A Mixed Methods Study of the Follow Up of Extremely Preterm Babies in the North East of England

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A Mixed Methods Study of the Follow Up of Extremely Preterm Babies in the North East of England - Abstract

1. Background

Neonatal intensive care medicine has improved considerably over time, leading to increased neonatal survival, and improved survival of preterm babies (babies born before 37 weeks gestation). In 2012, the WHO declared their commitment to reducing the mortality and morbidity related to prematurity by several interventions, including updated approaches to community-based follow up care for preterm babies.

According to the Office for National Statistics (ONS), 2,490 babies were born in England and Wales in 2018 between 23- and 27- weeks gestation, accounting for approximately 0.3% of all live births. The 2017 National Institute for Health and Care Excellence (NICE) guideline made recommendations for the developmental follow up of children and young people born preterm and acknowledged the conditions linked to preterm delivery. The follow up of preterm babies determines the baby's outcomes, their parents' needs, and informs planning of health and social care resources.

Previous research on barriers and facilitators to neonatal follow up showed that the birth of a preterm baby is a stressful event, for both mothers and fathers. Parents develop a different pattern of parenting, stemming from the concept of increased vulnerability of the preterm baby. The communication between parents and health professionals is important, and poor communication increases parental stress levels. Studies underlined the relevance of the relationships established between parents and neonatal staff to parents' experiences.

2. Aim

This study used a mixed methods design to assess the neonatal follow up of extremely preterm babies, focusing on attendance rates in relation to morbidities and demographic characteristics, as well as parents' and health professionals' perceptions of the neonatal follow up.

3. Methods

This study involved two phases. Phase one was an analysis of demographic, morbidity, mortality, and 2-year neurodevelopmental outcomes data of a cohort of babies born before 28 weeks gestation in the North East of England, over a 12-month period between July 2015 and June 2016, recorded in the Badger database.

Phase two was a qualitative study of parents' and health professionals' (HPs) views, perceptions, and experience of the follow up of extremely preterm babies. Parents were recruited to the study during their attendance for their baby's follow up appointments and were interviewed using a topic guide. Seventeen semi-structured interviews were carried out with 23 parents of babies born before 28 weeks completed gestation, between January and December 2018. Thematic analysis based on the Braun and Clarke model was used.

Twenty one-to-one, semi-structured interviews were carried out with HPs involved in the follow up care of preterm babies, between October and December 2018. Data were analysed using thematic analysis.

4. Results

The recruitment rate for phase one was 61% of the eligible babies; 86.2% of the babies included were born after 24 weeks gestation, with a mean gestation age (GA) of 25+3 weeks and a mean birth weight (BW) of 805 grams. More than three quarters of babies were discharged home on oxygen. Of the cases where information was available, half of the babies showed developmental delay, with half of these cases showing moderate to severe delay. There was no formal diagnosis of cerebral palsy recorded in the Badger database.

The analysis of the parents' interviews identified two key themes: 'Emotions' and 'Here and now'.

The first theme, 'Emotions', included three subthemes: 'The emotions related to the preterm birth - a rollercoaster', 'The post-traumatic stress syndrome' and 'The overprotective parent'. Following the birth of their preterm baby, parents experienced mixed and contradictory emotions, compared to a rollercoaster, which may contribute to developing symptoms suggestive of post-traumatic stress syndrome. Parent participants developed an overprotective type of parenting, as previously described in literature.

The second theme, 'Here and now', included four subthemes: 'The storytelling', 'The coping mechanism', 'The impact of being born early' and 'The value of the

follow up'. Future parents expected a normal term pregnancy, followed by a normal birth; the normality was interrupted by the onset of preterm labour. This interruption marked the beginning of a different experience, the quality of which impacted on the bonding and relationship between baby and parents, and the relationships between parents and HPs. Parents reported that follow up offered reassurance.

The analysis of the HPs' interviews identified two key themes: 'Communication' and 'The Child Not Brought'. The first theme, 'Communication', included two subthemes: 'The Journey' and 'The multi-disciplinary team post discharge'.

The HPs described the experience of the birth and the follow up of a preterm baby as a journey and continuity of care was a marker of quality. HPs understood that the follow up offers reassurance and support to parents. There was a diversity of job roles of HPs involved in the care and follow up of preterm babies, leading to the formation of a multi-disciplinary team (MDT). Communication occurred in every direction between the members of the MDT, in many ways (written/verbal, formal/informal, paper/electronic).

The second theme, ‘The Child Not Brought’ included three subthemes: ‘The impact on the baby’, ‘The NHS point of view’ and ‘Why do parents not attend?’.

HPs suggested several potential reasons why parents may not bring their child(ren) to the follow up appointments: parents may not understand the role of the follow up, especially if the child is well; parents fear bad news; families may have a busy life, have too many appointments or have just seen another HP; communication breakdown (related to system or human factors); neglect; distance and travel; psychological issues (fear to leave the house, bad memories linked to the hospital environment).

5. Discussion

Findings from this research provide important insights into the views and experiences of parents of preterm babies with regards to their baby's follow up appointments. The birth of a preterm baby is a stressful event; parents develop a different pattern of parenting, stemming from the concept of the increased vulnerability of the preterm baby.

HPs described the birth and follow up of an extremely preterm baby as a journey. The continuity of care and good communication contribute to improving this journey. Due to the complexity of the team involved in the follow up of the extremely preterm baby, there were challenges in communication, at different levels.

Relatively small changes in practice, such as allowing for normality by encouraging the parents to read to their baby at night-time, and ensuring adequate communication and appropriate reassurance, could improve the parents' experience, their engagement with follow up appointments, and therefore their baby's outcomes.

NICE recommends follow up of babies born extremely preterm to school age, however there is no established referral pathway into the paediatric services. Parents value continuity of care, which may

be challenging if there is no clear transition process between neonates and paediatrics. Ensuring a smooth transition at every level by designing a clear pathway for the neonatal follow up of extremely preterm babies and the transition to paediatric services may improve the follow up process, parents’ engagement with the system and their baby’s outcomes.

5. Key words

Preterm, follow up, parents’ experience, health professionals’ views, transition of care.

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Abbreviations used in thesis

ADHD Attention deficit hyperactivity disorder

ANS Antenatal steroids

APH Ante-partum hemorrhage

ASD Autism spectrum disorder

ASQ Ages and Stages Questionnaire

BAPM British Association of Perinatal Medicine

BPD Bronchopulmonary dysplasia

BSITD III Bayley Scales for Infant and Toddler Development III

BW Birth Weight

CAG Confidentiality Advisory Group

CI Chief Investigator

CNN Canadian Neonatal Network

CP Cerebral Palsy

DCCT Direct Clinical Care Team

EBM Expressed breast milk

EDD Estimated date of delivery

EPIBELL Extremely Preterm Infants in Belgium

EPICE Effective Perinatal Intensive Care in Europe

EPIPAGE Etude Epidémiologique sur les Petits Ages Gestationnels

EXPRESS Extremely Preterm Infant Study in Sweden

GA Gestational Age

GBS Group B Streptococcus

GDPR General Data Protection Regulations

GP General Practitioner

GMFCS Gross Motor Function Classification System

HP Health Professionals

HRA Health Research Authority

IQ Intelligence Quotient

IT Information Technology

IUGR Intrauterine growth restriction

IVF In-vitro fertilisation

IVH Intra-Ventricular Haemorrhage

JCUH James Cook University Hospital

LMP Last menstrual period

MBBRACE Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries

MDT Multi-disciplinary team

nCPAP nasal continuous positive airway pressure

NEC Necrotising Enterocolitis

NHS National Health Service

NICE National Institute for Health and Care Excellence

NICU Neonatal Intensive Care Unit

NNN Northern Neonatal Network

NNeTS Northern Neonatal Transport Service

ODN Operational Delivery Network

ONS Office for National Statistics

OPINE Outcomes of Preterm Infants in the North East

PARCA – R Parent Report of Children's Abilities-Revised

PDA Persistence of Ductus Arteriosus

PEG Percutaneous endoscopic gastrostomy

PG Participant group

PMA Postmenstrual age

PROM Prolonged rupture of membranes

PTSS Post traumatic stress syndrome

PVL Peri-Ventricular Leukomalacia

ROP Retinopathy of Prematurity

RVI Royal Victoria Infirmary

SD Standard Deviation

SDQ Strengths and Difficulties Questionnaire

SENCO Special educational needs coordinator

SGA Small for gestational age

SRH Sunderland Royal Hospital

UHNT University Hospital of North Tees

US United States

USS Ultrasound

WHO World Health Organisation

VICS Victorian Infant Collaborative Study

VP Ventriculo-peritoneal

Definitions

Gestational age (GA) is defined as the age of the fetus in terms of pregnancy duration in weeks, measured from the first day of the last menstrual period (LMP); by convention, gestation is recorded as completed weeks.[a]

Estimated date of delivery (EDD), or the due date, is 40 weeks added to the first day of the LMP and estimates the day when the infant will be born.[a]

Postmenstrual age (PMA) is the time elapsed between the first day of the LMP and the current day. It can be calculated as the gestational age plus the time elapsed after birth (chronologic age). PMA is used clinically during the neonatal period beginning after the day of birth.[a]

Corrected age describes children up to two years old who were born preterm, and it represents the age of the child since the EDD. [b]

Term birth is defined as birth at 37 to 42 weeks completed gestation. [a]

Preterm birth is defined as any birth prior to 37 weeks completed gestation, by international classification.[a]

Extremely preterm are babies born before 28 weeks completed gestation, by consensus. For this study, babies born before 28 weeks are named ‘very’ preterm. This term was used in the parental information leaflets as it appeared to bear less negative connotations, compared to the term ‘extremely’.[a]

Small for gestational age (SGA) is defined as weight less than 10th percentile at a given fetal gestation.[a]

Live birth is defined as the complete expulsion or extraction of the product of human conception regardless of the duration of pregnancy and following expulsion the infant breathes or shows other signs of life such as a beating heart, pulsation of the umbilical cord, or definitive movement of voluntary muscles. [a]

Fetal death is death of the product of human conception prior to complete expulsion or extraction from the mother regardless of the duration of pregnancy. Death is indicated by the fact that after expulsion/extraction, the fetus does not breathe or show any other evidence of life, such as a beating heart or pulsation of the umbilical cord. [a]

Stillbirth is legally defined as the birth of a baby with no signs of life at, or after, 24 completed weeks of gestation, in the UK.[a]

Viability (fetal viability) is the ability of a fetus to survive outside the uterus. There are controversies regarding the clear limit of development, age, or weight at which a human fetus becomes viable; survival rate increases with gestation. [c]

Outborn is a baby born preterm in a local unit and transferred to a tertiary/intensive care neonatal unit after delivery (ex-utero).[d]

Inborn is a baby born preterm in a centre with a tertiary neonatal unit. [d]

Stillbirth rate: number of stillbirths per 1000 live births and stillbirths.[a]

Infant mortality rate: number of deaths at age under 1 year per 1000 live births.[a]

Perinatal mortality rate: number of stillbirths plus number of deaths at age under 7 days per 1000 live births and stillbirths.[a]

Early neonatal mortality rate: number of deaths at age under 7 days per 1000 live births.[a]

Neonatal mortality rate: number of deaths at age 28 days and over, but under 1 year, per 1000 live births. [a]

Bronchopulmonary dysplasia (BPD) is defined as mechanical ventilatory support via endotracheal tube (ETT) or nCPAP (nasal continuous positive airway pressure) at 36 weeks PMA, or supplemental O_2 at 36 weeks PMA. [e]

Pulmonary hemorrhage is defined as copious blood secretions in the endotracheal aspirate associated with clinical deterioration, requiring change(s) in ventilator management.[e]

Necrotising enterocolitis (NEC) is defined as clinical and radiological concerns suggestive of bowel inflammation, stage Bell 2 or more, medically or surgically managed.[e]

Suspected NEC is defined as clinical and radiological concerns suggestive of bowel inflammation, not fulfilling criteria for Bell stage 2 or more.[e]

Bell stages for classification of NEC are: Stage 1: mild systemic and intestinal signs, plus non-specific radiological features; Stage 2: moderate systemic signs with prominent abdominal distension, abdominal tenderness and abdominal wall oedema, plus pneumatosis intestinalis and portal venous gas on abdominal x ray; Stage 3: worsening stage 2 signs and symptoms, plus hypotension, signs of peritonitis, severe metabolic acidosis and shock, and pneumoperitoneum on abdominal x ray.

Hypotension is defined clinically as need of volume and/or inotropes to maintain blood pressure within normal.[e]

Risk factors for infection are: invasive group B streptococcal infection in a previous baby; maternal group B streptococcal colonisation, bacteriuria or infection in the current pregnancy; prelabour rupture of membranes; preterm birth following spontaneous labour; PROM suspected or confirmed; intrapartum fever higher than 38 degree Celsius or confirmed/suspected chorioamnionitis; parenteral antibiotic treatment given to the woman for confirmed or suspected invasive bacterial infection (such as septicemia) at any time during labour, or in the 24-hour periods before and after the birth, which does not refer to intrapartum antibiotic prophylaxis; suspected or confirmed infection in another baby in the case of a multiple pregnancy.[f]

Prolonged rupture of membranes (PROM) is defined as rupture of membranes more than 18 hours prior to delivery of a preterm baby.[f]

Chorioamnionitis is defined as maternal fever $\geq$ 38.4 degree Celsius within 24 hours of birth, uterine tenderness, maternal leukocytosis >15000/mm^3; or inflammation on placental pathology.[f]

Sepsis is defined as a positive bacterial, fungal, or viral culture in blood and/or cerebrospinal fluid and need for course of antibiotics of at least five days. [e]

Suspected sepsis is defined as a course of antibiotics longer than 48 hours based on clinical concerns with negative blood culture.[e]

Clinical concerns for sepsis: increased oxygen requirements, increased ventilatory support, increased bradycardias/apnoeas, temperature instability, ileus/feeds intolerance/abdominal distension, reduced urine output <1 ml/kg/hr, CRT >3 seconds or mottled or core-peripheral temperature gap >2 degrees Celsius, hypotension, irritability or lethargy or hypotonia.[e]

Significant retinopathy of prematurity (ROP) is defined as stage 3 or more ROP, ‘plus’ disease or need for treatment.[e]

Significant patent ductus arteriosus (PDA) is defined as PDA that required treatment, medical or surgical.[e]

Significant intracranial abnormality is defined as grade 3 or 4 intraventricular hemorrhage (IVH) or ventricular dilatation >=10 mm, intra-parenchymal hemorrhage, or periventricular leukomalacia (PVL) on cranial USS or other imaging.[e]

Neurological impairment means that the capacity of the nervous system is limited or impaired with difficulties in one or more of the following areas: the use of memory, the control and use of cognitive functioning, sensory and motor skills, speech, language, organisational skills, information processing, affect, social skills, or basic life functions.[a]

Severe neurodevelopmental disability is defined as any one of: cerebral palsy with GMFCS level 3,4 or 5; score <-3 standard deviations below norm (DQ <55); no useful hearing even with aids (profound >90dBHL); no meaningful words or signs or unable to comprehend cued command; blind or can only perceive light or light reflecting objects.[c]

*Moderate neurodevelopmental disabilit*y is defined as any one of: cerebral palsy with GMFCS level 2; score -2SD to -3SD below norm (DQ 55-70); hearing loss corrected with aids (usually moderate 40-70 dBHL) or some hearing, but loss not corrected with aids (usually 70-90 dBHL); some language but fewer than five words or signs or unable to comprehend un-cued command but able to comprehend a cued command; moderate reduced vision or blind in one eye with good vision in contralateral eye.[c]

Mildly impaired is defined as GMFCS class 1 and/or mild hearing impairment and/or mild visual impairment and/or Bayley composite score 85 - 90.[c]

Moderately impaired is defined as GMFCS class 2 and/or moderate hearing impairment and/or moderate visual impairment and/or Bayley composite score 70 - 85.[c]

Severely impaired is defined as GMFCS class 3 - 5 and/or complete deafness and/or complete blindness and/or Bayley composite score <70.[c]

Learning disability includes the presence of a significantly reduced ability to understand new or complex information in learning new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning), which started before adulthood, with a lasting effect on development.[a]

Cerebral palsy (CP) describes a group of disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder.[c]

Gross motor function classification system (GMFCS) is a five levels clinical classification system that describes the gross motor function of people with cerebral palsy (CP), based on self-initiated movement abilities. Level I: walks without limitations; Level II: walks with limitations; Level III: walks using a hand-held mobility device; Level IV: self-mobility with limitations, may use powered mobility; Level V: transported in a manual wheelchair.[c]

Developmental delay is defined as a condition which represents a significant delay in the process of development.[c]

Developmental delay is defined as per BAPM criteria, based on the outcome of the 2-years Bayley III assessment, where *normal development* is defined as DQ >85 or less than 3 months delay, *mild developmental delay* is defined as DQ 70 - 84 or 3 – 6 months delay, m*oderate developmental delay* is defined as DQ 55 - 69 or 6 – 12 months delay and s*evere developmental delay* is defined as DQ <55 or more than 12 months delay.[c]

Unit 1 = Royal Victoria Infirmary Newcastle; *Unit 2* = James Cook University Hospital; *Unit 3* = University Hospital of North Tees; *Unit 4* = Sunderland Royal Hospital.[1]

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[a]WHO criteria; [b] **Age Terminology During the Perinatal Period,** Pediatrics Nov 2004, 114 (5) 1362-1364; [c]BAPM criteria; [d]BADGER definitions; [e]ELFIN trial definitions, adapted for this study; [f]NICE guidelines.

Chapter 1. Introduction

1.1. Background

In 2012, the WHO published ‘Born too soon’ – The Global Action Report on Preterm Birth.[1] The report shows that approximately 15 million babies are born preterm (less than 37 weeks gestation) every year around the world, and there has been an increase in preterm birth rates over the last 20 years. For example, in the US, according to the same report, the prematurity rate has increased by 30% between 1981 and 2010.[1] This may be due to changing antenatal care and obstetric practices, such as more caesarean sections performed before term, as well as changes in postnatal approach. [1]

The survival at extreme gestations depends significantly on the country of birth, with mortality rates as high as 90% in low-income countries. More than 60% of preterm births occur in South Asia and Sub-Saharan Africa. In 2012, the WHO proposed to reduce the neonatal mortality rate due to preterm birth by 50% between 2010 and 2025, in countries where neonatal mortality is more than 5 in 1000 live births, and to eliminate preventable preterm deaths and to reduce impairment in survivors in countries where mortality is less than 5 in 1000 live births. [1] In the UK, neonatal mortality rate in 2012 was 2.8 deaths per 1000 live births, according to the Office for National Statistics (ONS) data.

The WHO suggested interventions to improve antenatal care, to strengthen the availability and quality of data on preterm births, to conduct research into interventions to treat babies that are born preterm and to update the approach to community-based follow up care for preterm babies.[1]

Neonatal intensive care medicine has improved considerably over time, leading to improved neonatal survival, including improved survival of preterm babies. Our approach to extremely preterm babies (<28 weeks gestation) has changed significantly. [2] The perinatal management of extremely premature birth, from 22+0 to 26+6 weeks gestation, is guided by a risk stratification of every case, and parents are involved throughout the decision - making process. The risk stratification and counselling of parents are both based on existing evidence about outcomes of preterm birth. [3,4]

There is an apparent extension of the limit of viability, resulting from data suggesting that babies born at 22 weeks receiving active management have a chance of survival approaching that of babies born at 23 weeks. [5,6]

According to ONS data, 2,490 babies were born in England and Wales in 2018 between 23- and 27+6 weeks gestation, accounting for approximately 0.3 % of all live births. The Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBBRACE) Perinatal Mortality Surveillance report 2018 showed that the neonatal mortality rate in the UK was 1.64 per 1,000 live births (of babies born after 24 completed weeks gestation), with a mortality rate of 142.6 per 1,000 live births for babies born between 24 and 27+6 weeks gestation.[7] Almost three quarters of the babies who died were born before 37 weeks, with 45% of neonatal deaths occurring in babies who were born extremely preterm (22+0 to 27+6 weeks gestation). According to this report, Asian and African British newborn babies were 60% more likely to die than White babies, and women living in the most deprived areas are at an 80% higher risk of stillbirth and neonatal death compared to women living in the least deprived areas.[7]

Babies born early have a higher risk of developing associated health problems, developmental delay, and behavioural problems, with implications on family life and planning of health and social care.[8-12]

The follow up of preterm babies determines the baby's outcome and their needs, the needs of their parents or carers, and informs planning of health and social care resources. Achieving good outcomes is an aspiration of all neonatal care providers. Information regarding short term outcomes is generally collected in terms of survival at discharge from hospital, however practitioners strive to maximise survival without disability and/or minimise significant morbidity and longer-term outcomes.

1.2. Prematurity Associated Morbidity and Longer-term Outcomes

Babies born preterm are at risk of developing associated co-morbidities, such as bronchopulmonary dysplasia (BPD), necrotising enterocolitis (NEC), sepsis, persistence of ductus arteriosus (PDA), retinopathy of prematurity (ROP), intra-ventricular haemorrhage (IVH) and their complications. The National Institute for Health and Care Excellence (NICE) guideline published in 2017 [13] acknowledges the following conditions as being linked to preterm delivery: cerebral palsy (CP), motor function problems, learning disability, special education needs, speech language and communication disorders, attention deficit hyperactivity disorder (ADHD) and autism spectrum disorder (ASD), emotional and behavioural problems, [14] feeding and sleeping problems, visual and hearing impairment, and developmental delay.

1.2.1. Bronchopulmonary Dysplasia

BPD is a routinely reported outcome for this population. BPD is a chronic lung disease that predominantly affects babies born preterm and is currently described both in the population of babies who required prolonged respiratory support, and also in babies who had minimal lung disease initially. [15] The criteria used to diagnose BPD vary and there are differences in the natural course of the disease.[9, 15] Babies with BPD have increased respiratory morbidity in the first years of life and an increased number of general practitioner (GP) attendances and hospital admissions due to their increased vulnerability to common respiratory infections.[16]

1.2.2. Necrotising Enterocolitis

Another significant morbidity associated with prematurity is NEC. There is increasing evidence that the clinical course and surgical implications of NEC in preterm babies are variable and may be due to more than one pathophysiological mechanism.[17,18] NEC has a high mortality rate (almost 30%), it prolongs the hospital stay, has long term complications such as short gut and liver dysfunction and has a serious impact on neurodevelopmental outcome. About 50% of the NEC population have a poorer developmental outcome compared to babies who had meningitis.[19]

1.2.3. Developmental Delay and Behavioural Issues

Babies born preterm have a high risk of developmental delay, which can be multifactorial. The preterm brain is immature, and its development is affected by early nutritional deficits, [20] as well as infections (sepsis, NEC, meningitis). [21] Preterm babies have a higher risk of developing intraventricular hemorrhage (IVH) and periventricular leukomalacia (PVL), with further effect on brain plasticity and development.[22] Visual and hearing impairment are significantly higher in this population compared to babies born at term.[23,24] The development and social skills of extremely preterm babies who suffer from comorbidities and require frequent medical visits and re-hospitalisation in the early years of life, may be affected by their inability to participate in regular activities and may result in challenging behaviour.[12] Parenting behaviours may also be affected by the emotional distress associated with the birth of a very preterm baby. Parents may develop overprotective behaviours and failure to set limits, with further adverse impact on the child's ability to function in the social environment.[12, 25 -29]

1.3. Follow up Studies of Preterm Babies

Large epidemiologic studies have been performed with the aim of describing outcomes of preterm babies, including the EPICure 1 and 2 studies based in the UK and studies conducted in other European countries and Australia. [3,4,8 -11, 21,30 - 35] Some of these studies report longer term outcomes such as neurodevelopment and disability, up to school age.[33] A summary representation of these studies can be found in Table 1.

