letter from sponsor [FOUNDATION Study. Sponsorship approval letter 08.12.15]	1	08 December 2016
Non-validated questionnaire [FOUNDATION Study. Pre interview questionnaire. 12.10.16]	1	12 October 2016
Other [Information for recruitment to the FOUNDATION study for recruiters]	Version 1	28 December 2016
Other [FOUNDATION Study. Poster. 24.10.16]	1	24 October 2016
Other [FOUNDATION Study. Inclusion criteria for professionals in the clinic]	1	14 November 2016
Other [Parents Topic Guide Focus Groups]	1	27 December 2016
Participant consent form [FOUNDATION Study. Professional consent form. 22.11.16]	2	13 January 2017
Participant information sheet (PIS) [FOUNDATION Study. Professional information sheet. 28.10.16]	2	13 January 2017
Research protocol or project proposal [FOUNDATION Study. Protocol. Version 1. 22.11.16]	2	13 January 2017
Summary CV for Chief Investigator (CI) [CURRICULUM VITAE. Dr Melissa Gladstone]	1	09 December 2016
Summary CV for student [CURRICULUM VITAE. Ayuko Komoriyama]	1	15 December 2016
Summary CV for supervisor (student research) [CURRICULUM VITAE. Dr Chris Dewhurst]	1	12 December 2016
Summary CV for supervisor (student research) [CURRICULUM VITAE. Dr Fauzia Paize]	1	14 December 2016

Appendix B - Summary of HRA Assessment

This appendix provides assurance to you, the sponsor and the NHS in England that the study, as reviewed for HRA Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England to assist in assessing and arranging capacity and capability.

For information on how the sponsor should be working with participating NHS organisations in England, please refer to the, *participating NHS organisations, capacity and capability and Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria) sections in this appendix.*

The following person is the sponsor contact for the purpose of addressing participating organisation questions relating to the study:

Name: Dr Melissa Gladstone

Email: M.J.Gladstone@liverpool.ac.uk

HRA assessment criteria

Section	HRA Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	The applicant has confirmed the completed consent form will be placed on the site file, medical records and also provided to the participant.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The sponsor has provided a Statement of Activities and Schedule of Events. No other form of agreement is required or has been provided.
4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this

Section	HRA Assessment Criteria	Compliant with Standards	Comments
			research study.
4.3	Financial arrangements assessed	Yes	The study is not externally funded.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	REC Favourable Opinion was issued on 31 January 2017.
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England

This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.

There is one site type participating in this study. Research activity is the same at all participating NHS organisations as detailed in the study protocol.

Please note that the remit of HRA Approval is limited to the NHS involvement in the study. Research activity undertaken at non-NHS sites is therefore not covered and the research team should make appropriate alternative arrangements with relevant management at these organisations to conduct the research there.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England in order to put arrangements in place to deliver the study. The documents

should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. For NIHR CRN Portfolio studies, the Local LCRN contact should also be copied into this correspondence. For further guidance on working with participating NHS organisations please see the HRA website.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England which are not provided in IRAS or on the HRA website, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net. The HRA will work with these organisations to achieve a consistent approach to information provision.

Confirmation of Capacity and Capability

This describes whether formal confirmation of capacity and capability is expected from participating NHS organisations in England.

Participating NHS organisations in England **will be expected to formally confirm their capacity and capability to host this research.**

- Following issue of this letter, participating NHS organisations in England may now confirm to the sponsor their capacity and capability to host this research, when ready to do so. How capacity and capability will be confirmed is detailed in the *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* section of this appendix.
- The [Assessing, Arranging, and Confirming](#) document on the HRA website provides further information for the sponsor and NHS organisations on assessing, arranging and confirming capacity and capability.

Principal Investigator Suitability

This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and the minimum expectations for education, training and experience that PIs should meet (where applicable).

The sponsor has confirmed that a Local Principal Investigator would be required at each participating site and these have already been identified.

GCP training is not a generic training expectation, in line with the [HRA statement on training expectations](#).

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

The sponsor has confirmed that, all study activities at participating NHS organisations will be undertaken by local staff who have a contractual relationship with the relevant organisation. Therefore no honorary research contracts or letters of access are expected for this study.

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Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.