STUDY NAME	SETTING	POPULATION	STUDY PERIOD	OUTCOMES MEASURED	% FOLLOWED UP	COMMENTS
EPICURE 1	UK	<26 weeks	1995	Survival; neurodevelopment at 2.5-years		Follow up to age 19-years.
EPICURE 2	UK	<26 weeks	2006	Survival; neurodevelopment at 2-years	55.3%	Classification of outcomes as per 1995 definitions, to allow comparison between EPICure 1 and 2 cohorts.
EXPRESS	Sweden	<27 weeks	2004 – 2007	Survival at 1-year; neurodevelopment at 2.5-years	94%	Study showed 78% survival to 1-year.
EPIPAGE 1	France	<32 weeks	1997	Survival; cerebral palsy, developmental delay		Follow up to 12-years.
EPIPAGE 2	France	<34 weeks	2011	Survival; cerebral palsy, developmental delay	56%	This study had a low follow up rate at 2-years of age.
VICS	Australia	<28 weeks	2005	Disability rate; cognitive, academic, and behavioural outcomes at 8-years of age	90%	This study had a 90% follow up rate at 2-years, and more than 80% follow up at 8-years of age.

EPICE	11 European countries	<32 weeks	2012	Developmental delay	65%	Follow up at 2-years of age.
CNN	Canada	<29 weeks	2011	Survival; neurodevelopment	80%	Follow up at 2-years of age.
EPIBEL[44]	Belgium	<26 weeks	2000	Mortality; disability	54%	Follow up at discharge, at 3-years of age (54%) and 45% at 11-years

Table 1. Cohort studies of the follow up of preterm babies

The EPICure 1 and 2 studies collected data of two cohorts of babies born before 26 weeks gestation, in 1995 and 2006, respectively. In 2006, 13.4% of babies had severe impairment at three years of age, and 11.8 % babies had moderate impairment.[8] Severe impairment was defined as Gross Motor Function Classification System (GMFCS) levels 3 to 5 CP, blindness, profound hearing loss and a Bayley Scales for Infant and Toddler Development III (BSITD III) score of less than 3 standard deviations (SD) below the mean for age. Moderate impairment was defined as level 2 CP as per GMFCS, impaired vision and hearing, or a BSITD III score of 2 or 3 SD below the mean.[8] Data showed a 13% increase in survival at 3-years of age and increased survival without disability at 25 weeks gestation. These studies showed a possible change in the threshold for admission to intensive care and active intervention at low gestations.[8]

The EXPRESS study showed a 78% survival at 1-year of age, and a severe or moderate disability rate of 27% and any disability rate of 58% at 2.5-years of age.[10] Severe disability was defined as BSITD III composite score of less than 3 SD below mean for age, severe CP, or bilateral blindness or deafness. Moderate disability was defined as any BSITD III score between −2 and −3 SD from the mean, moderate CP, and moderate visual or hearing impairment. The severity of CP was defined based on the ability to walk with or without an aid.[10]

The French EPIPAGE group reported a 40% overall disability rate at 5-years of age for the cohort of children born before 32 weeks gestation in 1997. [34]

In Australia, in 2005, the overall disability rate for babies born before 28 weeks was 21%, with 4% severe disability, at 8-years of age.[35] VICS study used the term ‘major neurosensory disability’, defined as any of moderate or severe CP, an intelligence quotient (IQ) of less than -2 SD compared to term controls, blindness, or deafness.[35]

The EPICE cohort included babies born before 32 weeks gestation in 11 European countries. The study used parent completed questionnaires to assess development at 2-years of age (Parent Report of Children's Abilities-Revise (PARCA-R), and Ages and Stages Questionnaire (ASQ)).[31]

CNN – the Canadian Network study used BSITD III to assess babies born before 29 weeks and reported a rate of severe neurodevelopmental impairment of 17% and a rate of any neurodevelopmental impairment of 46%. This study used the term ‘significant’ neurodevelopmental impairment defined as a BSITD-III cognitive score of < 70, severe CP, blind or hearing aided.[30]

These are large studies involving complex multidisciplinary teams and significant funding. However, there is no clear consensus regarding the classification of prematurity, with each study using a different cut off gestation. The definition of disability or impairment in these studies also varies. While most studies used BSITD III, the definition of severity of CP, as well as the definition of overall disability/impairment varies with each study. There is variability in study design, possibly due to local variation in the organisational framework of neonatal care, as well as variation in the ethical processes. Most studies have a follow up rate of 60 - 80%.

The CNN suggests that the babies who were not brought for the follow up had an initial disease of less severity (higher gestation age (GA), higher birth weight (BW), less complications, less severe initial course). [30] However, a previous study by Tin et al., in the North East of England, showed that babies who are more difficult to follow up are more likely to be disabled and to suffer long term consequences of prematurity;[36] while Andrews et all raised the issue of neglect in the case of children not brought for their appointments. [37]

It is therefore important to address the issues related to the outcomes of preterm birth in the context of local frameworks for neonatal care.

1.4. UK Neonatal Follow Up Framework

The 2017 NICE guideline made recommendations for the developmental follow-up of children and young people born before 30 weeks. This guideline acknowledges the following conditions as being linked to preterm delivery: cerebral palsy, motor function problems, learning disability, special education needs, speech language and communication disorders, ADHD and ASD, emotional and behavioral problems,[13] feeding and sleeping problems, visual and hearing impairment, and developmental delay.[13] Some of these associations depend on the perinatal course; but there are also factors linked to the baby's social and economic background. For example, the risk of developmental delay is higher in babies of black and other ethnic minorities' background or when mother comes from a low income or disadvantaged background.[13]

NICE recommends that developmental follow up for babies at risk should be by face-to-face meetings, by phone or by emailing parents; by providing appropriate information and a single point of contact. A minimum of two visits face-to-face should take place in the first year of life, followed by a detailed developmental assessment at 2-years for children born before 28 weeks, as well as further assessment at 4-years of age. NICE recommends the use of the PARCA-R questionnaire at 2-years and the use of SDQ and ASQ at 4-years, as well as a standardised IQ test.[13] The NICE guideline underlines the importance of the multidisciplinary team.

Missed appointments impact considerably on the NHS. They are associated with high costs and may limit the access to services of others. Between November 2017- May 2018 (with data missing in December 2017), 6,840,160 'did not attend' appointments were recorded by NHS Digital in general practice, accounting for a possible loss of approximately 200 million pounds over the six months (with an estimate cost of £30.00 per appointment).[38] Previous studies have shown that children who miss appointments are more likely to be disabled[36] and at risk of ill health[37] or suffer from abuse or neglect. [39] A study by Pennefather et al. showed that the prevalence of health problems may be underestimated by incomplete follow up. [40]

The VICS study showed that while the engagement with the research project was very good, with a study follow up rate of 98%, only 50% of eligible children received follow up, and the engagement with the clinical pathway was very poor (32%), mainly due to loss of contact. [32-35]

Due to missed follow up appointments, it is possible that children will not benefit from early intervention and support. The lack of early intervention and prevention may translate in higher costs of care later.

1.5. The Bayley Scales of Infant and Toddler Development III (BSITD III) and other methods to assess neurodevelopment

BSITD III assessment is part of routine follow up care for babies born before 28 weeks in the North East of England. The BSITD III is a standardised assessment that can be used between 16 days and 3.5 years of life.[41] The assessment describes seven different aspects of development: cognition, receptive language, expressive language, fine motor skills, gross motor skills, adaptive behaviour, and socio-emotional development. The child is assessed according to their specific age and scored. The raw scores are converted to scaled scores. The scaled scores are available for all subtests and derive from the subtest total raw scores; they range from 1-19 with a mean of 10 and a SD of 3. The scaled scores are then converted to composite scores. Composite scores are derived from various sums of subtest scaled scores and are generated for the language scale, motor scale, and the adaptive behaviour scale. They range from 40-160 with a mean of 100 and SD 15. Composite scores equivalents are available for the cognitive and social-emotional scales. Percentile ranks are available for all five scales, and they range from 1 to 99 with a mean of 50. The confidence interval generally used is 95% with a p value of 0.05.[41]

Other types of developmental assessment can be used, such as Griffith's score, PARCA-R (Parent Report of Children's Abilities-Revised), or the Schedule of growing skills, however BSITD III is still considered to be the gold standard for neurodevelopmental assessment by many practitioners.

The NICE guideline (2017) [13] recommended the use of PARCA-R questionnaire as a suitable alternative to the Bayley's assessment. The PARCA-R was used routinely recently due to the Covid pandemic and the restrictions to face-to-face appointments. [42] PARCA-R is a parent completed questionnaire that can be used to assess children's cognitive and language development at 24 months of age. This questionnaire was originally developed by Professor Robert Plomin and colleagues to assess the cognitive and language development of 2-years old children in the Twins Early Development Study,[43] and was adapted and validated for use with children born very preterm in 2004. [42]

1.6. Knowledge Gap and Need for Research

Outcome data are used to counsel parents and influence decision making in the perinatal period. Large studies are expensive and involve a considerable amount of work, hence they are not easily reproducible and may become outdated. Local data are subject to biases, often related to small numbers. The use of national data such as data resulting from the UK National Neonatal Audit Programme (NNAP RCPCH) may improve the precision and provide a baseline for evaluating performance of individual institutions. However, the quality of data resulting from the national audit is variable and does not fully describe the outcomes of preterm babies or explain the reasons why parents do not bring their children to follow up appointments. There is, therefore, a further need to analyse the life course of a baby born extremely preterm and their prematurity associated needs, as well as a need to consider their parents' views and the impact prematurity and follow up processes and procedures have on parents, to understand the way parents engage with the follow up. [13, 44] This is in line with the WHO recommendations to update the approach to community based follow up for preterm babies.[1]

1.7. Study Aim and Objectives

The OPINE (Outcomes of Preterm Infants in the North East) study is a mixed methods study, assessing the neonatal follow up of extremely preterm babies, focusing on attendance rates in relation to morbidities and demographic characteristics, as well as parental and health professionals' (HPs) perceptions of neonatal follow up, with the aim of describing barriers and facilitators to attendance to follow up.

The study had several objectives:

- To analyse a cohort of babies born before 28 weeks GA in a defined geographical region and describe their perinatal course and the extent of postnatal care that they required.
- To describe the outcomes for this cohort at 2-years of age from the neurodevelopmental, behavioural and general health point of view.
- To analyse parents' views and experience of the routine follow up offered and the difference they considered this to have made to the care of their baby.
- To analyse HPs' views and experience with regards to the follow up of extremely preterm babies.

Chapter 2. Methods

2.1. Overview of methods

The study used a mixed methods approach to enable capturing different aspects of the neonatal follow up. The cohort of babies was described using quantitative data, while their parents' and the HPs' insights into neonatal follow up was analysed using qualitative methods.

2.1.1. Overview of methods

- Analysis of demographic, morbidity and mortality, development and behaviour data of a cohort of babies born before 28 weeks in the North East of England (Figure 1), over 1-year time.
- Thematic analysis of interviews exploring parents' views, perceptions and experience of the follow up of extremely preterm babies.
- Thematic analysis of HPs' views, perceptions and experience of the follow up of extremely preterm babies, as well as the HPs' insight into parents' views.

2.1.2. Methods of data collection

The study used several methods of collecting data:

- accessing demographic, morbidity and mortality data from the Badger database[1], case notes and parents' completed questionnaires.
- collecting 2-years developmental outcome data from the Badger database and the Strengths and Difficulties

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[1] The Badger database or The National Neonatal Research Database (NNRD) is a resource available for research and audit. Data (maternal demographic and health details, data about delivery, data about postnatal day to day care, and the health and neurodevelopmental assessment at 2-years of age) are entered into an electronic system (Badger.net) by clinicians. All neonatal units in England, Wales and Scotland contribute with information. [45]

Questionnaire(s) (SDQ) completed by parents (on paper or online on the study's website)

- collecting anonymised replies of parents of babies admitted previously to a tertiary neonatal unit, using online questionnaires and the social media channel of a charity.
- topic guided interviews with parents of babies born before 28 weeks, and with HPs involved in the care and follow up of babies born before 28 weeks.

2.2. Study design

2.2.1. Study phases

This study involved two phases.

Phase one involved an analysis of demographic, morbidity, mortality, and 2-year neurodevelopmental outcomes data of a cohort of babies born before 28 weeks gestation in the North East of England, over a 12-month period (between 1st of July 2015 and 30th of June 2016).

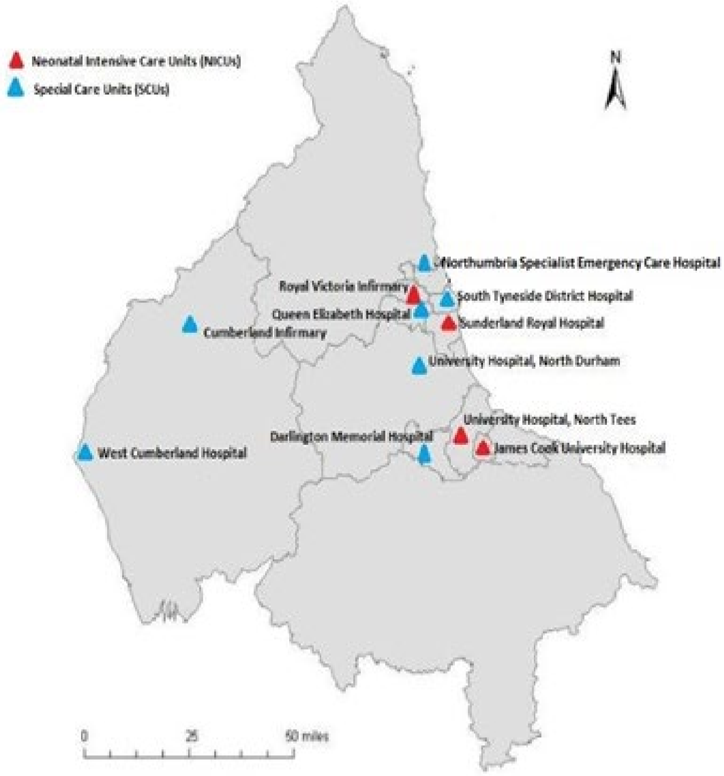
Phase two was a qualitative study of parents' and HPs' views, perceptions, and experience of the follow up of extremely preterm babies. This phase involved parents of babies born before 28 weeks in the North East of England between 1st of July 2015 and 30th of June 2016; and HPs involved in the follow up of extremely preterm babies born in the North East of England.

A short, anonymised survey through the website of a charity providing support to babies and their parents was used to capture views of a wider group of parents of babies admitted to a NICU.

2.2.2. Neonatal follow up in the North East of England

Figure 1 shows the geographical region that the OPINE study took place in and the location of Trusts with NICUs.

Figure 1. Map of study area



The neonatal care in the North East of England is coordinated by the Northern Neonatal Network (NNN), one of the 11 designated and mandated Operational Delivery Networks (ODNs) for neonatal care in England.

At the time of the study, there were four tertiary neonatal units in the North East of England: Royal Victoria Infirmary, Newcastle; James Cook University Hospital, Middlesbrough; University Hospital of North Tees, Stockton-on-Tees and Sunderland Royal Hospital, Sunderland. All babies born before 28 weeks were admitted to one of these four units for intensive care. Once their clinical status improved, babies were transferred back to the local special care unit, for further care. The follow up was provided by the local unit and/or by the tertiary unit, depending on the baby's status on discharge and parents’ preferences. The neurodevelopmental follow up at 2-years of age was usually provided by the tertiary unit the baby was initially admitted to.

The NNN benefits of the services of the Northern Neonatal Transport Service (NNeTS), based in Newcastle.[46]

2.3. The recruitment process

2.3.1 Recruitment methods

Babies born before 28 weeks in the North East of England, between 1st of July 2015 and 30th of June 2016, were identified by the direct clinical care team (DCCT) using the Badger database correlated with Spine, the NHS number tracking system. The variables used were date of birth between 1st of July 2015 and 30th of June 2016, GA less than 28 weeks and admission to one of the four tertiary neonatal units in the North East of England. The NHS number was used to ensure that data were not duplicated. Babies who were alive at 2-years corrected age underwent developmental, behavioural and general health assessment. This assessment is part of the routine neonatal follow up of babies born extremely preterm, in the North East of England. Data resulting from the assessment are entered in the Badger database by the clinician who administers the assessment. These data are part of the national neonatal audit process. Routine attendance for the developmental follow up at 2-years of age was used to introduce the parents to the study by the DCCT; parents were provided with information leaflets, Strengths and Difficulties Questionnaires (SDQ) and consent forms (Annexes 1, 2, 3). When parents did not bring their baby to the 2-years follow up appointment, a similar information pack was sent by post by the DCCT. If parents chose to reply by completing the study developed questionnaire (Annexe 4), the information obtained by the DCCT was anonymised prior to being submitted to the researcher. Parents who consented to enroll their baby(ies) in the study completed the consent form on behalf of their baby.

Parents were also asked if they were happy to be contacted later to discuss their experience in more depth, about the follow up processes and the impact of the follow up in the care of their child in the form of a topic guided interview (Annexe 6). If parents agreed, the researcher then followed up with a phone call explaining the purpose of the interview. Parents were asked to complete a separate written consent form expressing their consent to interview, at the time of the interview (Annexe 5).

Due to limited time and resources, only one pack was sent in the post to parents who did not attend the 2-years follow up appointment. In the case of parents who consented to the study, the researcher sent between two and five follow up reminders if the parents had not returned the questionnaires.

The researcher also approached HPs involved in the care and follow up of extremely preterm babies. The criteria for inclusion were based on accessibility and willingness to participate. Efforts were made to include a group of HPs representative for the multi-disciplinary team involved in the care of babies born preterm, by approaching HPs with different roles, working across the region. HPs were provided with information about the study (Annexe 7) and asked to provide written consent by completing a consent form (Annexe 9).

Following the issuing of the Data Protection Act 2018, implementing the General Data Protection Regulations (GDPR), a transparency declaration was also added to all information leaflets (Annexe 8).

A short, anonymised questionnaire (Annexes 11 and 12) was also used to capture views from a wider group of parents of babies admitted to a NICU, through the Facebook page of The Tiny Lives Trust, a charity providing support to babies and their parents. This approach was used to mitigate the selection bias, that will be described in detail in a subsequent chapter.

Both topic guides (Annexes 6 and 10) used a mix of open questions (for example: 'How do you feel the routine clinic appointments helped?' or 'How do you think the follow up visits were important?') and closed questions (such as: 'How many health professionals do you see currently for your baby?'). The interviewer adopted an active listening approach.

2.3.2. Ethical approval

This study was registered with the UK Health Research Authority (HRA), IRAS number 225912, and obtained ethical approval (IRAS number 225912, North East - York Research Ethics Committee, reference 17/NE/0265 on 27/09/2017; Annexe 13).

All activities related to this study have been compliant with the standard operating procedures for research of South Tees

Hospitals NHS Foundation Trust and Newcastle University guidelines for researchers and data handling.

Written information was presented to the potential participants explaining the nature of data collection, the way that data will be used and the implications of the findings. The information leaflets stated that there is no obligation for the potential participant to take part in this study. All participants provided signed consent forms.

All documents were stored securely in a locked cabinet in a locked room in the James Cook University Hospital - Neonatal Unit. Data were stored safely on NHS computers, password protected. No identifying information was stored outside NHS computers.

2.3.3. Challenges in obtaining ethical approval

A recent study assessed the acceptability of the methods used to facilitate recruitment in studies to UK RECs, focusing on the acceptability of opt-out consent.[47] This study identified a need for guidance for RECs in relation to opt-out consent processes. In the case of the OPINE study, the initial proposal involved overseeing of the project by the Chief Investigator (CI). The CI would identify all patients, collect all perinatal data existing in the Badger database, as well as follow up data resulting from the attendance at the 2-years follow up, and then attempt to contact parents who did not bring their children to the appointments. This approach had several advantages: consistency in the way perinatal data were collected, with one clinician interpreting the data and making sure that in every case the definitions were followed; a lower risk of duplicating or missing babies. However, this approach involved accessing identifying patient data without consent by the CI (i.e. person outside the DCCT). Therefore, as per existing HRA regulations, the study applied for support from the Confidentiality Advisory Group (CAG), under section 251 of the NHS Act 2006, a law meant to support research in the NHS when there is a conflict between the study requirements and the Data Protection Act 1998, while also protecting the patient’s rights and avoiding litigation. The support for the study was requested on the following grounds: CAG precedent Category 1: to identify cohort of patients and subsequently ask consent and CAG precedent Category 2: access to deceased person data. Also, support for accessing identifiable data without consent was requested in those cases where parents did not bring their child to the routine appointment, and in those cases where parents could not be contacted despite reasonable efforts. The research team also referred to managing non-response guidance, referring to those cases where there is a ‘legal interplay’ between the NHS Act 2006 section 251 and the Data Protection Act 1998.[37] We highlighted the fact that the follow up appointment benefits the child, who is therefore being denied the right to access good quality care by not being brought to the appointment.

We considered the reasons why parents may not bring their high – risk children to their medical appointments. Access to the records of those patients whose parents proved impossible to contact maybe important to understanding these reasons.

We argued that by applying the ‘managing non-response’ guidance in this case, the study will become prone to selection bias, as the parents likely to take part in the study will be those who already engage with services, by attending the follow up appointments. It may be that the most vulnerable group of parents, represented by those parents who either do not understand the significance of the follow up, or do not have the means to bring their children to appointments, or are neglecting their children’s needs will not have the opportunity to take part in the study and make their voice heard.

Following analysis, the CAG appreciated that there are options to conduct the study that will not involve accessing identifiable data without consent by people who are not members of the DCCT. Therefore, we applied for a substantial amendment to HRA, and the final version of the study protocol stated that only DCCT members may access identifiable patient data without consent. This led onto the study design used in this project.

2.4. Support for the study

2.4.1. Patient and Public Involvement

Parents and public members have been consulted during the set-up phase of the study. Their opinion was sought when designing the parent information leaflets, the questionnaires, and the lay summary of the study (Annexe 15). The information leaflets and the lay summary have been presented to an event with patients and public involvement and further advice was sought from VoiceNorth. Their feedback was included in the final form of the lay summary and the information leaflets. I made changes to the parent information leaflets, so that they are clearer, based on the advice received from VoiceNorth and from parents of preterm babies that we cared for. I sought the opinion of parents who already come to the follow up clinic with regards to the questionnaires used and how they felt about discussing the follow up process. The parents offered positive verbal feedback. I was invited to write on the VoiceNorth blog, and I reflected on the role of shared decision-making in research (Annexe 14).

Information regarding the study is accessible online on the *neonatalresearch.net* website.

2.4.2. The Northern Neonatal Network

The study benefited of support from the Northern Neonatal Network, the neonatal consultant teams, and the research nurses on all four sites involved. I presented about the study at several meetings, including The Northern Neonatal Network Research Conference, Boldon, September 2018; The Northern Neonatal Network Research Meeting – virtual, September 2020; presentations for the clinical teams involved in the study (as a mean to keep the teams updated and involved), and poster presentations at conferences such as the European Academy of Paediatric Societies Conference 2020 and The Perinatal Update Virtual Conference – BAPM 2020 (Annexe 16).

2.5. Description of data

2.5.1. Quantitative data

Quantitative data were used to describe the cohort of babies involved in the study.

Data were analysed separately, for the two main groups of babies: eligible and non-eligible, where non-eligible babies were considered babies who did not survive to the time of the 2-years neurodevelopmental follow up.

In the case of the babies who did not survive to the time of the 2-years neurodevelopmental follow up, the study collected anonymised perinatal data regarding demographic and health data of the mother (maternal age and parity, index of deprivation, maternal health data: infection risk, antenatal hemorrhage, maternal diabetes, pregnancy induced hypertension, other maternal health problems) and baby (gender, GA, BW, antenatal steroids (ANS), type of delivery, type of intervention and birth, temperature on admission, time and cause of death).

For the cohort of eligible babies, the
parameters analysed were demographic data regarding the baby (gender, GA, BW) and mother (parity, age, index of deprivation, infection risk, antenatal hemorrhage, maternal diabetes, pregnancy induced hypertension, other maternal health problems), birth data (ANS administration, type of delivery, type of intervention at birth, temperature on admission) and short-term outcomes for the baby: type and length of respiratory support, development of BPD and need for home oxygen, use of postnatal steroids for BPD, incidence of sepsis, incidence of NEC (surgically or medically managed), other surgical or medical problems (treated PDA, significant cranial ultrasound (USS) abnormality, type of feeding and availability of expressed breast milk (EBM) on discharge, discharge weight.
The study aimed to provide a comparison between the two groups, in terms of possible outcome contributing factors, such as maternal health, degree of prematurity, BW, ANS, temperature on admission and complications of prematurity.

Secondly, the study included the assessment
of neurodevelopment, based primarily on the results of the BSITD III at 2 years corrected age, assessment of behaviour and the assessment of the baby’s general health. Data were obtained from the Badger database, study-developed parental questionnaire, and the SDQ 2-4y full. The SDQ is not currently part of the NICE recommendations for the assessment at 2-years of age, as it is not yet fully validated for this age group. As the study started prior to the release of the NICE guidelines, the

choice of questionnaire was not based on this guideline.
Scoring for SDQs was completed by hand by the researcher.

At 2-year corrected age, babies underwent neurodevelopmental assessment using BSITD III. For this study, the age ranges were: 18 months 16 days (18m 16 d); 19m15d; 19m16d-22m15d; 22m16d-25m15d; 25m16d- 28m15d, however children were assessed as near to the age of 2-years corrected for GA as possible. Data obtained from the electronic records and the questionnaires returned by parents were used to describe the developmental outcome (normal, mild delay, moderate delay, severe delay), the association with significant long-term morbidity and the existence of behavioural problems.

Quantitative data were analysed using descriptive statistics (using the statistical analysis software for Microsoft Excel).

2.5.2. Qualitative data

Two subsets of qualitative data were obtained from the topic guided interviews with: a) parents, and b) HPs.

The interviews were transcribed verbatim. The parents' interviews were transcribed by the researcher, to ensure consistency and complete anonymity throughout, as the researcher appreciated that some of the data resulting from the parents' interviews were particularly sensitive and potentially identifying. The HPs' interviews were transcribed using a transcription company recommended by the University and then checked by the researcher for accuracy.

For both groups, interviews continued until saturation of themes was obtained and/or the participants' cohort appeared inclusive.

Saturation occurs when no new themes are emerging from the interviews.[48] Inclusive meant that, in the case of the parents, the study included parents living in different parts of the region, and of different social and ethnic backgrounds; in the case of the HPs, the study included HPs working in all four tertiary units and in varied job roles.

The two subsets of data were classified using the NVivo12 software and were analysed separately, using thematic analysis, based on the Braun and Clarke model.[48] The complete coding approach was used, in a thorough, inclusive, and systematic way. Transcripts were entered in the NVivo software, each interview was marked as participant group (PG) and numbered. Data were then explored, to observe the emergence of themes. Key words and phrases were highlighted, by using the software as well as paper and coloured visual aids, leading to creating the initial codes. These codes were reviewed by the researcher and their supervisors and data meetings were held to identify the recurring themes, language, opinions and believes, and to define the themes and sub-themes.

The researcher has acknowledged the supervisors' contribution to data collection and analysis in Chapters 5 and 6.

2.5.3. *Web based survey*

A short, anonymised survey was launched with the help of Tiny Lives Trust's Facebook page for a period of three months (September – November 2018) (Annexes 11 and 12). The survey asked parents who are members of the Tiny Lives Facebook group of their opinions about neonatal follow up, with the aim to assess the representability of the parents interviewed for the general population of parents of babies admitted to the neonatal unit. The survey used a mix of closed and open-ended questions; data obtained were a mix of numeric data and parents’ quotes.

Chapter 3. Description of a cohort of extremely preterm babies born in the North East of England, from the demographic, morbidity, and neurodevelopmental outcomes perspective

3.1. Introduction

Quantitative data were used to describe the cohort of babies involved in the study and were analysed using descriptive statistics.

Data were retrieved from:

- The Badger database
- Electronic records
- The Study Developed Parental Questionnaire and the SDQ 2-4y full (Annexes 3 and 4).

3*.1.1. The Badger database*

The Badger database is used by all four units involved in the study; the input into the database is however variable. At the main surgical unit, the database is completed by the nursing staff, on admission and then every day. The information regarding diagnosis of co-morbidities may depend on the interpretation given by the nursing staff at the time. For example, a baby may be suspected of developing sepsis and started on antibiotics, however these may be stopped after 48 hours if suspicion was not confirmed.

At the other three units, the database is completed by the consultant team, on admission, and by the junior staff on discharge; the discharge details are used as the discharge letter. There is no day-by-day information available.

3.1.2. The electronic records

All sites use electronic records; however, some sites are completely paper lite, and other still use paper notes. The information is often scattered and may not be easily found. Due to limited resources, paper notes have not been retrieved. Therefore, there are limited data about mother's ethnicity, occupation, smoking status and BMI, as well as limited data regarding the babies' cranial USS results.

3.1.3. Questionnaires

Parents were asked to complete questionnaires about their children's health when they were contacted by post (Annexe 4), as well as the SDQ 2-4full.

3.1.4. Data definitions

Due to the variability in the use of the Badger database in the different units as well as the different types of resources available for each baby, care was taken to define the variables used. Some variables from the Badger database were grouped and coded together. For example, 'maternal health problems' were grouped as follows (where the numbers in brackets represent the original Badger code):

1 - none (00),
2- drug/alcohol abuse (10, 11),
3- mental health problems (23),
4 - diabetes (15),
5 - other (12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 24, 25, 26, 27, 28, 29, 30, 88),
6 - infection (HIV, hepatitis B/C, syphilis,)
7 - not recorded.

A similar approach was used to code 'problems pregnancy mother':

1 - None (00),

2 - concerns regarding fetal wellbeing (10, 11, 12),

3 - fetal/amniotic fluid abnormality (13, 14, 15, 16, 17),

4 - infection concerns (18, 19, 20, 22, 23, 24),

5 - Rh/other haemolytic disease (25, 26),

6 - cervical suture (21),

7 – antepartum haemorrhage (APH) (27, 28, 29),

8 - hypertension (30, 31, 32),

9 - gestational diabetes (33),

10 - other (34, 88),

11 - not recorded.

The categories were grouped together based on categories of disease, for example all types of bleeding in pregnancy were coded in the same category: ante-partum haemorrhage (APH), to facilitate analysis.

The main co-morbidities for the neonate were defined separately. For example, *sepsis* is defined as a positive bacterial, fungal, or viral culture in blood and/or cerebrospinal fluid and need for course of antibiotics of at least five days; while *suspected sepsis* is defined as a course of antibiotics longer than 48 hours based on clinical concerns with negative blood culture, for the purposes of this study. Definitions considered sources such as previous studies,[49] the Badger database definitions and BAPM criteria for disability.[50]

3.1.5. Statistics

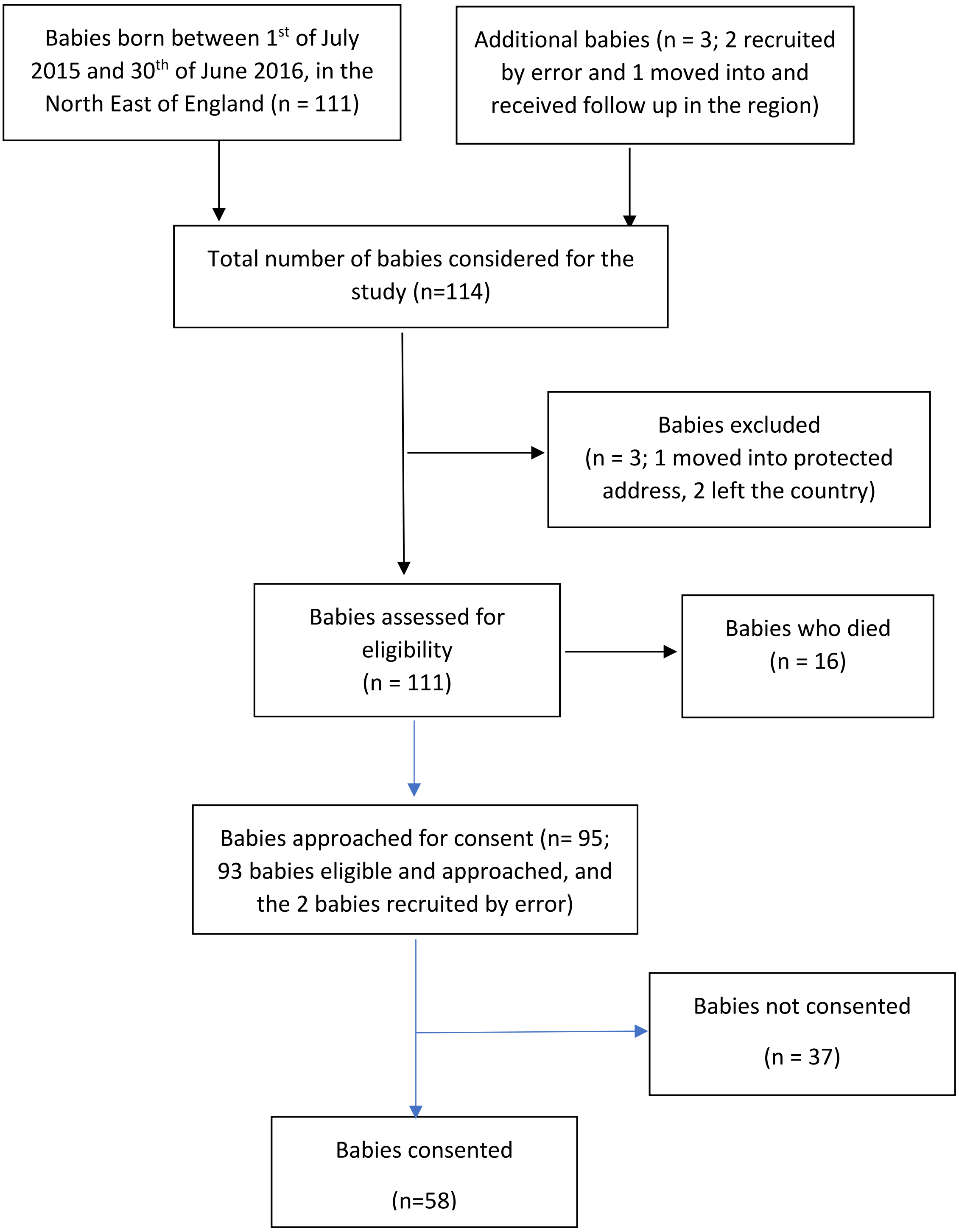
Quantitative data were analysed using descriptive statistics and included percentages, means, and SD. Due to the limited number of participants and missing data in some cases, in-depth statistical analysis was not considered appropriate.

3. 2. Defining the population

This study included all babies born before 28 weeks completed GA, in the North East of England (Figure 2), between 1st of July 2015 and 30th of June 2016, who were admitted to one of the four neonatal tertiary units and were eligible to receive neonatal follow up at 2-years corrected age.

3.2.1. Cohort description

Figure 2. Flow diagram of cases through the study



A total of 111 babies met the study’s inclusion criteria: were born before 28 weeks completed GA in the North East of England between 1st July 2015 – 30th June 2016 and admitted to one of the four tertiary neonatal units in the region: Royal Victoria Infirmary, Newcastle (RVI, Unit 1); James Cook University Hospital, Middlesbrough (JCUH, Unit 2); University Hospital of North Tees, Stockton on Tees (UHNT, Unit 3) and Sunderland Royal Hospital, Sunderland (SRH, Unit 4).

Three babies were excluded: one had been adopted and two babies had left the country. Sixteen babies died before the age of 2-years.

Two other babies were recruited in error, in two different units, one at the beginning of the recruitment period and one at the end. They were both born before 28 weeks completed gestation, however their date of birth was outside the pre-established recruitment period. One baby was born in June 2015 and one baby was born in August 2016. However, both babies have been included in the data analysis. This was because the initial cohort of babies was selected opportunistically (a one-year cohort of babies likely to be 2-years corrected age by the time of the study), and the added two babies were not likely to change the results. Also, a parent of one of these babies expressed their interest in participating in an interview so it was decided to invite the parent to do so.

A further baby was booked for delivery in one of the four units included in the study, but was born out of region, however received the 2-years follow up at Unit 1, hence was included in the study.

3.2.2. Distribution of cases per unit

Table 2 shows the distribution of the study cases by each unit.

Table 2. Distribution of cases per unit

UNIT	NUMBER/ TOTAL	BIRTH POPULATION	MORTALITY AT DISCHARGE	MORTALITY BEFORE 2Y	BABIES ELIGIBLE FOR FOLLOW UP	RECRUITED TO COHORT
Unit 1	57 (50%)	6,752	4 (7%)	5[1]	51[2]	36[4] (70%)
Unit 2	17 (14.9%)	4,865	5 (29.4%)	5	12	5[5] (41.6%)
Unit 3	15 (13.1%)	3,075	4 (26.6%)	4	11	4 (26.6%)
Unit 4	25 (21.9%)	3,092	2 (8%)	2	21[3]	13 (61.9%)
TOTAL	114	17,784	15 (13.1%)	16	95	58 (61%)

[1] One baby died before age 2 y, following discharge from the neonatal unit. [2] One baby was adopted and moved into protected address. [3] Two babies left the country. [4] One extra baby was recruited by error and one other baby moved into region. [5] One extra baby was recruited by error.

Half of the babies recruited during the study period were born at Unit 1. The mortality rate on discharge from Unit 1 was 7% and the recruitment rate for the unit was 70%. Almost a quarter of the babies were born at Unit 4, with a mortality on discharge of 29.4% and a recruitment rate of 61.9%. The mortality rate for Unit 2 was 29.4% with a recruitment rate of 41.6% and the mortality rate for Unit 3 was 26.6%, with a recruitment rate of 26.6%.

3.3. Data analysis

Data were analysed separately for the two cohorts of babies: eligible and non-eligible.

3.3.1. Demographic and perinatal data analysis of the cohort of babies who died

For the cohort of babies who died, data on maternal characteristics and perinatal data were analysed.

The age range of mothers of babies who died was 16 - 36 years of age, with a mean maternal age of 25-years (SD 6.48).

The mean index of multiple deprivation was 10893.81, on the 3.87 decile.

The Index of Multiple Deprivation ranks every small area in England from 1 (most deprived area) to 32,844 (least deprived area); they are divided in 10 equal groups to generate deciles. [51]

Table 3. Maternal characteristics for the cohort of babies who died*

VARIABLE	CHARACTERISTICS	NUMBER	PERCENTAGE
Primigravida	Yes	3	18.7
	No	13	81.2
Infection risk	Yes	8	50
	No	8	50
Antenatal haemorrhage	Yes	4	25
	No	12	75
Maternal diabetes	Yes	1	6.25
	No	15	93.7
Pregnancy induced hypertension	Yes	4	25
	No	12	75
Antenatal steroids	Yes	12	75
	No	4	25
Other maternal health problems	Yes	6	37.5
	No	10	62.5

*There were no available and/or reliable data in the Badger database with regards to maternal ethnicity, smoking status, or maternal BMI.

Table 4. Perinatal and mortality data for the cohort of babies who died

VARIABLE	CHARACTERISTICS	NUMBER	PERCENTAGE
Gender	Male	8	50
	Female	8	50
Singleton	Yes	12	75
	No	4	25
Gestation (weeks)	<23	2	12.5
	23 -23+6	6	37.5
	24 – 27+6	8	50
Mean GA (weeks)		23+2	
Mean BW (grams)		654.37	
Main cause of death	Extreme prematurity	16	100
Other	Palliation	1	6.2
	Sepsis*	5	31.25
	NEC	7	43.7
	Other**	3	18.7

*positive blood cultures; **lung disease, pneumothorax

3.3.2. Demographic, perinatal and morbidity data of the consented babies

Data regarding the cohort of consented babies were analysed separately to the babies who died. Some of the parameters analysed were similar, such as maternal characteristics, GA, BW and morbidity.

The age range for the mothers of consented babies was 16 – 41 years, with a mean maternal age of 29.5-years (SD 5.77). The mean index of multiple deprivation was 7746.4, on the 2.85th decile.

Table 5. Maternal characteristics for the cohort of consented babies

VARIABLE	CHARACTERISTICS	NUMBER	PERCENTAGE
Maternal age			
Primigravida	Yes	26/58	44.8
	No	32	55.1
Infection risk	Yes	23	39.6
	No	35	60.3
Antenatal haemorrhage	Yes	15	25.8
	No	43	74.1
Maternal diabetes	Yes	4	6.89
	No	54	93.1
Pregnancy induced hypertension	Yes	10	17.2
	No	48	82.7
Antenatal steroids	Yes	56	96.5
	No	2	3.4
Other maternal health problems	Yes	10	17.2
	No	48	82.7

The main outcomes recorded for consented babies were the incidence of BPD (postnatal steroids administration and home oxygen), the incidence of NEC and sepsis, significant cranial USS abnormalities and feeding with maternal milk.

Table 6. Description of the cohort of consented babies and their morbidity data

VARIABLE	CHARACTERISTICS	NUMBER (Total 58)	PERCENTAGE
Gender	Male	26	44.8
	Female	32	55.1
Singleton	Yes	40	68.9
	No	18	31
Gestation (weeks)	<23	0	0
	23 – 23+6	8	13.7
	24 – 27+6	50	86.2
Mean GA (weeks)	25+3 (range 23+1 – 27+6)		
Mean BW (grams)	805 (range 500 – 1200)		
Neonatal factors	Hypothermia on admission	25	43.1
	Surfactant in delivery suite	51	87.9
	Postnatal steroids for BPD	22	37.9
	PDA treated	28	48.2
	NEC*	10	17.2
	Sepsis**	37	63.7
	Significant cranial USS abnormality***	6	10.3
	Received any EBM	55	94.8
	Breast milk on discharge	21	36.2
	Home oxygen	46	79.3

*included surgical NEC or NEC that received conservative treatment more than 5 days. **included positive B/C or episodes treated with more than 5 days of antibiotics. ***cranial USS not recorded in 13 cases.

The mean maternal age was similar between the two groups of babies, and the mothers of babies who died lived in less deprived areas on average. In both groups, there were associated maternal health problems, with 50% incidence of maternal infections in the group of babies who died. A higher percentage of eligible babies received ANS. The babies who died were younger and smaller.

3.3.3. Neurodevelopmental outcomes of the consented babies

Neurodevelopmental outcome data were collected mainly from the Badger database.

Table 7. Neurodevelopmental outcomes of the consented babies

VARIABLE	CHARACTERISTICS	NUMBER	PERCENTAGE
Developmental delay*	None[1]	23	39.6
	Mild[2]	12	20.6
	Moderate[3]	8	13.7
	Severe[4]	5	8.6
Significant long-term morbidity**	Yes	3	5.1
Behavioural problems***	None	13	33.3[6]
	Mild	7	17.9
	Moderate	3	7.6
	Severe[5]	16	41

*no information available in 10 cases. [1]none or <3 months delay. [2]3-6 months delay. [3]6-12 months delay. [4]>12 months delay. **tracheostomy/ventriculo- peritoneal (VP) shunt/gastrostomy (PEG) fed/visual impairment/hearing impairment. Information is not readily available. ***as resulting from the SDQ questionnaires returned by 39 parents. [5] based on SDQ scoring system. [6] of the 39 questionnaires returned.

Almost a quarter of the babies included in study showed moderate to severe developmental delay, based on the results of the neurodevelopmental assessment at 2-years of age.

Thirty-nine parents returned completed SDQ questionnaires. A further questionnaire was completed online on the study website; however, the parents did not return the consent form, hence the child was not recruited to the study. Of the 39 children whose parents completed the SDQs, 15 children had developmental delay. Where there was severe delay or long-term morbidity, a high impact score by the SDQ reply was observed.

3.4. Summary

One hundred and eleven babies were born before 28 weeks completed GA in the North East of England, between 1st of July 2015 and 30th of June 2016 and were admitted to one of the four tertiary neonatal units; of these, 95 babies were eligible for the study. Fifty-eight babies were recruited in the study, with a total recruitment rate of 61%, comparable to the recruitment rate of larger studies, such as EPICure.[8]

The number of babies included is small and the data were missing in some cases. With this in mind, descriptive statistics were used for analysis.

Half of the babies were born at the regional surgical unit, that also had the lowest mortality rate. Overall mortality for the babies considered for the study was 13.1%. The cohort of babies who died were smaller and younger and their mothers had a higher percentage of antenatal infection risk.

Within the consented group, a significant number of babies were hypothermic on admission to the neonatal unit (43.1%). Almost half had their PDA treated, and there was a high incidence of sepsis events (63.7%). Most babies received their mum’s milk at some stage and almost a quarter were still receiving breast milk on discharge. More than two thirds were discharged home on oxygen.

Almost a quarter of the babies included in the study showed moderate to severe developmental delay. In those cases where there was severe developmental delay and/or long-term morbidity, parents also reported a high impact score resulting from the SDQ.

Chapter 4. Descriptive Review of Literature - What Do Parents Think About Neonatal Follow Up?

4.1. Abstract

Background and aim: Missed appointments occur in every paediatric setting and cost the NHS up to one billion pounds per year. This descriptive review of the literature synthesised data about parental perceptions of the birth of their preterm baby, the care received and the process of neonatal follow up, to identify barriers and facilitators to attending follow up clinics.

Methods: Searches of electronic databases and websites (Cochrane, Prospero, Medline, Pubmed, Psychnet, NICE, Google search, NHS website, Tiny Lives, Bliss) were conducted for papers published between 1st January 2013 and 26th April 2018 and identified 937 potential papers. Of these, 35 papers were deemed relevant after reviewing the abstract, of which 24 papers met the inclusion criteria of papers exploring parents' feelings and perceptions related to the birth of their preterm baby, the care offered and the neonatal follow up. An updated search conducted between 26thApril 2018 and 18thJune 2020 identified a further 2502 papers; of which 198 were selected by title and abstract screen. Of these, a further 15 papers were added to the final analysis.

Results: Four key themes resulted from the review: the stress related to the birth of a preterm baby; the increased vulnerability of preterm babies; barriers and facilitators to attending follow up; and communication/relationships between parents and HPs.

The birth of a preterm baby is a stressful event, for both mothers and fathers. Parents develop a different pattern of parenting, stemming from the concept of increased vulnerability of the preterm baby. The communication between parents and health professionals is important, and poor communication increases parental stress levels. Studies underlined the relevance of the relationships established between parents and neonatal staff to parents' experiences.

Discussion: Parents' ongoing engagement with health services is influenced by their existing experiences. Improved understanding of parents' perception of their baby's journey may improve the follow up process.

4.2. Introduction

This is a descriptive review of the literature to assess current evidence regarding parental experiences after preterm delivery and the neonatal follow up. This literature review synthesised data about parental perceptions of the birth of their preterm baby, the care received and the process of neonatal follow up, to identify barriers and facilitators to attending follow up clinics. PRISMA criteria for systematic reviews were used to define the search methods for this descriptive review.

4.3. Methods

4.3.1. Eligibility criteria and studies selection

I conducted searches using a combination of the following terms: (parental OR parents OR family OR mother OR father) AND (premature OR preterm OR low birth weight OR born early) AND (follow up OR clinics OR home visits OR development OR perception OR view OR understanding OR experience). The search included papers published in English only, electronically available, published between 1st of January 2013 and 26th of April 2018, to retrieve studies published in the previous five years.

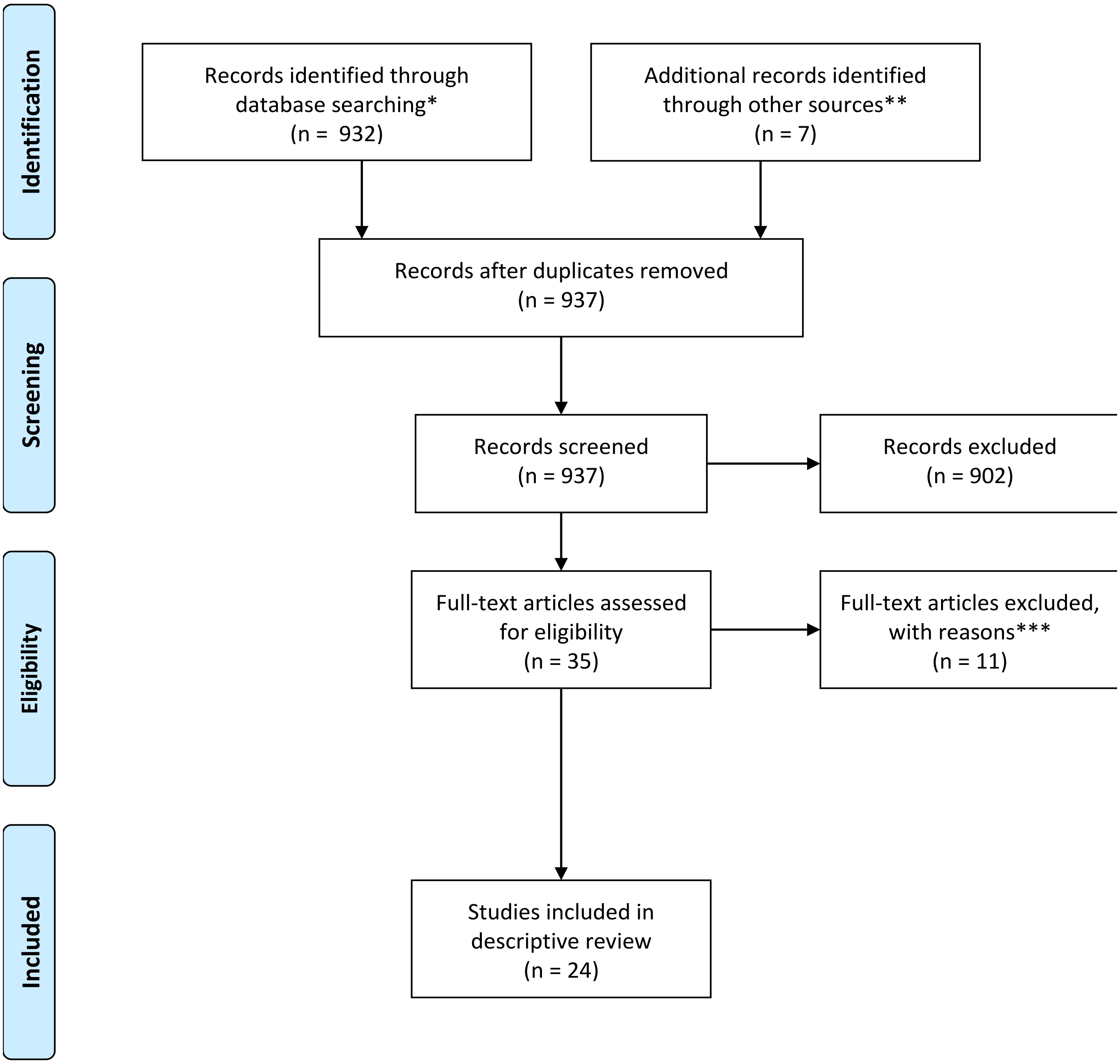
The following databases were searched: Cochrane database of systematic reviews; Prospero database of systematic reviews; Medline; Pubmed; PsycNET; NICE website; Google search; NHS website; Charities' websites (http://www.tinylives.org.uk/; https://www.bliss.org.uk/health-professionals/healthcare-professionals-e-comms).

An updated search was conducted between 26th April 2018 and 18th June 2020, using the same inclusion criteria.

4.3.2. Papers resulting from the literature search

Initial search identified 937 non duplicate citations; 35 publications were retrieved following title and abstract screening. Following full text screening, 24 publications met the criteria of publications exploring parents' feelings and perceptions related to the birth of their preterm baby, the care offered and the process of neonatal follow up and were retained for narrative analysis. The remaining 11 papers did not meet the criteria for inclusion.

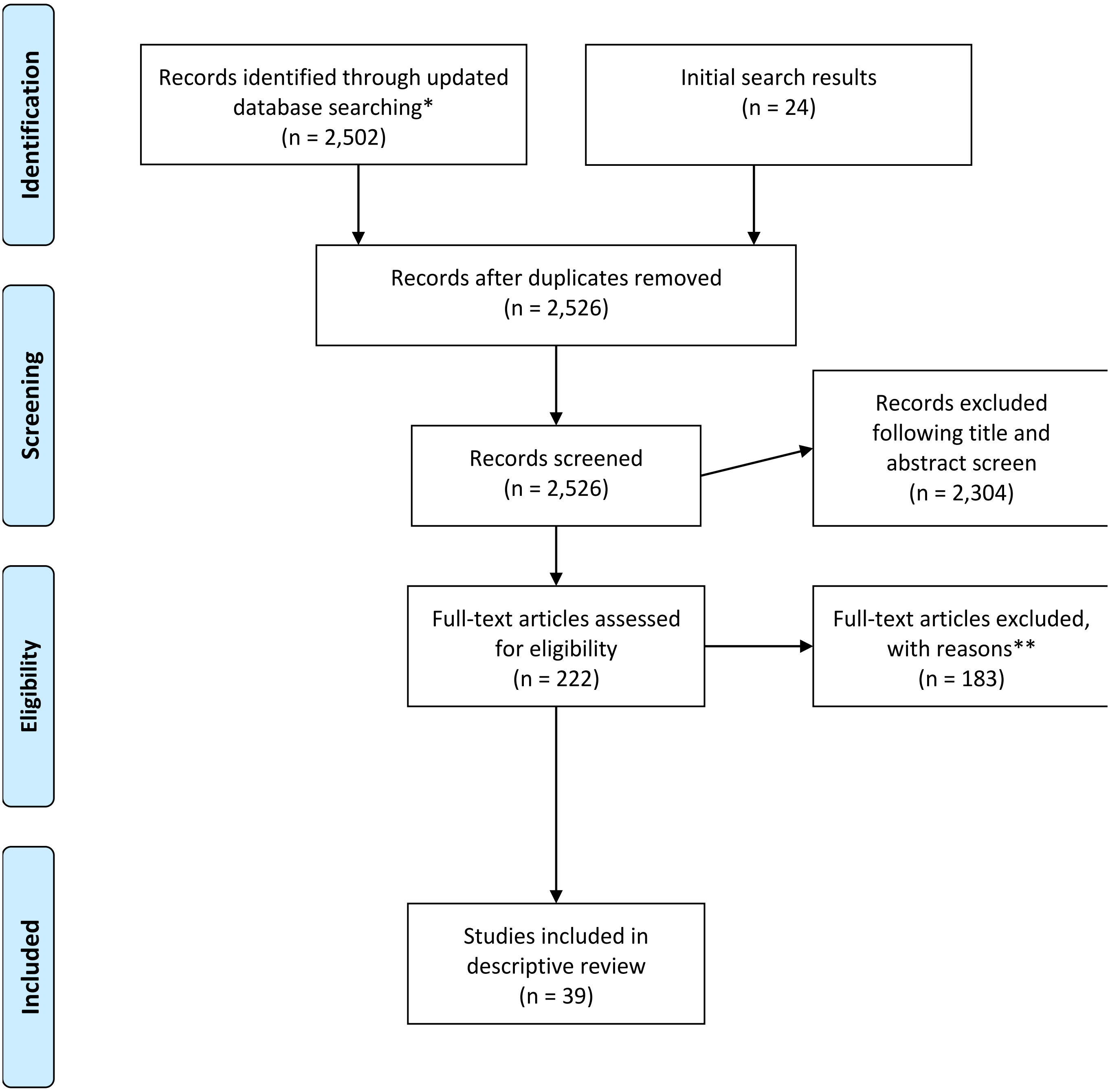
Figure 3. Initial literature search results



*Cochrane 35 papers; Prospero 56 Papers; Medline 369 papers; Pubmed 463 papers. ** NICE 1 citation; Google search 1st page 5 papers; NHS website 1 citation. ***Papers excluded because they did not refer to parents' views and perceptions of neonatal follow up.

The updated search identified a further 2,502 publications published over the following 26 months; of which 198 were selected by title and abstract screen. Of these, 15 studies met the criteria for inclusion and were added to the analysis.

Figure 4. Final literature search results



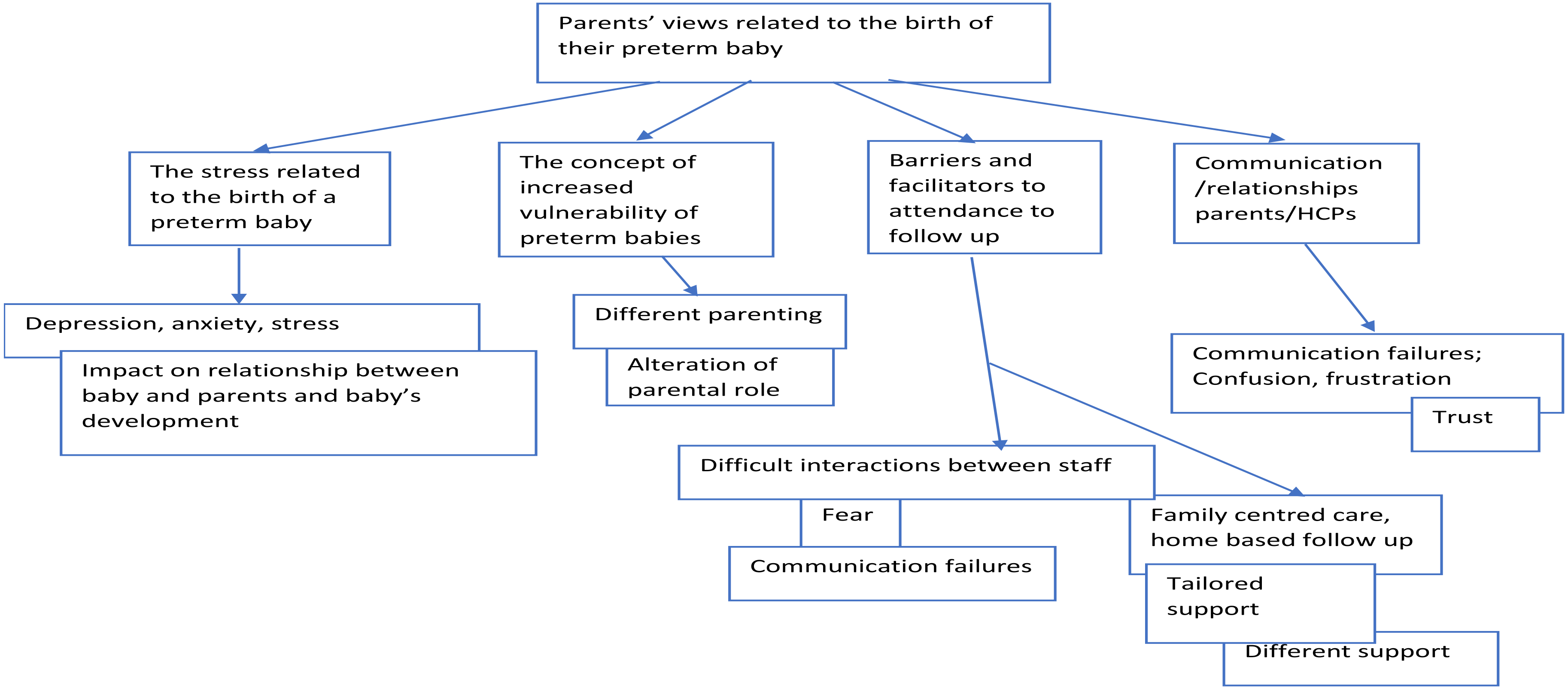
*Pubmed and Google, Apr’18 – Jun’20; ** Papers excluded because they did not refer to parents’ views and perceptions of neonatal follow up.

4.4. Results

A total of 39 studies met the study's inclusion criteria of papers exploring parents' feelings and perceptions related to the birth of their preterm baby, the care offered and the neonatal follow up, and were retained for final analysis.[25-28, 52-86] Nineteen of these were qualitative studies, the remaining were studies using mixed methods, reviews of literature, surveys and one randomised control trial.

This resulted in a high variability between studies, in terms of design, methods and ways of reporting results, which precluded meta-analysis. After reading the studies and collating their results, it also became apparent that a narrative style of reporting for the review was more appropriate, that lead to the development of themes that arose in the studies. Four themes resulted from an analysis of the included papers. These themes are represented in Figure 5.

Figure 5. Themes resulting from an analysis of the included papers - Parents' views related to the birth of their preterm baby



4.4.1. The stress related to the birth of a preterm baby

The birth of a preterm baby is a stressful event for the parents. Parents of preterm babies develop a different type of behaviour and emotional reactions;[52, 53] they show more depression, anxiety and stress and have different hormonal levels compared to parents of term babies.[54] Mothers have more anxiety, fatigue and flashbacks[55] and higher stress levels[56] due to the alteration of the parental role – they feel that they have to 'become advocates for their babies'.[57]

Woodward et al. showed that the alteration of the parental role due to stress led to poor language development and anxiety for the babies,[56] while Yoldas et al. analysed the impact of parental depression, post-natal attachment style and social support on the development of a preterm baby and concluded that interventions to improve developmental outcomes of preterm babies should take into account parental mental health.[58]

Other studies investigated the impact of parental experience on the baby and showed that parental stress, maternal anxiety, social factors, and the quality of interaction between mother and child, as well as the attachment experiences have an impact on the baby's development and outcomes.[59-62] Interestingly, Neri et al.[60] analysed the impact of birth weight and maternal anxiety at three months corrected on the baby's developmental outcome in the first year of life; they showed that specific areas were particularly affected, such as hearing, language, and locomotor scores. O'Donovan and Nixon[63] analysed the experiences of parenting of mothers and fathers of preterm babies and found four themes: An unnatural disaster: The traumatic nature of preterm birth; The immediate aftermath: Disconnected and displaced; Breaking the ice: Moving from frozen to melted;

Aftershocks: Transitioning home. Both parents found the preterm birth to be traumatic, and the challenges related to the preterm birth translated in anxiety and over-protective parenting behaviour.

Most studies analysed the impact of the birth of a preterm baby on the mother, although the impact on the father is also recognised.[64] Provenzi and Santoro undertook a systematic review of studies published between 2000 and 2014 describing fathers' experience of preterm birth and identified five themes: Emotional roller-coaster; Paternal needs; Coping strategies; Self-representation; Caregiving engagement. Some studies also investigated the impact that stress has on the relationships between baby and parents and subsequently on the baby's development.[65]

A meta-synthesis by Nilsson et al. underlined the role of health professionals in supporting new parents and the way the discharge process influenced the parents' confidence. Ten studies were included in the analysis and identified four themes: Feeling and taking responsibility; A time of insecurity; Being together as a family; Striving to be confident.[66]

4.4.2. The concept of increased vulnerability of the preterm babies

Several studies described the concept of increased vulnerability of the preterm baby. Parents of preterm babies develop a different type of parenting, based on the perception of increased vulnerability of preterm babies. The development of this concept does not seem to be related directly to the stress or anxiety experienced by the parents,[25] although Fleury et al. found that the relationship between mothers and their preterm baby was difficult because of the fragile appearance of the baby;[26] however, the perception of vulnerability may depend on the birth weight.[27] Mothers of very preterm babies anticipate more difficulties in caring for the baby compared to mothers of term babies.[28]

A literature review in 2016 showed that parents of babies born before 37 weeks feel that there is a disruption of the parental role, leading to a different type of relationship between parents and babies, possibly due to the preterm birth and the admission to hospital; parents have to learn different ways of parenting, and they need support.[67] A 2020 study analysed the effect of a follow up intervention program on parental perceptions of the child behaviour from 2 to 7-years; parents in the follow up intervention group reported less negative emotions in their children compared to the control group.[68] Parents' perception of their own 'self-worth' depends on the care they can provide to their preterm baby and feeding plays a very important role. Parents' concerns about feeding contribute into the concept of vulnerability.[69]

A qualitative study in 2016 found six themes: A life uncertain – my baby's vulnerability; An unfamiliar and intimidating environment; Relationships with health professionals; From fear to emotional connection; An enabling support network.[70] Mothers of very low birth weight babies have specific concerns and coping mechanisms, mainly linked to reconstructing the normality of the relationship between mother and baby, mothers' role and baby's development.[71]

4.4.3. Barriers and facilitators to attendance to follow up

Several studies assessed the factors that influence parents' engagement with, and attendance to, the follow up appointment. The study designs used varied reflecting the variability in services in different countries/regions. Most studies analysed the parents' point of view, such as Harmon et al. in 2013 who compared compliant and non-compliant infants discharged from the NICU; they showed that lower appointment compliance was associated with maternal drug misuse, multiple gestation, male sex and greater distance from the hospital.[72]

Another study in 2015 used a questionnaire, the PREEMIE; The Parent Risk Evaluation and Engagement Model and Instrument, to identify parents of late preterm babies who are at risk of low engagement.[73] Gunes et al. analysed the effect of a home follow up program on care problems, anxiety and depression levels of mothers of preterm babies; they found that the study group who received the follow-up program showed fewer problems of care and had lower risk of anxiety and depression. The authors concluded that a home based follow up for preterm babies and their mothers may decrease post-natal care problems, anxiety and depression levels of mothers.[74]

Two studies investigated both the parents' perceptions and the health professionals' views of the neonatal care and follow up of preterm babies.[75,76] Communication failures impacted on early intervention provision,[75] whereas support, family centered care and mothers with adequate resources were facilitators for attendance.[76]

4.4.4. Communication/relationship parents – health professionals

Several studies underlined the relevance of the relationships between parents and staff in the neonatal unit to parents' engagement with services later. Appropriate communication plays a very important role to the parents' experiences,[77-79] while communication failures break the trust between the parent and the clinician.[80] Communication is important both between clinician and parents, and within the clinical team; parents are sensitive to difficult interactions between the staff in the neonatal intensive care unit.[80]

Bry et al. explored the need for psychological support of parents of extremely preterm babies and identified four themes: Emotional support; Feeling able to trust the health care provider; Support in balancing time spent with the infant and other responsibilities; Privacy.[81] Parents felt that the roles of the health professionals were often not clear, but that they needed to trust the staff. Poor communication impacted on trust. This study showed that while the parents of preterm babies need support, the characteristics of this support are variable depending on each family, which was also reflected in the findings of Avindaogo et al.[82]

Lack of appropriate and tailored advice causes confusion and frustration.[83,84] The attitudes of health professionals were also important as shown by a study that explored the knowledge and attitudes towards extremely preterm babies by health care providers.[85] Health care providers' views appeared pessimistic compared to current evidence about preterm babies' outcomes, but improved with increasing gestation, and differed between units. The study suggested that the attitudes of health professionals may influence the decision-making and the parents' perceptions of the baby's outcome. A study by Dos Santos et al. showed that the parents' satisfaction with the care offered is related to the quality of the relationship with the health professionals; this study underlined the importance of continuity in care.[86]

4.5. Discussion

The approach to the follow up of preterm babies depends on local resources and structure of services, reflected by the variability in design of the studies included. Four key themes resulted from this descriptive review of literature: the stress related to the birth of a preterm baby, for both mothers and fathers; the concept of increased vulnerability of preterm babies; the barriers and facilitators to attendance to follow up; communication- relationships between parents and health professionals. The birth of a preterm baby is a stressful event; parents develop a different pattern of parenting, stemming from the concept of increased vulnerability of the preterm baby.

This review suggests that parents' experiences and opinions formed during their baby's admission to the neonatal unit influence their further engagement with services. The communication between parents and HPs is important at all stages. Parents need appropriate and clear information, and poor communication increases parental anxiety and stress levels.

NICE recommends the further assessment of the enhanced developmental follow up for children born preterm and its impact on the outcomes for parents and carers.[13] As this literature review shows, the quality of the follow up does have an impact on parents' anxiety and depression levels, which in turn has an impact on the child's development.

Future research should enquire into the correlation between the parents’ experience of the neonatal unit and their perception of the follow up. A better understanding of the process, the feelings and beliefs of parents could help design appropriate guidance and resources for the follow up. These may improve parents’ perception of their baby’s journey, the efficiency of follow up programmes and thus the baby’s outcomes.

Chapter 5. Parents’ Views Related to the Birth and Follow Up of their Preterm Baby

5. 1. Introduction

Previous studies have shown that the birth of a preterm baby is a stressful event, for both mothers and fathers. Parents develop a different pattern of parenting, stemming from the concept of increased vulnerability of the preterm baby. The communication between parents and health professionals is important, and poor communication increases parental stress levels. Studies reviewed in Chapter 4 underlined the relevance of the relationships established between parents and neonatal staff to parents’ experiences. Parents’ ongoing engagement with health services is influenced by their existing experiences. Improved understanding of parents’ perception of their baby’s journey may improve the follow up process, and the babies’ outcomes.

Parents of babies included in the OPINE study were approached and consented to take part into a qualitative study regarding their perception of their baby’s follow up.

5.2. Parents’ cohort description

5.2.1. Parents’ characteristics

Seventeen interviews were carried out with 23 parents of babies born before 28 weeks completed GA, in the North East of England, between July 2015 – June 2016. The interviews were carried out in 2018, when their babies were approximately 2 years corrected age. I used an interview guide with open questions. Parents were approached on their attendance for their babies follow up. Recruitment to the study ended when saturation of themes was achieved.

I used a topic guide for the interviews (Annexe 6); this was developed based on the results of the literature review as well as my own knowledge of the area of research.

The parents' characteristics are described in Table 8.

Table 8. The characteristics of the parents interviewed

VARIABLE	CHARACTERISTICS	NUMBER
Gender	Mother	16
	Father	7
Ethnicity	White British	19
	White other	1
	Black other	1
	Indian	2
Employment	Employed	14
	Unemployed	9
Single parent	Yes	1
	No	22
Child's health status*	Well child	10
	Some concerns**	9
	Severely disabled	3

*total number of children of the 23 parents interviewed is 22. ** mainly concerns regarding behaviour.

5.2.2. The interviewer's bias

The interviewer's position in qualitative research will have an impact on the data collected, and this impact should be considered when analysing the data and drawing conclusions. While a detailed account of my interactions with the parents during the interviews may lead to identifying them, it is important to recognise my role as a paediatrician who has been involved in the care of some of these children and was known to the parents.

So, not only my personality, but also the profession I represent will have influenced the parents’ answers. Also, my own preconceptions, while limited by adherence to a topic guide and professionalism, will have played a role as well.

5.2.3. The selection bias and the Tiny Lives Facebook Survey results

Due to the ethical considerations and the inability to access personal data without consent, the study has a selection bias: we could only approach parents who attended their children’s follow up appointments, meaning they were already engaging with the follow up.

To establish if these parents are representative to the general cohort of parents of babies admitted to neonatal intensive care, we developed an anonymised survey which was sent out to parents on the Tiny Lives Trust Facebook page.

The results of the survey can be found in the table below.

Table 9. Tiny Lives Trust Facebook page Survey results

VARIABLE	VALUES	NUMBER	PERCENTAGE
Gestation	<28 weeks	25	69.4
	28-36 weeks	9	25
	>36 weeks	2	5.5
Number of appointments	<5	11	30.5
	5-10	14	38.8
	10-20	7	19.4
	>20	4	11.11
Usefulness of appointments	Not useful	1	1.6
	Little useful	3	8.3
	Quite useful	5	13.8
	Very useful	27	75

Thirty-six replies were obtained. The Facebook group members are parents or carers or children who have been admitted to the NICU at the RVI. Of the responding cohort, most children were babies born before 28 weeks, four of those being born between July 2015 – June 2016.

Most parents found the appointments very or quite useful. In the comments section, parents talked about how the appointments brought reassurance and helped them understand their child’s development: *‘It was definitely reassuring and more than welcomed to have those follow up appointments, not only to check that my sons were ok development wise but also for us to raise any concerns or questions we had’.* One parent who found the appointments little useful expressed the wish to have had more input from the allied health professionals: *‘Useful to discuss concerns but would have been helpful to have access to a range of* *clinicians e.g. physio, somebody who could advise on nutrition or developmental concerns'*. One parent found the appointments not useful: *'I don't think he had follow up appointments, he was on research for milk and I think the appointments were for that and nothing more'.*

The survey results appear in keeping with the results of the parents' interviews, suggesting that the cohort of parents who participated to the in depths interviews are representative for the wider cohort of parents of babies born preterm.

5.3. Analysis

I transcribed the interviews verbatim. This maintained anonymity and guaranteed consistency. Thematic analysis based on the Braun and Clarke model was used.[48]

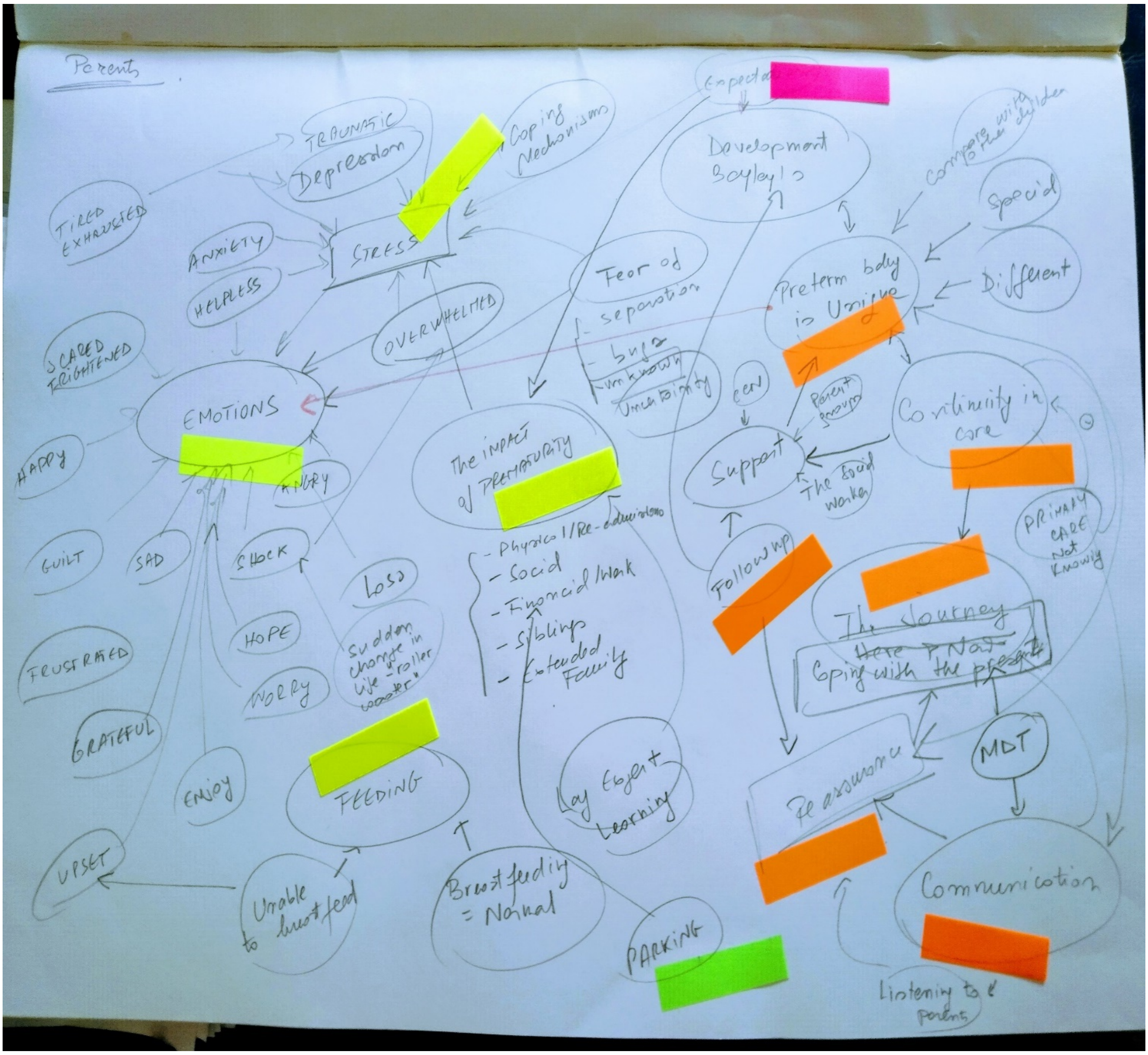
Transcripts were entered in the NVivo software, each interview was marked as participant group (PG) and numbered. Data were then explored, to observe the emergence of themes. Key words and phrases were highlighted.

Patterns were identified in the transcripts and emergent themes and subthemes were identified. The subthemes were reviewed, and some were merged into themes. I arranged and lead data meetings. My supervisors and myself read through transcripts independently then came together in the data meetings to discuss themes that we each identified. This helped to ensure the accuracy of the analysis and the objectivity of theme development. Themes and subthemes were agreed.

Analysis was ongoing and interviews were finalised when saturation of themes was achieved, i.e. no new themes resulted from interviews, and the parents interviewed were recruited from the whole region and were of different social and ethnic background.

Figure 6 illustrates the emerging key themes.

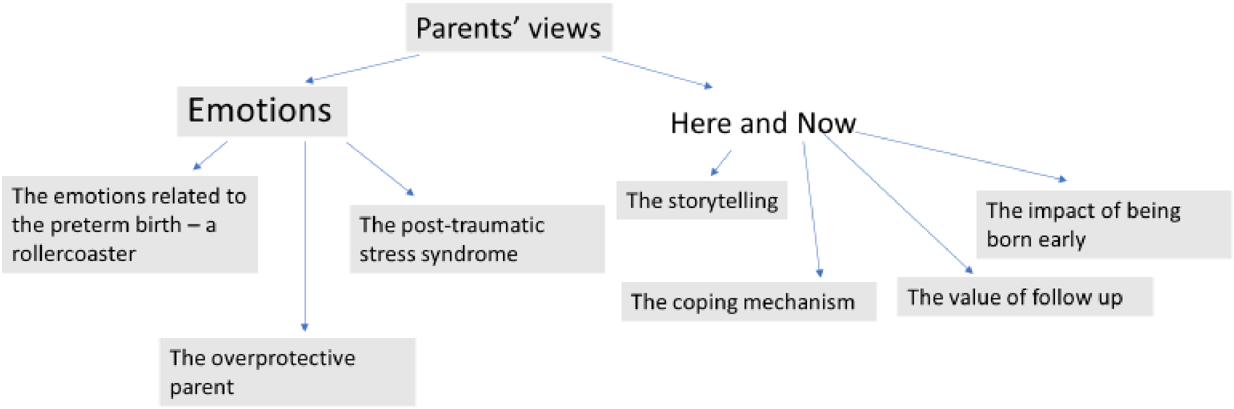
Figure 6. Diagram to show the development of themes and subthemes to emerge from the analysis of the parents' interviews



5.4. Results

Thematic analysis of the parents' interviews identified two key themes: 'Emotions' and 'Here and Now'. These key themes were divided further into subthemes as shown in Figure 7. The themes and subthemes are described below using illustrative quotes. Each quote is given a code relating to each interview e.g. PG1.

Figure 7. Themes and subthemes to emerge from the analysis of the parent interviews



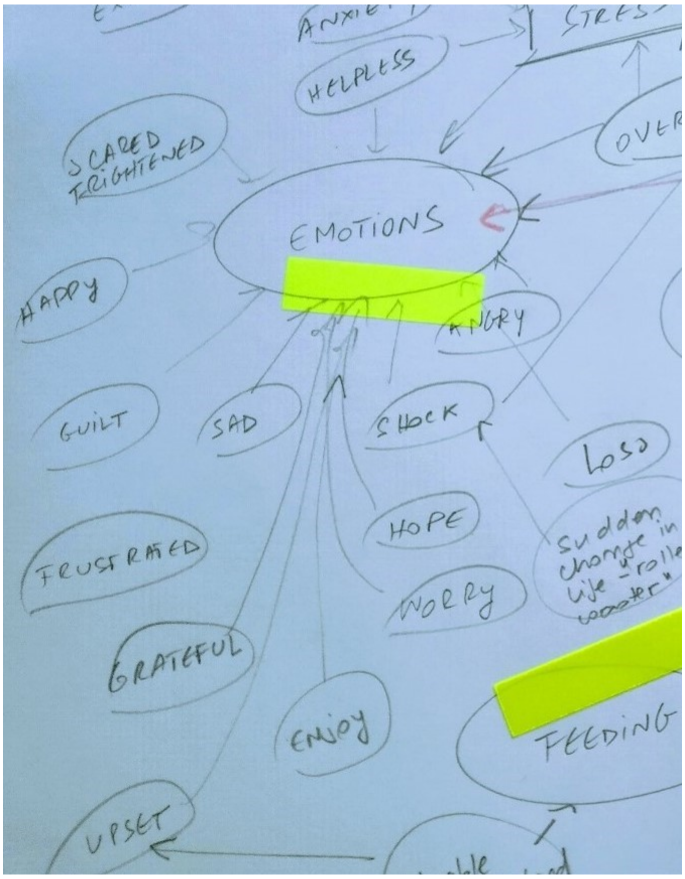
5.4.1. *Theme 1: Emotions*

The first theme 'Emotions' included three subthemes: 'The emotions related to the preterm birth - a rollercoaster'; 'The Post Traumatic Stress Syndrome' and 'The overprotective parent'.

i. <u>Subtheme 'The emotions related to the preterm birth – a rollercoaster'</u>

Following the birth of their preterm baby and even before, parents experienced a range of emotions, one after another, in what may be described as 'a roller-coaster'. Most of the emotions experienced by the parents were negative - type emotions such as guilt, scare, worry, fear, as represented below.

Figure 8. Representation of the main theme 'Emotions' and its subthemes



One of the first emotions that emerged was the feeling of 'guilt', experienced mostly by mothers when they learned that their baby will be born early, and they worried that something they had done might have caused it or that they had not done enough to prevent it.

'all this body had to do was to keep her in' (PG7)

Feelings of sadness were often described by parents and may have reflected multiple different reasons. Many mothers may have felt sad because they have been deprived of their full pregnancy. Some of the medical reasons for preterm delivery have a risk of recurrence and parents may be scared that it can happen again in a future pregnancy. Often parents appeared to feel 'bad' about having to leave their baby behind, in hospital. The moment of her discharge home was difficult for the mother.

Fear seemed to accompany parents throughout.
Parents expressed many fears of the unknown, such as uncertainty of what might happen to their baby tomorrow, and uncertainties about what will happen when they go home.

'there was no reassurance basically, it was just take every day as it comes and we were… They did talk about options of... ahem ... (long pause and starts to cry) … no, it's ok, I just get upset … they said they couldn't guarantee whether she'll…' (PG11)

While going home meant that the parents and baby were now on their own, it also brought positive emotions, such as the relief that the baby was well enough to go home.
'he's like a normal boy now … it was like a relief, 'cause obviously every time we went we're just getting better… so it was like a relief every time that we went and came home… '(PG15)

Sharing experiences may have helped as it brought hope and alleviated some of the anxiety and fear.

'… so, we got moved onto the ward, from there on became a little easier, because there's other people there, with you know similar

stories, similar … you know, then you share stories, and you feel that … a bit more relax, that there's a hope ... ' (PG11)

Parents were proud to show off their babies who had been through a lot. However, most of the time parents were painfully aware of the existing or possible differences between their baby and babies born at term. This was one of the reasons why parents of babies born early did not always seem to enjoy taking their children to what they called 'normal' play groups.

'…you know when I went to play group first … their development so delayed, the kids there normal born... I would see the difference, a lot … From the Sure Start, they have the group every week with the kids who's similar... so I'm feeling brilliant at this group… you know there like one kid don't speak as well and he's three-year-old, another have like a little Down syndrome, or … I just feel with them better.' (PG10).

The word 'normal' seemed to have an important role in the way parents perceived their babies born preterm and perceived 'normality' offered moments of happiness:

" I think reading to him helped me in hospital as well…we had our little bedtime routine … … and when he was asleep, I felt I could go home… and I'd feed him as well. And I'd be happy I read him a story. And he loves books now". (PG2)

Maintaining 'normality' was an important mechanism of coping for parents which will be discussed in depth later.

'… I'm sorry, she is normal but not as you know a normal baby would be and I know it's a horrible thing to say normal in this way, but this is the way we feel about it. '(PG 17).

ii. Subtheme 'The post-traumatic stress syndrome (PTSS)'

The emotions quoted by parents were compared to a roller-coaster. These mixed and sometimes contradictory emotions related to the birth of a preterm baby contributed to developing symptoms similar to the post-traumatic stress syndrome.

The NHS website states that 'someone with PTSS often relives the traumatic event through nightmares and flashbacks, and may experience feelings of isolation, irritability and guilt. They may also have problems sleeping, such as insomnia, and find concentrating difficult'.[87] The www.ptsduk.org site states: ' At the time someone is being exposed to this intensely fearful situation, their mind 'suspends' normal operations and it copes as well as it can in order to survive. 'The memories such as the facts of what happened, the emotions associated with the trauma and the sensations touch, taste, sound, vision, movement, and smell can be presented by the mind in the form of nightmares, flashbacks and intrusive unwanted memories.'

Parents expressed similar thoughts and feelings during the interviews. They described feelings of deja-vue; returning to hospital for the baby's appointments could bring back bad memories and therefore prove difficult.

'… and every time I used to take her for appointments, even if I bumped into somebody, I used to be in the right state, I couldn't talk… memories, flash backs, I was getting lots of flash backs … (PG11)

The lack of sleep was frequently mentioned, which may be due to every day demands related both to caring for their preterm baby in hospital and for the rest of their family, or maybe simply due to fear of what might happen to their baby.

'I wasn't even driving me car, 'cause I was scared in case I fall asleep… … because it was starting to build up on us, like I was waking up, more exhausted than I went to sleep ...'(PG12)

'… it was a strange feeling … getting home and start thinking, what if he gets an apnoea in the night, what if... you know all of those things that he had machines for… he didn't have it anymore… yeah…and it was like 'this is him on his own'… I used to wake up like every half an hour and feel he was breathing' [PG8]

During the baby's admission to the neonatal unit, parents described benefitting from support from the nursing staff. The health professionals involved in the care of their baby (nurses, doctors, allied health professionals) are all trained to recognise when a parent may struggle and to offer help. Post-discharge, the stress and development of PTSD appeared to go unrecognised, possibly due to the timing of onset, which may be years after the event. Sometimes the onset of mental health problems coincided with the time when the mother was due back to work, due to the background of feelings of guilt (for leaving baby), worry (of how baby will do when they are not there) and sadness (because they had to be then, once more, separated from their baby).

'I suffered a bit post-traumatic stress but that was quite a long time after (child's name) had been born, it did take me until about

... maybes he was eight months old and it was very, very sudden…' (PG8)

When confronted with mental health problems, parents may be unable to access help, and this challenge may be intrinsic i.e. simply cannot talk about it, or extrinsic i.e. support is found to be inappropriate or there are other barriers to accessing support, such as cultural or language barriers. One mother could not speak about it, so she wrote a letter to the GP:

'So, I couldn't speak to the doctor, so I wrote them a letter and tell them… cause every time I would talk about it, I get upset… … I just try and block it out sort of thing. I just try and talk about it like getting her home sort of thing instead of being in there, it's easier.' (PG12)

Another mother felt that help offered was not appropriate because the psychologist she was referred to did not know a lot about preterm delivery, but instead felt the interaction was too intrusive:

'I got some support, they gave me a phone number for counselling, I phoned once, it wasn't for me, you know, it was a bit too … delved a bit too much… it was making it a bit worse' [PG8]

Sometimes there were perceived cultural barriers to accessing psychological support, as in some cultures it is not acceptable to need mental health support and people avoid open discussions about mental health problems:

'… it's a bit of a stigma … seeking help for any mental condition is … is taboo, it's not good, people think you're mad, you know... I

don't know about the rest, but generally, yes, in our culture, community as well' [PG11]

The parents' mental health is essential to their ability to provide and bring up their children. Hence, interventions facilitating the recognition and management of PTSS in parents of preterm babies may facilitate better long-term outcomes for their babies.

iii. Subtheme 'The over-protective parent'

Previous literature described the development of a different, overprotective type of parenting for some parents of preterm babies, based on the concept of vulnerability of preterm babies, which was mirrored by the parents involved in this study.

Parents of preterm babies are taught early in the process about the importance of washing their hands regularly while caring for their baby, of using a clean procedure when expressing breast milk, of infection control methods and they may have seen their babies becoming quickly unwell with infections. It is therefore not surprising that one of the most quoted fears by the parents interviewed was the 'fear of bugs', which appeared to influence their behaviour towards the baby.

'Because I'm nervous about getting her into groups....
just 'cause of picking up anything, like colds and things, I'm always nervous.' [PG1]

Parents described several situations that they avoided or were nervous as they were concerned about the risk to their baby. Parents were fearful of their children attending play groups, because they may pick up infections. They did not like to take their children to accident and emergency when unwell to share the waiting area with everyone else. They may have become pro-active in obtaining antibiotic treatment because they knew from previous experience that their child is likely to become more unwell quicker. Parents did not like people coming to touch their baby, kiss their baby or even stare at their baby when they are out for a walk.

Many of the parents interviewed acknowledged their overprotectiveness but found it justified by their baby's past medical history.

'… yeah, but she had breast milk, but I didn't physically do it because I felt she's been through so much trauma, I don't want to force her to train to suck in a certain way, I just thought she's had such a rough start, I don't want to do things with her that she's going to find difficult…' [PG11]

At other times, they may have made a conscious effort to avoid the overprotectiveness.

'I knew she was going to… but her lungs have been a bit better, so… can't keep her wrapped up in cotton wool…' [PG12]

Both mothers and fathers could be overprotective, and some aspects were common. However, some dads also felt like they were too big to handle such a small baby.

'Yeah, I didn't want to take her out… we were just protective, overprotective...' [PG11]

'I'm so… big… you know what I mean, my hands was bigger than her hands, I'm bigger than her and … I was scared that if I picked her up I'd break her…' [PG17]

This different, overprotective type of parenting may impact on the baby's upbringing, their subsequent development, and their social interaction skills.

5.4.2. Theme 2: Here and Now

The second key theme 'Here and Now' included four subthemes: 'The storytelling', 'The coping mechanism', 'The impact of being born early' and 'The value of follow up'.

i. <u>Subtheme 'The storytelling'</u>

Future parents expected a normal term pregnancy, followed by a normal birth, with the definition of 'normal' varying depending on cultural, educational and social background. When the pregnancy and birth were completed, parents expected to take home their new baby or babies. The onset of preterm labour interrupted this normality and unfolded a story, with all the events combining into one big experience. Parents may not see the difference between the period before and after birth, or before and after discharge. The experience and the feelings related to it impacted on the bonding and relationship between baby and parents and also determined the quality of the relationships between parents and health professionals. One very powerful example of this is a mother who recalled all her journey starting with the first presentation to the obstetrics unit, up to the present (i.e. time of the interview):

'So, she was born at 25 weeks and the birth was very traumatic. […] the pregnancy was horrific, I was really poorly, I couldn't eat, I couldn't keep anything down … […] he came in, examined me and he said, I'm really sorry, you are... I think he said seven centimetres dilated, the baby's coming, there's… there's nothing

we can do to stop it now… I was like, this can't be! there's no way, and I was furious, because I'd been down a handful of times and been fobbed off, that's how I felt, and I thought... why me… why is this happened to me, you know … […] … we were saying, you know, will the baby survive? And we were… can you let us know what the chances are… and nobody would… […] we've been through a lot as a family, but this was like the worst thing we've been through… […] So, they then took us round to theatre, and I was like having to not push, while … like stop me body from pushing, and I was … and I thought I was gonna die […] The care in high dependency was amazing […] but I've never felt pain like it ... and they say it's because obviously I never had a spinal, I just had the section, and then obviously I've woken up to this pain. And then I was told the baby's doing ok, which was good, but I couldn't even lift me head up of a pillow… and then I was put on the ward, which was another experience, horrific experience, just felt like I was just left. […] it took us a long time to get well enough to go… go around to see her. […] I really lost it with the nurse who was looking after her, because […] she said… he is doing really ok … the… and I just went HE'S A SHE, and like start crying […] she just tipped us over the edge... because she … I felt like she didn't know that my baby was a 'she'… '(PG16)

During her account of the birth of her preterm baby, it became obvious that the negative experiences have simply added up to make the whole event one unhappy experience overall. This was not changed by the fact that the child was doing well or by the acknowledgement of the positives by the mother:

'No, I'm just obviously… I've said a lot… I've said everything that I didn't … not like, but you know what I mean. Negative things if you like… but there was lot of good experiences and I think often

people do tend to focus on: this wasn't good, and this wasn't good, but at the end of the day they saved her life, and that's the most important thing, and we've got through it now and I'm just so grateful for the amazing work what they do, cause this little one wouldn't be here without them.' [PG16]

It is important to note that the main issues identified in this interview were related to the communication between health professionals and parents, which all contributed to create an overall unhappy experience that started antenatally, with the interaction with the obstetric team, and continued after birth, in the neonatal unit.

ii. Subtheme 'The coping mechanism'

Parents made use of an array of coping mechanisms to enable them to support their child, themselves, and their family through a difficult process. Such strategies included living in the present, peer support, family support, maintaining normality and tailored psychological support.

An important way of coping was living in the present because there was no reassurance of what tomorrow will look like. Parents could keep negative thoughts at bay by creating and keeping routines.

'I mean, obviously it was really upsetting and unexpected and I had no idea what was going on, for the first month or so, but you kind of get into a routine and you learn how to deal with spending all day in hospital, I don't know, you just adapt.' (PG4)

Sometimes parents may have benefited from peer support and found the company of other parents in the unit who have been through similar things as helpful and reassuring.

'you just…look around and you think … actually do you know what? he's not alone in this…' (PG8)

Extended family/grandparents may have also offered support, both in terms of practical help but also helping them process what was going on.

'…like we don't know how me and him would have took us, like if we didn't have his mum and like my dad and everyone supporting us, we could have took the wrong…we could have took the wrong turn of what … well, there's nothing we can do, we might have pulled the fight off, do you know want I mean?' (PG3)

Creating the illusion of normality was important to parents; when a baby is born early, the 'normal' is lost - touching or cuddling the baby, changing the baby's nappy, giving the baby a bath and reading to the baby to sleep. Helping parents to create a routine in the neonatal unit that included these normal actions, helped them cope and gave them a routine they used later, when discharged home.

'… sometimes I think … I wanted to do… cause I suppose being a mother gets taken away from you a bit, doesn't it? Like you aren't the first person to hold him, or feed him, or change his nappy… or things… like everyone else is doing it for you… and so like I think to … to express and breastfeed and stuff like that… it made you feel like you were doing something for him…' (PG2)

Feeding was a very important marker of normality. Expressing breast milk was often the only activity that a mother could do for her child and that provided the child with nourishment, and protection from disease.

'Yes! Yeah, just constantly keeping your mind busy with what you're doing and that … I was obviously expressing all her milk around the clock as well, so even though I was home, it was three hourly getting up through the night to express milk, but just knowing that you can do that for her, even though I wasn't with her, I'm doing something for her, which was nice I think, which helps as a mum… '(PG7)

Previous literature has shown the importance of feeding the baby for the parents' feelings and perception of their own self- worth, as well as the impact that feeding difficulties have on the relationship baby – parents, and this was reflected by the parents included in this study.

'… it was frustrating, I used to be in tears, because I used to be sitting for an hour feeding her, we had to distract her, iPad, TV… as soon as she knew she's eating, she would then do that… take everything out…' (PG11)

Breastfeeding support was important to mothers and the perceived lack of support impacted on the parents' experience.

'I'd asked for to have a hold of (child's name) and… ah, we're too busy!... and I said: yes, I understand that, but I've came over and I want a hold of my child, so it was really hard… wrestling with that…' [PG16].

Another important source of support for parents was the input of the neonatal unit psychologist. When compared to other mental health interventions, the input from the specialist psychologist was universally recognised to be appropriate and tailored to the needs of the mothers.

'Also, V (psychologist), as well, because I didn't even know she was there until, one of the nurses mentioned her, and I saw her for quite a while, and even after they left […] I still went to see her, and that was massive help, definitely. […] definitely, not all places offer that, I found out, so yeah, and that's a massive thing, isn't it, emotional health…' (PG4)

Fathers' emotional health may have been overlooked, possibly because of the perceived social obligation for men to be strong.

'… it was hard for me, I just kept on crying all the time… and obviously he did not… he was keeping strong because he wanted to like comfort me and say everything's gonna be alright, but deep down like I did know what was running through his head' (PG3)

iii. Subtheme 'The impact of being born early'

'Expecting a baby' is a well-used term, and it involves future planning. This may change significantly when a baby is born preterm, and parents must adjust to the new reality.
Being born early impacts both on parents and baby, and this was reflected in this study.

1. The impact on parents was emotional as discussed in a previous chapter.

There was an impact on future planning and future pregnancies, as often there is a risk of recurrence of a preterm delivery depending on the medical background.

'But I do feel sad still, and I do feel nervous that again it could happen, there's a 40 percent chance it could happen to me again, so I do feel nervous.' [PG1]

There was an impact on the parents' social life, due to barriers that were both physical and emotional. It was difficult to leave the house with a child who requires oxygen, due to the challenges of travel and lack of facilities in most places.

'Restaurants aren't designed for people with big prams and big equipment'[PG6]

Parents did not like the extra attention given to their baby, and fear of infections played a role.

'well, it wasn't very nice because people were looking and going ... ah, look at her… like, how tiny she is and stuff... I think that's rude! Like, if you see someone carrying an oxygen thing and surely if it was on the bairn, you wouldn't look… '[PG3]

'*With prem babies is nothing worse than when all the oldies come to the pram, 'oh hyia', hang on a minute, I've just spent I don't know how long in the hospital'[PG6]*

Finding appropriate respite for a child with special needs proved challenging. There is limited provision for respite care, and this has become even more challenging during the current Covid 19 pandemic. Grandparents often became carers, and parents were aware of the extra burden on them, such as having to train in delivering basic life support, using the oxygen tank or a nasogastric tube, caring for a tracheostomy, or giving the child medicines.

'My mum and dad – too scared. So, it's only me and you (points at dad) and your dad, trained. … my mum has issues too, she's too old to, and my grandma would do it, but she's too old too.'[PG6]
There was also a significant financial impact. Often mothers had to take unpaid leave or give up work entirely. This was because while maternity leave started straight away, it was no longer than if the baby was born at term. This meant that the mother of an extremely preterm baby had to return to work very soon after her baby was finally home, which proved difficult and added to the emotional difficulties.

'… and I went back to work, yeah, I went back to work… he'd been home four weeks … and that's when the post-traumatic stress kicked in'[PG8]

Parents may have had to buy a bigger car, spend time on sick leave when the baby was readmitted to hospital (which may happen frequently especially in the first couple of years), and often became the main carer for their child with special needs. There were costs associated with transport to hospital, as well as parking. Parking was classed as expensive, and parents often did not know how to access a parking pass. Even with a parking pass, finding a parking space may have been a challenge. Parking was quoted as a challenge to coming to hospital even by parents who did not own a car but were brought to hospital by family members.

'That was a massive thing the parking … it was the biggest… probably the only annoyance we had when he was in hospital, was parking, wasn't it?'[PG8]

2. Another aspect of this subtheme was the direct impact on the baby.

Preterm babies have breathing problems, with virtually all babies born before 28 weeks requiring some degree of respiratory support. Often, they are discharged home on oxygen and are at increased risk of developing a respiratory illness. Some preterm babies require ligation of the arterial duct, an intervention, with risks on its own account. The digestive system of a preterm baby is immature, and preterm babies are vulnerable to developing NEC. Feeding is different, and sometimes babies experience feeding difficulties after discharge. Preterm babies have higher risk of neurodisability, as well as behaviour and social communication difficulties.

'… just the concerns with their health, cause they're ill every two… three months, they've got like chest infection, spent few times in the hospital as well, with their oxygen, 'cause they had problem with their breathing… their development is so delayed, so they was … referred to the autism assessment as well. And they've seen as well the speech language, cause they can't say any word yet… '[PG10]

Preterm babies may have complex needs, and their parents may appear overwhelmed.

iv. Subtheme 'The value of the follow up'

Every parent's story was different; following discharge all parents had expectations regarding their babies' growth and development. Often parents feared what the future would bring, and anticipated problems related to their baby's development.

'I don't know, I mean, we expected him to be like really far behind compared to other kids, but as he was growing, he seemed … he's caught up straight away. I mean we expected him to, like, be tiny and still be like a baby but he wasn't. He just caught up straight away. '[PG15]

For some parents, behaviour was a reason for concern, while others were simply happy that their baby survived. The follow up appointments offered reassurance and the confidence that their baby was growing and developing as expected. Appointments offered parents the opportunity to ask questions and parents felt reassured when they could access advice.

'… well, it was just letting us know, cause obviously we know what he's like at home, but like from a doctors' point of view we like to know like … his development in that way, so it was actually quite helpful that … have him constantly there so we can get like that side of it, as well as what we see […] so it was nice to know what's happening on both sides.'[PG15]

'… we wouldn't know what problems, especially with her being premature, we wouldn't get ... you know, you can get books with term babies, you know books will say a term baby should do this at this age, do this, do this … you get all those books, but you

don't get books saying, oh, a premature baby should do this, shouldn't do this, there's nothing… '[PG11]

' … and I called and spoke over the phone, that's what … that gave me confidence, that I could speak to somebody…'[PG11]

Sometimes, appointments had an educational value for parents who may have learned better what their baby can do and gained confidence playing with their baby.

'I don't know how to explain… cause… mhm… they helped me… everything to me, like how to play with them, what the toys to use, because the… ahem… how to… even to brush the teeth, cause they wouldn't open their mouth … it is very hard, ahem… how to feed them as well, because they are very… they can't eat the lumpy food, and the finger food, they can't put anything in their mouths, so I still have to feed them with the blend, all blended food you know, so I got like help … ' [PG10]

Most parents interviewed appreciated the number of appointments as 'just right', even though there was a wide variation in the way the follow up was organised by the different hospitals, and sometimes even from case to case depending on the baby's needs.

For the parents interviewed in this study, the formal developmental assessment (BSITD III) had an unexpected reassuring value, even in the case of babies who had recognised difficulties that parents were aware of. For example, a baby with significant delay showed to their parent that they can pick something up, or say a few words, or watch a book read.

In other cases, the appointments simply confirmed the parents' expectations.

'I … I thought on the whole it went well, it was good to see the … the girls with the blocks thing, they knew to put them in the shapes, starting to know what colours, what … what items, what … different… babies or dogs or apples, and just knowing what things are... they're starting to … to pick that up, so I think on the whole, it was nice to see that they… they are making progress, and yeah…' [PG14]

5.5. Discussion

Thematic analysis of the parents' interviews identified two key themes: 'Emotions' and 'Here and Now'. The first key theme 'Emotions' included three subthemes: 'The emotions related to the preterm birth - a rollercoaster'; 'The Post Traumatic Stress Syndrome' and 'The overprotective parent'. The second key theme 'Here and now' included four subthemes: 'The storytelling', 'The coping mechanism', 'The impact of being born early' and 'The value of the follow up'.

There was a broad spectrum of emotions that were part of the experience of the parents who have had a preterm baby. These emotions covered a vast range of human emotion that are both positive and negative, described by many as a 'roller-coaster'. These mixed and sometimes contradictory emotions related to the birth of a preterm baby contributed to developing symptoms similar to the PTSS.

Parents of preterm babies developed a different, overprotective type of parenting; this different type of parenting may impact the baby's upbringing, their development, and their social interaction skills.

Parents frequently appeared to live in the 'Here and Now' as a way of coping. The onset of preterm labour interrupted normality. The experience and the feelings related to it impacted on the bonding and relationship between baby and parents but also determined the quality of the relationships between parents and health professionals. Parents made use of an array of coping mechanisms to enable them to support their child, themselves, and their family through a difficult process. Such strategies included living in the present, peer support, family support, maintaining normality. Feeding was an important marker of normality.

The follow up appointments had a reassuring value; parents felt that issues could be identified on time and also that their own perception of their child's needs was in keeping with the reality, i.e. the professional assessment.

This study highlighted that there is a complex set of issues for parents of extremely preterm babies. Findings from this research provide insights into the feelings and experience of parents of extremely preterm babies, which may help to inform heath care planning. It is possible that relatively small changes in neonatal practice can significantly improve the parents' experience, their engagement with the follow up, and therefore their babies' outcomes.

Chapter 6. Health Professionals' Views on Neonatal Follow Up

6.1. Introduction

Previous studies underlined the relevance of the relationships established between parents and neonatal staff to their engagement with services. Appropriate communication plays a very important role to the parents' experiences, and communication failures break the trust between the parent and the clinician. Communication is important both between clinician and parents, and within the clinical team. However, few studies actively sought the opinion of health professionals regarding their involvement in the care and follow up of extremely preterm babies. I undertook a qualitative study exploring HPs' views on neonatal follow up.

6.2. Description of Health Professionals' Sample

6.2.1. Health Professionals' characteristics

I carried out interviews with 20 HPs involved in the care and follow up of extremely preterm babies in the North East of England.

Potential participants were approached based on previous knowledge regarding their job roles and given information about the study prior to obtaining informed consent. Participants were interviewed using a topic guide (Annexe 10); this was developed based on the results of the literature review, as well as my own knowledge of the area of research.

Interviews were carried out until saturation was reached. The sample included HPs from across the region and incorporated those in different job roles as described in Table 10. This was considered necessary based on the assumption that different job roles offer different perspectives and that the follow up process is variable within the region depending on a hospital's resources and geographical characteristics.

Table 10. Characteristics of the HPs interviewed

JOB ROLE	SPECIALTY	NUMBER
Doctor	Neonatal Consultant	4
	Community Paediatrics	2
	Speciality Doctor	2
Nurse	Neonatal	2
	Paediatrics	3
Allied specialities	Neonatal Physiotherapist	2
	Paediatric Physiotherapist	2
	Speech and language therapist	2
	Health visitor	1

6.2.2. The interviewer's bias

The interviewer was known to most of the HPs interviewed in a professional capacity, and this may have influenced the answers received, despite ongoing reassurance that the participation in study is voluntary and answers are confidential. Also, it is important to underline the fact that all NHS staff have the obligation to maintain patient and professional confidentiality and anonymity.

6.3. Analysis

Interviews were transcribed verbatim by a Newcastle University approved transcribing company. Thematic analysis based on the Braun and Clarke model was used.[48]

Transcripts were entered in the NVivo software, each interview was marked, and every participant received a number. For the analysis however I used the job role of the participant as descriptor, because data suggested that the job role has an impact on the professionals' perceptions and views. Data were then explored, to observe the emergence of themes. Key words and phrases were highlighted. Patterns were identified in the transcripts and emergent themes and subthemes were identified. The subthemes were reviewed and some were merged into themes. I arranged and lead data meetings. My supervisors and myself read through transcripts independently then came together in the data meetings to discuss themes that we each identified. This helped to ensure the accuracy of the analysis and the objectivity of theme development. Themes and subthemes were agreed.

Analysis was ongoing and interviews were finalised when saturation of themes was achieved, i.e. no new themes resulted from interviews, and the health professionals interviewed were recruited from the whole region and had different job roles.

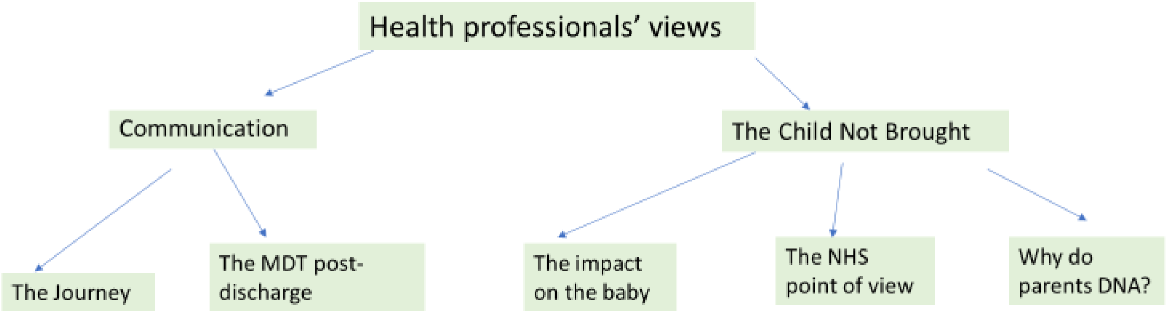
The figure below shows the emergence of the key themes from the HPs' interviews.

Figure 9. Diagram to show the development of themes and subthemes to emerge from the analysis of the HPs' interviews

6.4. Results

Two key themes resulted from the analysis of the HPs' interviews: 'Communication' and 'The child not brought'. The first key theme 'Communication' included two subthemes: 'The Journey' and 'The MDT (multi-disciplinary team) post discharge'. The second key theme 'The Child Not Brought' included three subthemes: 'The impact on the baby', 'The NHS point of view' and 'Why do parents not attend?'. The key themes and subthemes are represented below. Illustrative quotes are provided and each HP is described by their professional group.

Figure 10. Themes and subthemes to emerge from the analysis of the HPs' interviews



6.4.1. Theme 1: Communication

<u>i. Subtheme 'The Journey'</u>

HPs described the experience of the birth and the follow up of a preterm baby as a journey. HPs understood the importance of peer support and the reassurance offered by other people with similar journeys and understood that the process of follow up offered reassurance and support, and that positive feedback was important for the parents. HPs told us that parents appreciated going back to see the team they already know.

‘The ones who come quite often from a distance are really looking for that reassurance. … they'll say to us: "Well you've known them throughout their whole journey."’ [Nurse]

’ Yes, that was said to me this morning, actually, "Oh, I'm so pleased it's you because you know what she's like." … You know the families as well… you do build up really good relationships. They class us as part of their extended family and it's massive for them. ’ [Nurse]

Family centered care in the community was important and members of the team who have the opportunity to see babies in their own environment were afforded a unique insight into the influence of family dynamics and social environment on the baby’s development.

‘I think what parents have told me is this is a whole journey, the whole thing. We need to be supporting and empowering them through that whole journey, not just when their baby is really sick on the unit. I think that’s generally what we need to get better at. Challenge our preconceptions of what our roles are.’ [Physiotherapist]

Follow up and support in the community was seen to prevent unnecessary hospital admission and improve outcomes by early intervention.

‘We’re not there to stop family life. We’re there to support it, really … So, for the babies, it is actually making sure that everything is progressing well …. So that we can put help in place sooner […] going quite regularly, you would catch a problem early.‘ [Nurse]

Continuity in care was seen as a marker of good care and was valued by the parents. While parents may come from far away for a follow up appointment, it appeared that the continuity in care was important enough to justify the travel in most cases. Continuity in care and the existence of a point of contact, i.e. a health professional who knows their baby reassured parents that any significant issues will be picked up.

‘Well, of course there’s no evidence on the randomized controlled trial scale and quantitatively assessing the parents’ view. I’m sure there are ways to do that, but it’s very obvious … when you saw them back on the follow up clinic regardless of the age you can see that they often seem much more relieved to see someone that they know, they’re familiar with.’ [Neonatal consultant]

HPs appreciated the fact that the involvement of a new team or team member can be daunting for families. This may influence the way families perceive the transition between services, for example when the baby is discharged from the neonatal unit to the care of the community team, or when the baby is discharged from the neonatal follow up into paediatric follow up. These moments of transitioning from one service to another can be stressful for the parents and may influence the parents’ engagement further. HPs interviewed introduced brought the notion of a transitional clinic in the neonatal follow up process.

‘There’s not a transitional clinic, which I think might be a downfall for these families. Because, as I say, they have developed that relationship with the neonatal team, and then moving on to us things work slightly differently in community paediatrics. Although we’re there to support, we’re perhaps not seen as much as they saw professionals in the past. ‘[Community paediatrician]

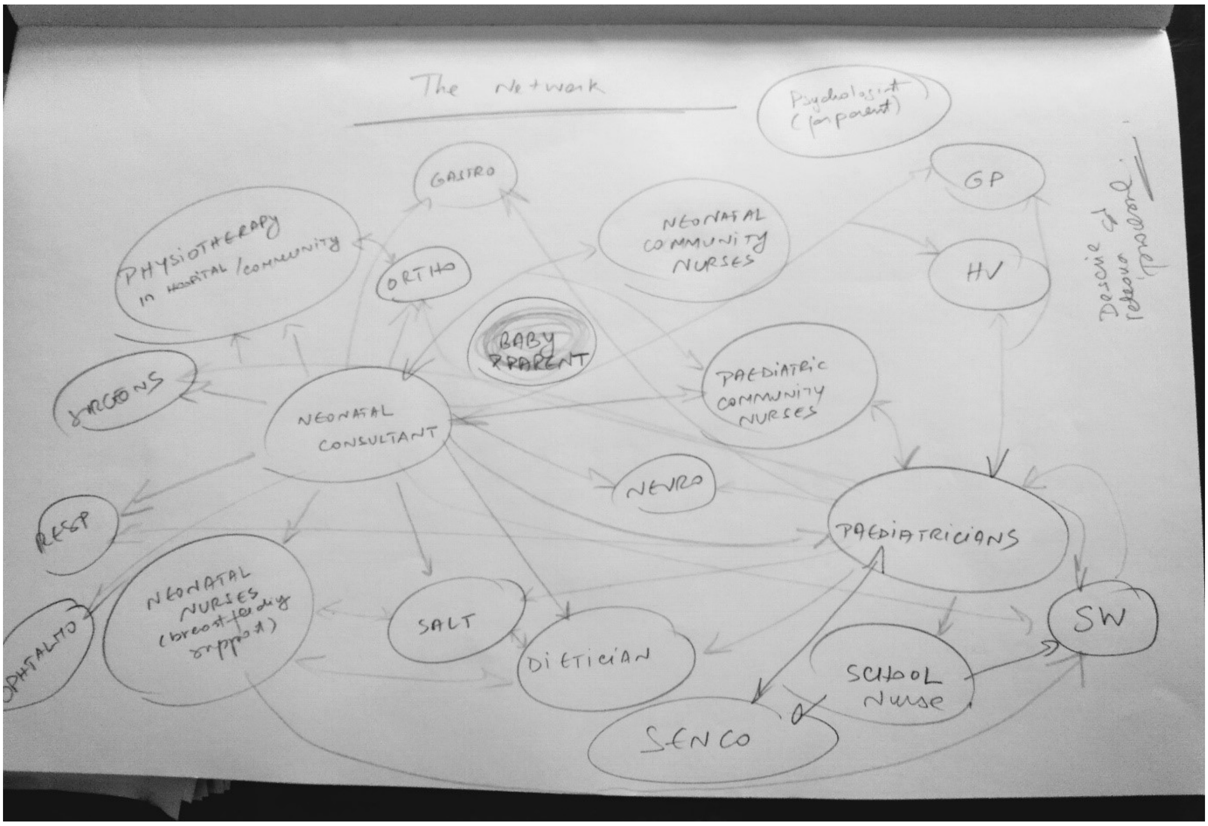
ii. Subtheme ‘The MDT post discharge’

There was a diversity of job roles of professionals involved in the care and follow up of preterm babies, with a diverse and sometimes rather large team involved, depending on the baby’s needs:

‘I'm a neonatal nurse, been working on the neonatal unit for 23 and a half years. I've been a sister on the unit for the last 17 years. … I'm a Neonatal Clinical Specialist Physiotherapist. …I am a speech and language therapist. …I am a … doctor working at the … in the Special Care Unit. …It’s just a neonatal consultant… (‘s job). … a Community Children’s Nurse … I’m a health visitor. …I’m a Consultant Paediatrician and I work within both the Acute Paediatric Service and the Community Paediatric Service. … I’m a community paediatric physiotherapist.’

Figure 11 illustrates some of this diversity and the complex interactions within this team. Baby and parents are in the centre of these interactions and receive input from all members of these team. The more complex the medical neonatal background, the more interactions within the team.

Figure 11. The multidisciplinary team (MDT) involved in the care and follow up of a preterm baby (including Neonatal Consultants, Surgeons, Physiotherapy (hospital/community), speech and language therapist (SALT), Dieticians, Social Worker, Psychology, special educational needs coordinator (SENCO), Gastrology, Orthopedics, Ophthalmology, Neonatal/ Paediatric Community team, Neurology, Neonatal Nurses/breastfeeding support, Respiratory team, School Nurse, Paediatric Consultants, GP, health visitor)



There was a high variability across the region in the way the follow up is organised, depending on funding, staff availability and geographical characteristics. The MDT also included the specialist teams that may be involved in the care of more complex babies, such as neurology, gastroenterology, orthopedics, ophthalmology, and audiology. Each job role was specific and offered a different perspective to the follow up of a preterm baby. While different aspects of care are potentially just as important, it may be important to consider which matters most to parents. Communication occurs in every direction between the members of this network, and in various modes including written/verbal, formal/informal, paper/electronic, etc. Accurate communication has been shown to be important to maintain trust. Communication breakdown may occur at any stage and may depend on system factors or human factors.

'Communication between colleagues, communication to parents. Communication to parents, to colleagues and just more on educational communication. Important issues, here, because most things are because of some misunderstanding, or because the information was not clear. '[Community paediatrician]

System factors play an important role, such as lost letters, IT breakdown, the lack of consistency and communication between different IT systems over the region. HPs interviewed noted the importance of human factors into the process.

The transition between services was recognised as a challenging as well as important moment in the process or journey, and the first encounter may be key for the way the parents will engage with health professionals in the future.

There are three transition moments that have been mentioned by the HPs interviewed. One moment is <u>the discharge from the neonatal unit</u>. Most babies will continue to be followed up by the neonatal team however other professionals also become involved at that stage, such as the health visitor.

'I think it's really important that we do get invited {to the pre discharge MDT}. I do feel there's a bit of a breakdown in communication sometimes… We don't always get the letters passed on to us' [Health visitor]

Another important milestone is <u>the transition to the paediatric services</u>. The main issue underlined in interviews was around the timing of the diagnosis of cerebral palsy. Different teams have different approaches, as expressed below:

'We wouldn't be giving a diagnosis at all, but we would be slowly dripping that that might be where we would be going. […] 'It does surprise you sometimes. You think you've dripped that information. Then they come in, and the consultant says, "They've got cerebral palsy," and they're gobsmacked. And you think, "God, we've been doing loads of work trying to get…" So that it's a drip, drip, drip rather than a, "Your child is fine," bang, "This is an issue." '[Physiotherapist]

'The other thing is often around the diagnosis of cerebral palsy. … then with the transition often the … diagnosis has not been given … They transition to us. They meet us for the first time. … And that's not right, because they meet us for the first time and hear bad news. It's almost like they kind of know but no-one has told them. ' [Community paediatrician]

The neonatal team has often been involved with the baby and family for a long time and has built a relationship with the parents. The timing of diagnosis may coincide with the transition to paediatrics, which means that the diagnosis was not communicated by the neonatal team to the parents but will have to be communicated by the paediatric team. This may mean that the first encounter between the parents and the paediatric team will be complicated due to the need to deliver ‘bad news’, which may then add a strain to the relationship between parents and the community paediatric team and potentially impact on parents’ future engagement with the services. It also appeared that there was a difference between what health professionals thought they have said (‘dripped’) and what parents understood.

‘Then it’s a really awkward time. They transition to us. They meet us for the first time. Here are we, and we tell them that their child has cerebral palsy. And that’s not right, because they meet us for the first time and hear bad news. It’s almost like they kind of know but no-one has told them. ‘[Community paediatrician]

A third and sometimes forgotten milestone is <u>the start of school.</u> HPs, particularly those involved in the community care of babies born preterm, recognise the importance of liaising with the school and education; not only for those children who have a diagnosis of disability, but also for children who, by being born premature, are at higher risk of developing behavioural or other issues at school age. HPs recognise the limitations of the routine follow up, however it is not clear who should lead the process of explaining and planning for potential difficulties in the school setting for children born preterm.

‘I also think we know the Bayley’s assessment doesn’t necessarily predict ability at school. I think there needs to be a big piece of work done. We don’t use any of that information and we don’t liaise with the schools and parents at that stage.’ [Physiotherapist]

‘Teachers probably. I don't know. I think a lot of them get missed. I think there are loads of them missed. Even just as a mum, my experience as a mum in school, loads of them will be getting missed and just put down as, “Oh…” … but they’ve always been there. The signs have always been there. It’s just whether you’ve got the right people that can identify… ‘[Physiotherapist]

6.4.2. Theme 2: The Child Not Brought

<u>i. Subtheme ‘The impact on the baby’</u>

The follow up is offered depending on gestational age and a range of other factors that predict the risk for longer term challenges. For parents, precise gestation maybe just a number and having a baby in the neonatal unit will result in stress and need for reassurance, regardless of the actual gestation in weeks. However, previous research has shown that the more preterm a baby is the more likely they are to develop prematurity associated complications. The aim of follow up is to improve longer term outcomes, by offering monitoring and early intervention. Every baby has different needs, and HPs understand that preterm babies are different compared to term babies.

‘Feeding, changing, consoling them, them being able to regulate themselves is always… There’s never a baby that you see you think, “Yes, they're 100% spot on, like a term baby.” They're not.‘ [Physiotherapist]

These challenges appear common for many preterm infants and affect the parents, siblings and extended family. Family centered care improves the bonding and relationships between baby and parents and therefore the baby's outcome. The variability of the follow up process across the region means that some units offer joint clinics, involving the neonatologist, the physiotherapist and/or the dietician in one visit, whereas in other areas appointments for the different professionals always occur at different times. During school holidays some families find it difficult to manage appointments, and outreach clinics or home visits are likely to facilitate attendance to follow up.

'With it just being the school holidays, some parents find it really difficult when you've got lots of other siblings as well. Having us visiting them rather than them coming into the hospital all the time makes a massive difference as well, a huge difference.' [Nurse]

A very important aspect of the follow up is feeding, nutrition and growth. Previous literature showed that feeding plays an important role in the bonding between parents and baby, and feeding problems influence parents' perception of self-worth, their emotional wellbeing, and their behaviours, with further impact on baby's development. The ability to offer feeding support may increase the rates of successful feeding, as well as successful breastfeeding rates. Gastroesophageal reflux is seen to have an important impact on baby's behaviour and overall morbidity. Feeding issues are more likely to be emphasised by the community team, including physiotherapists and speech and language therapists.

‘If it’s going wrong, it’s huge because it takes over life. […] They’ve got home. They’ve been sent home with the expectation that their baby can feed, then they get home and they can’t. Then they feel that’s a personal failure on themselves….’ [SALT]

‘I think feeding is a massive one that, if you can get them home and offer the same support as you would in hospital, but in their own environment, I think you would get better breastfeeding success rates.’ [Nurse]

‘I think reflux is massively underestimated, the effects that can have on a child’s movement and posture. “What’s your respiratory status?” All these things come together to play into how you demonstrate how you move. ‘[Physiotherapist]

HPs recognised the role played by feeding for the baby’s general health (such as the impact on breathing), their behaviour (for example the unsettled baby with reflux) and their parents’ behaviour (parents may associate their ability to feed their baby with their own self-worth, as reflected in previous chapters), as well as the role of family integrated care to helping parents and babies in their own environment.

ii. Subtheme ‘The NHS point of view’

‘The NHS is always about money, isn't it?’ [SALT]

The NHS point of view may mean two different perspectives. The follow up has financial implications for the NHS, and all HPs interviewed showed awareness of the financial restrictions and the limitation of resources, particularly in certain settings.

HPs recognised the role of good follow up and efficient community services in saving money on long term for the NHS, as a result of many factors, some identified in the interviews.

Efficient outreach community service may mean early discharge for babies. This not only offers the baby the opportunity to be cared for in their own home, but it also means a free special care cot (i.e. less costs per individual case and opportunity to care for another baby in need of admission). Identifying health problems early offers the opportunity for early intervention, which may save costs on long term.

'Hopefully - and we will see this through our data collection - it will be a cost saving for the NHS. I don't know exactly what the figures are for a special care cot, but I know it's way more expensive than twice-weekly visits for a home oxygen baby.' [Nurse]

'I think if you looked at it long term, we're saving a lot of money, because we're getting in there early, and if you get in early you are pre-empting problems that would have a bigger consequence financially. '[Physiotherapist]

All HPs interviewed appreciated the fact that the NHS needs 'more funds, more staff'. The team work was quoted as something that improves follow up, and health professionals observed that the way services are developed at a local level often depends on the interest and time invested by one of the team members.

'On top of that, I think our clinics are quite unique in being multidisciplinary clinics; at the same point, a baby can be seen by

a consultant, community nurse, physiotherapist as well as dietician.' [Consultant neonatologist]

Follow up is also important for its role in benchmarking and audit. By describing outcomes, it allows comparison between hospitals, it influences future management and helps inform counselling for parents in the future. There are however limitations in the way outcome data are recorded, and some health professionals are aware of those limitations. This has an impact in defining future strategies and providing accurate data to inform counselling and educate parents.

'*We also need to know that, if we are producing good outcomes, then we need to fight with these politicians because you imagine, still, in this day and age, there is a huge discrepancy between the funds to neonatal intensive care unit to paediatric intensive care unit and to adult intensive care unit.' [Consultant neonatologist]*

iii. Subtheme 'Why do parents not attend?'

This study set up to understand reasons why parents of preterm babies do not bring their children to follow up appointments, hence 'Why do parents not attend (DNA)?' was an important question, that led to a variety of answers.

The study did not obtain the approval of REC to access identifying data without consent, which meant that we could not approach the parents who did not bring their children to the appointments. Therefore, we set out to analyse the views of parents who brought their children to appointments and of the HPs involved in the follow up of preterm babies, to understand what the barriers may be to follow up.

Having a preterm baby brings an element of chaos to a family's life and an added burden. This emerged from the analysis of behavioural concerns in the cohort of babies interviewed, and from the parents' interviews, and is also recognised by the HPs interviewed.

The HPs interviewed offered several reasons why parents may not bring their children to the appointments. Parents may not understand the role of the follow up if the child appears well to them, and therefore they may not make it their main priority or may forget about it. Parents may not understand the reason for the appointment, may have just seen someone else for a similar issue, or may feel that appointments are duplicated. This may be due to the way the process is organised, and to the complexity of the network of the HPs involved in the follow up of a preterm baby. Distance and travel may play a role, although health professionals recognised that most parents prefer to travel if this means meeting a team who knows their baby. Neglect and social concerns have also been quoted by the health professionals interviewed, although there did not seem to be an emphasis on this reason. Communication breakdown was noted, including lost letters or conflicting information. Parents may have psychological barriers, of their own (such as a fear to leave the house, the unwillingness to come back to hospital as it brings bad memories) or related to their babies (such as fear of bad news or fear of bugs). HPs summarised these reasons in powerful quotes.

'Our demographics mean that we have quite a lot of parents that miss appointments. Either because they don't remember them, they don't see the value in them, or they don't see the point of them. They can't afford to come. They've got a hairdressing appointment. They've got other children. They're scared. We've

got a certain group of parents who are just scared of what we're going to tell them, so they don't come, because then they don't need to hear it.' [Physiotherapist]

'For very disabled children, sometimes, they end up with so many appointments. They have to see the ophthalmologist, physiotherapist, dietician, paediatrician, orthopaedic surgeon, nurse specialists, home oxygen, and then they have an appointment with us. I think we need to understand that, and the reverse is equally true, that these children, if they were not brought into the clinic, you should be very careful because children who are not brought back to the clinic, we're not supposed to say, "Did not attend." Children who were not brought back to the clinics are the children who may have more problems. That's one aspect, one way to look at it.' [Consultant Neonatologist]

6.5. Discussion

HPs described the birth and follow up of an extremely preterm baby as a journey. The continuity of care and the good communication contributed to improve this journey. Due to the complexity of the team involved in the follow up of the extremely preterm baby, there were challenges in communication at different levels. Improving communication will have a positive impact on the parents' and baby's journey, will ensure a smooth transition between services and therefore will improve the baby's outcome.

There are multiple challenges in achieving good communication, within the team and with the parents. This could be due to system failures, including IT issues or issues around the postal service, co-ordination issues within the Network, and due to human factors, involving lack of understanding, such as inadequate understanding of the reason for the appointment or lack of understanding of different health professionals' roles. Communication may miss completely when members of the network are not recognised as such, for example teachers. This will be discussed further in the next chapter.

Chapter 7. Discussion

7.1. Summary

7.1.1. The qualitative approach to research

The quantitative approach to research assumes that reality is objective, and phenomena can be measured and described using numbers. It has roots in the Antiquity, when people first started to describe the Universe by measuring the relationships between Earth and the stars. They concluded then that Earth is the centre of the world. Later, also by using mathematics, Copernicus (re)discovered the heliocentric model. During centuries, our trust in numbers and their ability to describe our world increased.

In the 19th century, Edmund Husserl established the philosophical school of phenomenology. Husserl proposed a new way of looking at objects by examining how we, by being intentionally directed toward them, actually "constitute" them. This is reflected in the basic assumption of qualitative research that a phenomenon can be best understood by observing and being aware of the researcher position compared to the phenomenon itself.

Qualitative methods apply themselves to the study of behaviours and perceptions to explain behaviours resulting from perceptions.

Qualitative research involves qualitative methodology and treats context as important; it uses different types of data and values subjectivity and reflectivity.[48] While the starting assumptions are different to quantitative research, the process is rigorous,[88] and data are treated with respect.

"The worst thing that contemporary qualitative research can imply is that, in this post-modern age, anything goes. The trick is to produce intelligent, disciplined work on the very edge of the abyss". [89]

"As a general rule, researchers should assume an unobtrusive stance in public settings. A researcher should strive to blend into his or her surroundings in order to reduce his or her impact on the research setting. The art of blending into a research setting entails conscious decisions about how to dress in a research setting, what mannerisms to exhibit, whether to take notes openly or in a concealed manner, and other strategies that allow a researcher to become invisible in the field". [90]

7.1.2. The interviewer's position in qualitative research

The interviewer's position in qualitative research impacts the data collected, and this must be considered when analysing the data and drawing conclusions.[88] In this study, I collected two sets of qualitative data.

The parents' interviews

It is important to acknowledge my role as a paediatrician who was involved in the care of some of those children and was known to some of the parents interviewed. This meant that my personality, my own assumptions, and the profession I represent may have influenced the data. My personality cannot be changed, however maintaining professionalism, and following the topic guide meant that I aimed to make the interviews' structure as consistent as possible from one participant to another.

As a researcher, it is important to identify my own assumptions about the data I am about to collect. As a paediatrician, I had been involved in the care of some of those children and I had met some of those parents before. When analysing my own preconceived ideas about the parents I was going to interview, I identified some key factors that may have influenced my approach. Some stemmed from my previous knowledge about the families and others were my own preconceived ideas.

Examples of preconceptions:

- very young mothers do not want to breastfeed usually,
- parents with higher levels of formal education may have a greater understanding of their child's condition, and vice versa,
- parents' anxiety stems from same reasons for everyone.

Such preconceptions are common and maybe based on society's expectations depending on age, gender, marital status, etc., [91,92] or on previous knowledge, for example the link between parental mental health and child's outcome. [93,94]

I also understood that the parents may expect a benefit from the interview, for example proving that the children are 'just fine' or bringing forward an appointment; this may impact on their answers, and need be considered when analysing the data.

My social background allowed my better understanding of the perspective of mothers from minority ethnic background, and I found myself feeling for them and their struggle to communicate their needs and fulfil their role as their children's advocates.

My previous knowledge and the parents' awareness of the fact that I am a paediatrician and I had looked after babies like theirs or even their own babies had a positive impact, as one parents said: ‘it is easy to talk to you, you know what it’s like’.

While trying to minimise my influence as a paediatrician, I also had to remember my duty of care and safeguarding children, which brought conflict into the way I had to approach my interviews – one side of me remained a detached listener, while the other was actively assessing the context.

The health professionals’ interviews

As I knew most HPs interviewed in a professional capacity, I was aware of the possible influence on the answers. I consistently re-assured the participants that the participation in study is voluntary and answers are confidential. During the analysis phase, data meetings have been held, to acknowledge these facts and minimise their influence on the analysis.

7.1.3. The OPINE study

The aim of this study was to determine the reasons for non-attendance to neonatal follow up. The description of the cohort of babies was informative but unlikely to adequately explain their parents’ behaviours towards the process of neonatal follow up. Hence an in-depth analysis of parental perceptions of neonatal follow up was required. During the study we understood better the triangulated relationship baby-parent-HPs and the need to hear the voice of the HPs as well.

7.1.4. Summary of findings

Description of a cohort of extremely preterm babies born in the North East of England, from the demographic, morbidity, and neurodevelopmental outcomes perspective

One hundred and eleven babies were born before 28 weeks completed GA in the North East of England, between 1st of July 2015 and 30th of June 2016 and admitted to one of the four tertiary neonatal units. Another 3 babies were added to the study, 2 recruited by error and 1 booked but not delivered in the region. Of these 114 babies, 16 died, 2 moved out of the country and 1 was adopted in protected address, hence were not considered eligible for the study. Out of the 95 eligible babies, 58 were included in the study, leading to a recruitment rate of 61.05%.

Out of the full cohort of babies considered for the study, half were born at Unit 1, mortality rate on discharge was 7% and the recruitment rate for the unit was 70%. Almost a quarter of the babies were born at Unit 4, with a mortality on discharge of 29.4% and a recruitment rate of 61.9%. The mortality rate for Unit 2 was 29.4% with a recruitment rate of 41.6% and the mortality rate for Unit 3 was 26.6%, with a recruitment rate of 26.6%.

The cohort of babies who died were smaller and younger and their mothers had increased percentage of antenatal infection risk factors, antenatal haemorrhage and hypertension and they received less antenatal steroids.

Within the survivor group, 43.1% of babies were hypothermic on admission to the neonatal unit. Almost half (48.2%) had their PDA treated, and there was a significant incidence of sepsis events

(63.7%). Most babies (94.8%) received mother's own milk at some stage and almost a quarter were still receiving breast milk on discharge. More than two thirds (79.3%) of babies were discharged home on oxygen. Almost a quarter (22.5%) of the babies showed moderate to severe developmental delay.

According to NNAP data, in 2019, 15.3% babies had a temperature of less than 36.5 Celsius on admission at a national level; 15.88% babies had a positive blood culture during admission, and 82.4% babies received their own mother's milk at 14 days of age.[95]

The neurodevelopmental outcome of the survivors included in study was similar to the outcomes reported by previous studies.[8]

Of the 39 children whose parents completed the SDQs, 15 had developmental delay, however this was not corelated with the SDQ score, or the impact score, apart from those cases where there was severe developmental delay and/or long-term morbidity, which corelated with high impact scores.

The SDQ is a behavioural screening questionnaire, that includes items on psychological attributes on five scales (emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems, and prosocial behaviour), as well as a section dedicated to the impact score. [96]

BSITD III analyses child's development on five scales as well, however the structure of the test and the scales are fundamentally different. Three scales are administered with the child (cognitive, motor, language) and two are administered with parents’ questionnaires (social-emotional, adaptative behaviour).[41]

Therefore, it may be difficult to compare the results of these two different tests to assess whether a child and/or family need ongoing support.

Parents’ Views Related to the Birth and Follow Up of their Preterm Baby

The analysis of parents’ interviews revealed two main themes, ‘Emotions’ and ‘Here and now’ and their subthemes.

The first theme ‘Emotions’ included three subthemes: ‘The emotions related to the preterm birth - a rollercoaster’; ‘The Post Traumatic Stress Syndrome’ and ‘The overprotective parent’.

Following the birth of their preterm baby and even before, parents experienced most of the human emotions, one after another, in what seemed like a roller-coaster; most of the emotions experienced by the parents were negative types of emotions, such as guilt, scare, worry, fear. These mixed and sometimes contradictory emotions contributed to developing symptoms similar to the post-traumatic stress syndrome (PTSS). The parents’ mental health is essential to their ability to provide for and bring up their children. Hence, interventions facilitating the recognition and management of PTSS in parents of preterm babies will likely facilitate a better outcome on long term for the babies. The obstetric services offer a debrief to parents following an unexpected, complicated delivery, including in the case of a preterm delivery. The debrief however focuses on the obstetric management and often takes place soon after delivery.

As resulting from the analysis of the parents' interviews, and based on previous knowledge regrading PTSS, the onset of symptoms in the case of parents of preterm babies may be after years following the birth of a preterm baby; mothers interviewed seemed to link it with their return to work after the maternity leave.

Parents may need support at any stage following the birth of a preterm baby. When planning the resources, it should be considered offering access to tailored psychological support without a time limit post discharge from hospital.

Previous literature described the development of a different, overprotective type of parenting for parents of preterm babies, based on the concept of vulnerability of preterm babies, which was mirrored by the parents involved in this study. The different overprotective type of parenting will impact on the babies' upbringing, their development and their social interaction skills.

The second key theme '<u>Here and Now</u>' included four subthemes: 'The storytelling', 'The coping mechanism', 'The impact of being born early' and 'The value of follow up'.

Future parents expect normality - a normal term pregnancy, followed by a normal birth (with the definition of 'normal' varying depending on cultural, educational, and social background). When the pregnancy and birth are 'completed', parents expect to take home their new baby or babies. The onset of a preterm labour interrupted this normality, and a different journey started to unfold, with all the events seemingly placed together in one big experience. Parents did not make a clear distinction between before and after birth, or before and after discharge. The experience and the feelings related to it impacted on the bonding and relationship between baby and parents and determined the quality of the relationships between parents and health professionals.

Parents made use of an array of coping mechanisms to enable them to support their child, themselves, and their family through a difficult process. Such strategies included living in the present, peer support, family support, and maintaining normality. Feeding is a very important marker of normality and expressing breast milk is often the only active thing that a mother can do for her child in the neonatal unit; hence breastfeeding support is important to mothers and the perceived lack of support impacts on the parents' experience.

Allowing parents to create a routine in the neonatal unit that included normal activities, such as reading to their baby a night-time story, helped them cope and gave them a routine they could use later, when discharged home.

Prematurity has long term consequences, and good medical care of extremely preterm babies, with the purpose to ensure adequate growth and avoid complications is important. While there are natural limitations to the care that can be offered, this study shows that there are circumstances in our control that can improve the parents' experience, and therefore their baby's outcome.

Health Professionals’ views on neonatal follow up

Two key themes resulted from the analysis of the health professionals’ interviews: ‘Communication' and 'The child not brought'.

The first key theme ‘Communication’ included two subthemes: ‘The Journey’ and ‘The MDT (multi-disciplinary team) post discharge’.

Several studies underlined the relevance of the relationships between parents and staff in the neonatal unit to parents’ engagement with services later. Appropriate communication plays a very important role into the parents’ experiences, while communication failures damage the trust between the parent and the clinician, as explored in Chapter 4.

Continuity in care was seen as a marker of good care, was valued by the parents and was important enough to justify travel in most cases. Continuity in care and the existence of a point of contact (i.e. a health professional who knows their baby) reassured parents that any significant issues will be picked up. Health professionals understood that the involvement of a new team or new team member can be daunting for families. This may influence the way families perceive the transition between services, for example when the baby is discharged from the neonatal unit to the care of the community team, or when the baby is discharged from the neonatal follow up into the paediatric follow up. These moments of transitioning from one service to another can be stressful for the parents and may influence the parents’ engagement further.

Health professionals interviewed brought up the notion of a transitional clinic in the neonatal follow up process.

There is a high variability across the region in the in the way the follow up is organised, depending on funding, staff availability and geographical characteristics. The Network includes the specialist teams that may be involved in the care of more complex babies, such as neurology, gastroenterology, orthopedics, ophthalmology, and audiology. Each job role is specific and may bring a different perspective to the follow up of a preterm baby. While different aspects of care are potentially just as important, it may be important to see which matters most to parents. Communication occurs in every direction between the members of this network, and in various ways (written/verbal, formal/informal, paper/electronic). Accurate communication has been shown as important to maintain trust. Communication breakdown may occur at any stage and can depend on system factors, human factors, or more likely a combination of both. System factors play an important role, such as lost letters, IT breakdown, the lack of consistency and communication between the IT systems over the region. Health professionals interviewed noted the importance of human factors in the process.

The transition between services was recognised as a challenging, as well as important moment in time. The first encounter with a new team was important for the way the parents would engage in the future.

There were three transitional moments mentioned by the health professionals interviewed.

One such moment is the discharge from the neonatal unit. Most babies will continue to be followed up by the neonatal team in community, however other professionals become involved at that stage, such as the health visitor.

Another key moment is the transition to the paediatric services. One issue underlined in interviews was around the timing of the diagnosis of cerebral palsy, with different teams having different approaches. The neonatal team has been involved with the baby and family for a long time and has built a relationship with the parents. The timing of diagnosis may coincide with the transition to paediatrics, which means that the diagnosis was not communicated by the neonatal team to the parents but will have to be communicated by the paediatric team. This may mean that the first encounter between the parents and the paediatric team may be complicated by the need to deliver 'bad news', which may then add a strain to the relationship between parents and the community paediatric team and potentially impact on parents' future engagement with the services. It also appeared that there was a difference between what health professionals thought they have said ('*dripped*') and what parents understood.

A third, and sometimes forgotten, important event is the start of school. Some health professionals (in particular, members of the community teams) recognised the importance of liaising with the school and education, as part of the MDT post discharge. The role of liaising with school is important, for children who have already a diagnosis of disability, and also for children who, by being born premature, are at higher risk of
developing behavioural issues or specific learning needs. By increasing teachers' awareness with regards to the above, there

may be an increased opportunity to diagnose these problems early and improve long term education outcomes.

The second key theme ‘The Child Not Brought’ included three subthemes: ‘The impact on the baby’, ‘The NHS point of view’ and ‘Why do parents not attend?’.

Follow up is offered depending on gestational age and other factors, with the aim to improve the outcome, by offering monitoring and early intervention. The follow up has financial implications for the NHS, and all health professionals interviewed showed awareness of the financial restrictions and the limitation of resources, particularly in certain settings. Health professionals recognised the role of good follow up and efficient community services in saving money on long term for the NHS, for example by developing efficient outreach community service.

Follow up is also important for its role of benchmarking. By describing outcomes, it allows comparison, it influences future management and helps inform counselling. There are however limitations in the way outcome data are recorded, and some HPs are aware of those limitations. This has an impact in defining future strategies and informing counselling.

‘Why do parents DNA (do not attend)?’ was the main question of this study. It is important to understand that the notion of DNA is misleading when referring to children. Children do not usually have a choice and it is the parent who decides which appointment is important and whether they should attend or not. Sometimes this may be a conscious decision (such as choosing an appointment based on the perceived importance), or it may be by chance – the parent forgot about the appointment.

When analysing the parents' interviews, parents did consider appointments valuable, and made all efforts to attend. Of course, these were the parents who were recruited following attendance, hence possibly biased and part of a cohort of parents who considered *a priori* the appointments as important. However even in this cohort parents discussed the difficulties of attending, and one mother expressed the fact that at some point she chose to attend the appointments at the tertiary unit, that she considered to be more relevant and cancelled similar appointments with the health visitor as she felt that duplication was likely of no benefit.

The health professionals interviewed offered several reasons why parents may not bring their children to the appointments. Parents may not understand the role of the follow up if the child appears well to them, and therefore they will not make it their main priority or may forget about it. Parents may not understand the reason for the appointment, may have just seen someone else for a similar issue, or may feel that appointments are duplicated. This may be due to the way the process is organised, and to the complexity of the network of the health professionals involved in the follow up of a preterm baby. Distance and travel may play a role, although health professionals recognised that most parents prefer to travel if this means meeting a team who knows their baby. Neglect and social concerns have also been quoted by the health professionals interviewed, although there did not seem to be an emphasis on this reason. Communication challenges were noted, including lost letters or conflicting information. Parents may have personal psychological barriers such as a fear to leave the house, the unwillingness to come back to hospital as it brings bad memories or barriers related to their babies, such as fear of bad news or fear of infections.

In summary, health professionals described the birth and follow up of an extremely preterm baby as a journey. The continuity of care and the good communication contributed to improve this journey. Due to the complexity of the team involved in the follow up of the extremely preterm baby, there were communication challenges at different levels. Improving communication will have a positive impact on the parents' and baby's journey, will ensure a smooth transition between services and therefore will improve the baby's outcome.

7.1.5. A comparison between the parents' and health professionals' opinions

The value of reassurance attached to the follow up and the value of facilitating early intervention depend on the quality of the follow up process. This depends on the quality of communication between parents and health professionals and within the team of health professionals.

There are several common themes that emerged from the parents' and health professionals' interviews:

- Staff are often seen as part of the family. This was recognised by the health professionals and expressed by parents.
- Continuity of care and the existence of a point of contact reassured parents that significant issues will be picked up. This was recognised by health professionals and expressed by parents.
- Feeding is very important to the relationship between parents and baby; supporting breastfeeding was important. Simple

interventions such as offering a breastfeeding mother a sandwich for lunch in the unit made a difference.

This study set up to understand reasons why parents of preterm babies do not bring their children to follow up appointments, hence 'Why do parents do not attend (DNA)?' was an important question. This was answered mainly by the health professionals, because, due to restrictions set out by the ethics committee, we were not able to directly approach the parents who did not bring their children to the appointments.

However, within the group of parents who did, there were identified several barriers to follow up:

- Travel and parking,
- Many appointments, sometimes overlapping,
- Child is well.

7.2. Strengths and limitations of the study

7.2.1. Strengths of the study

The use of mixed methods

This offered a unique insight into parents' and health professionals' perception of the neonatal follow up.

The interviewer's position

The interviewer's position as a doctor involved in the care of extremely preterm babies may be both a strength and a limitation. However, this unique position appeared to encourage both parents and health professionals to open their hearts. One mother said: '*it is easy to talk with you, because you know what it's like*' referring to the interviewer's experience in caring for babies born extremely preterm.

The cost efficiency

The study had a limited budget. It was sponsored by one of the units involved by paying the salary of the researcher. The expenses were indirectly supported by the researcher using the University's OSR account. However, despite the relatively limited resources, the study achieved a reasonable recruitment rate, and was cost efficient.

The regional aspect of the findings

While the findings apply very well to the North East of England, there is an opportunity to share these findings and consider applying in practice for a wider audience. For example, the parents' comments around health visiting may be used to inform the development of the national training programme for health visitors.

The networking

The data resulting from the study have been presented to several meetings (Annexe 16) and were received with interest. Sharing the results may facilitate the implementation in practice of the emerging recommendations.

The public and parents' involvement

Parents and public members have been consulted during the set-up phase of the study; their opinion was sought when designing the parental information leaflets, the questionnaires, and the lay summary of the study. I was invited to write on the VoiceNorth blog, and I reflected on the role of 'shared decision making' in research.[47] We will publish our findings on the *neonatalresearch.net* website, for parents and public.

7.2.2. Limitations of the study

The small number of babies

The study does not describe in depth a population – based cohort of preterm babies, so attempts to draw conclusions regarding their parents' behavior in term of engaging with the services based on their morbidity, level of disability or demographics reflect the cohort studied. This is in part due to the small study population (95 eligible babies), corelated with an overall recruitment of 60%, which reduced the study population to 58 babies.

The routinely collected data

The use of routinely collected data did not appear reliable to describe outcomes, due to lack of consistency. Routinely collected data are as good as the systems' users. While the definition of disease may be same, the understanding of it may vary and a very good example is the diagnosis of NEC. This was mitigated by creating a study specific definition for diagnosis such as NEC or sepsis and following this while data were collected.

The availability of data in the Badger database and other records is also variable and reflects the differences in documentation from one unit to another, depending on the prevalent IT system, as well as the operator. Data such as mother's ethnic origin or smoking status, or treatment for ROP were consistently missing from the Badger, and were not easily available, due to limitations related to the study's design and resources.

The selection bias

Due to the ethical considerations and the inability to access personal data without consent, the study developed a selection bias: we could only approach parents who attended their children's follow up appointments, meaning they were already engaging with the follow up. We used several strategies to mitigate this issue:

- by using qualitative methods to describe parents' perceptions and behaviour,
- by ensuring diversity of the cohort of parents interviewed, in terms of geographical location, ethnicity and social background, as well as level of disability and associated morbidity of their children born preterm,
- by aiming to establishing the parents interviewed were typical to the general cohort of parents of babies admitted to neonatal intensive care. With the help of The Tiny Lives Trust we conducted an anonymised survey on their Facebook page. The survey results appear in keeping with the results of the parents' interviews, suggesting that the cohort of parents who participated to the in depths interviews are typical to the overall cohort of parents of babies born preterm.

The interviewer's bias

This bias had two aspects. During the interviews with the parents, it was important to acknowledge my role as a paediatrician who was involved in the care of some of those children and was known to some of the parents interviewed. This meant that my personality, my own assumptions, and the profession I represent will have influenced the data. During the interviews with the health professionals, I was aware of the possible influence on the answers, as I knew most health professionals interviewed in a professional capacity. I consistently re-assured the participants that the participation in study is voluntary and answers are confidential. During the analysis phase, data meetings have been held, to acknowledge these facts and minimise their influence on the analysis.

7.2.3. Strengths and limitations in relation to other studies

The use of mixed methods offered a unique insight into parents' and health professionals' perception of neonatal follow up. This approach was used previously and proved valuable to deepen our understanding about human behaviour, and in this case, about barriers and facilitators to neonatal follow up.

Ballantyne et al. described barriers and facilitators to follow up in a Canadian cohort.[76] There are differences in the way the follow up is organised in Canada compared to UK. While corresponding with the main author of this study, I observed two important aspects: in Canada, follow up is extended to school age (and children are tested for 'school readiness' at 3 or 4-years of age), and it is done by a multi-disciplinary team, whether at the tertiary unit where the baby was born or in community (meaning near home).

The interviewer position, and the inherent bias, while may be perceived as a limitation, is unique and encouraged both parents and health professionals to open their hearts. This offered deeper insight into the participants' perceptions, views, and experiences of the neonatal follow up.

Despite limited resources, the study achieved a reasonable recruitment rate, and became cost efficient. The recruitment rate was comparable to the recruitment rate of large studies. It is important to also note the main difference in the recruitment process. In the case of large studies, usually the recruitment starts before discharge; in the case of this study, the recruitment was undertaken at around 2-years of age, using the attendance for the follow up appointments. Due to restrictions by the REC, we were not able to contact parents directly if they did not attend the appointment. This may have had an impact on the recruitment rate, and led to the selection bias, that was discussed previously.

The study describes the behaviours of parents, their views and experiences, as well as the HPs views and experiences, in the context of the North East of England; this may enable the application in practice of the study findings, at a regional level. However, the findings may also be applied to a wider area; for example, the parents’ comments around health visiting may lead into improving the national training programme for health visitors.

In conclusion, the use of mixed methods, in the context of a defined region, by a researcher who was an ‘insider’ offered the opportunity to collect unique data about the neonatal follow up of the extremely preterm babies, their parents’ views and needs, and the health professionals’ opinions.

7.3. Recommendations for practice and future research

7. 3.1. Developing a Transition Process to Paediatrics

There is an emphasis in practice on transition of young people with chronic conditions to adult services; this process is framed by a NICE guideline published in 2016.[97] The population of young people who require transition includes children with CP, complex needs and special educational needs, all long-term complications of prematurity. There is no specific provision for long term behavioural issues linked to prematurity such as ASD or ADHD, or for follow up to school age, as recommended by NICE.

In practice, the discharge of a preterm baby from the neonatal unit is usually preceded by an MDT, involves a formalised process, and includes a follow up plan. The follow up plan depends on the existing guidelines and the local set up and resources. In the North East of England all babies born before 28 weeks receive follow up for general health and development up to 2-years corrected of age.

The discharge from the neonatal follow up, however, does not follow a certain pathway, and does not involve an MDT.

If the baby appears well and developmentally appropriate, they will be discharged by the neonatal team. If they need further follow up, a referral into the paediatric services will be made, sometimes by letter. Parents may not have the opportunity to meet the clinician who will look after their child in the future, and the first encounter with the paediatrician maybe difficult, for example if the paediatrician must break bad news.

While some of the babies born extremely preterm may develop easily recognisable co-morbidities associated with prematurity, such as cerebral palsy or blindness, others may remain within 'normal' at 2-years corrected age. However, these babies may also experience behavioural issues and difficulties at school, compared to their peers born at term, and may require additional support to achieve their full potential. The use of different types of assessment may also play a role in the way the follow up is deemed necessary or not. For example, while the BSITD III focuses on motor and cognitive skills, the use of SDQ may facilitate the recognition of behavioural problems as well as the impact on the family and child.

A formalised process for transition to paediatric services for all babies born extremely preterm, with further assessments up to school age may help identify concerns early and allow early intervention and support for these children.

7.3.2. Prematurity – a chronic illness?

Prematurity may be considered a chronic illness with different degrees of severity. Some of the babies born extremely preterm may develop easily recognisable long-term consequences of prematurity, while other may have a normal development at 2-years of age but a higher risk of behavioural issues and difficulties at school, compared to their peers born at term. From this perspective, long term follow up may appear 'natural' as for any other chronic illness. However, it is important to assess the parents' and the children's views with regards to considering prematurity a chronic illness.

7.3.3. To explore the parents' and children's views with regards to creating a 'Preterm Passport'

This concept has been previously used to flag people who suffer from certain diseases that either put them at risk or bring extra needs in certain situations. For example, there are diabetes and epilepsy passports, or allergy bracelets. A ‘preterm passport’ may be used to flag up the fact that the child has been born early and may require additional help in school, or to offer information to teachers about the type of support required.

However, a ‘preterm passport’ may also create unwanted disadvantage, because while it may be useful to early diagnosis and intervention, it could add an unwanted label.

Therefore, while this study suggests that there is a need to ensure continuity in care and smooth transition for children to school time and beyond, we recommend as the first step an analysis of parents’ and children’s views with regards to the use of a ‘preterm passport’, as well as a further enquiry into which is the best way to ensure the continuity and the transition process.

7.3.4. The specialist health visitor for preterm babies

Parents trust the health visitors, their knowledge and experience, and expect them to offer advice and support. The advice expected from health visitors maybe around feeding and sleeping problems, managing behaviour by means of play that is appropriate to the child’s developmental stage, practical advice (for example on how to brush the baby’s teeth or how to fill in the papers for disability living allowance).

Parents feel reassured when the health visitor is aware of their baby’s medical background, and this may prove important when explaining existing scars resulting from lines insertion while in the neonatal unit, for example.

Parents are comfortable with health professionals already known to them. Therefore, it is important that the health visitor is part of the pre-discharge multi-disciplinary meeting. In some cases, this may be the first time the health visitor has had the opportunity to meet the family.

Health professionals may need to be aware of cultural differences and the parents' background when assessing the baby as part of a family.

Parents are happy when health professionals offer positive comments about their baby's progress. Parents of preterm babies worry more and create a different type of parenting based on the concept of increased vulnerability of the preterm baby. They are often very aware of what their baby cannot do, and sometimes overlook what their baby can do. They respond well to reassurance that their baby's progress is as expected.

Parents expect health visitors to understand the concept of corrected age for gestation, and to assess their baby's development based on corrected age rather than actual age. Unrealistic expectation with regards to the baby's development may create a strain on the relationship between the health visitor and the parents.

Parents have issued the idea of a health visitor specialised for preterm babies, able to pick up existing issues in early stages and at the same time to reassure parents appropriately with regards to their baby's progress. While this may not be easy to achieve, health visitors should have access to education and specialised advice when managing families with preterm babies.

7.3.5. Other recommendations

Education of the health professionals involved in the care and follow up of extremely preterm babies, into parents' views, with particular focus on:

1. The need to know the baby (their name, their gender, their past medical history). Parents worry if the clinician does not seem to know about their baby, do not understand why this happens and worry that this will influence the care their baby receives.
2. The need to listen to the parents, who know their preterm babies, may have seen them unwell in the past, and may have a breadth of experience to use.

Tailored psychological support, with no time limit

Parents of preterm babies describe symptoms similar to PTSS, which may become apparent later, after the baby's discharge. This means that it is difficult to assess parents for PTSS and offer support. When parents understand the need to access support, they may find that the support offered is not appropriate for their needs. They may benefit of psychological counselling by a psychologist with experience in counselling parents of preterm babies, and this may be needed at a later stage, following the discharge from hospital.

Debriefing

Parents of extremely preterm babies could be offered an opt-in type of appointment to discuss about the birth and the care offered to their baby. This could be offered later, after discharge from the neonatal unit and may have two outcomes: parents have the chance to discuss about issues they may have not been able to discuss while the baby was very sick, and/or parents may be offered further support if needed (such as the tailored psychological support).

Information tailored to parents’ needs

Most neonatal units have leaflets explaining what to expect when a baby is born preterm, how the unit works, how to access parking permit, the option for respite for the other children or other practical advice. However, this information is offered usually around the time of admission and may not be repeated later. The parents in the study referred to the first few days as being extremely confusing, with a reduced capacity of retaining information. Several parents said that they only found out about parking permits after a month or that they did not understand at all the role of the social worker. Repeating the information – even if it is only a quick reminder by the nurse at the bedside, may enable its retention and help parents.

Encouraging the development of outreach community-based follow up services

This may allow the follow up to go to the baby, who is cared for in their own home environment, with positive effect on the babies and their families.

How did Covid change parents' experience?

The Covid pandemic added to the stress and difficulties faced by the parents of preterm babies. This has happened in several ways, such as: the limitations to visiting, with parents sometimes having to face decisions and upset by themselves, with no support from the extended family; limited peer support; added financial strain by unemployment; loosing friends or family members; fear for their own life and fear for the baby (fear of yet another 'bug').

In the future other effects of the pandemic may become apparent, including possible long-term effects on mental health. It is important to understand parents' views and to continue to adjust our practice to improve babies' outcomes.

7.4. Conclusions

NICE recognise the conditions linked to preterm delivery: cerebral palsy, motor function problems, learning disability, special education needs, speech language and communication disorders, ADHD and ASD, emotional and behavioral problems, feeding and sleeping problems, visual and hearing impairment, developmental delay; they make recommendations for developmental follow up for babies at risk and underline the importance of the multidisciplinary team. The provision of service by the NHS should facilitate attendance to follow up.

Previous literature has shown that parents' ongoing engagement with health services is influenced by their existing experiences. Improved understanding of parents' perception of their baby's journey may improve the follow up process, as reflected in Chapter 4.

Further findings from this study highlighted that there is a specific set of issues for parents of extremely preterm babies, and it is possible that relatively small changes in practice may significantly improve the parents' experience, their engagement with the follow up, and therefore their babies' outcomes.

Previous studies also underlined the relevance of the relationships established between parents and neonatal staff to their engagement with services. HPs interviewed described the birth and follow up of an extremely preterm baby as a journey. The continuity of care and the good communication contributed to improve this journey. Due to the complexity of the team involved in the follow up of the extremely preterm baby, there may be communication challenges at different levels. Improving communication may have a positive impact on the parents' experience and their babies' outcomes. The involvement of a new team or team member can be daunting for families. Therefore, it is important to make links between teams early in the process, to ensure a smooth transition.

Ensuring a smooth transition at every level by designing a clear pathway for the neonatal follow up of extremely preterm babies and the transition to the paediatric services may improve the follow up process, parents' engagement with the system and their babies' outcomes.

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Annexes

List of Annexes

Annexe 1 Parent information leaflets

Parent/Carer Information Leaflet No 1

MICB5631a -
Preterm Baby Resear

Parent/Carer Information Leaflet

'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Dear Parent/Carer,

You and your baby are invited to take part in a research study.

Before you decide whether you wish to take part, it is important for you to know why we want to carry out this research and what taking part would mean for you.

This leaflet is for you to keep. Please read it carefully and take time to decide if you want to take part in the study or not.

This leaflet is divided into two parts:

Part 1 informs you about the purpose of this study and what it means for you and your baby if you take part.

Part 2 gives you more detailed information about what the study involves.

Please feel free to ask us if there is anything you don’t understand or if you would like more information.

Thank you for reading this leaflet.

PART ONE

What is the study about?

We know that having a premature baby can affect how they grow and develop, as well as many aspects of family life. We are keen to learn more about this so we can continue to improve the care we give to babies and families in the future.

For this study, we want to look at your baby's progress from birth up to two years of age. We will look at your baby's health records, the results of their routine health assessments and ask for your views by using a questionnaire, when your baby is two years old. All the information we store will remain anonymous.

Why have I been asked to take part in the study?

You have been asked to take part because your baby was born before 28 weeks gestation.

Do I have to take part?

No, it is up to you to decide. If you decide to take part you will be asked to complete a questionnaire.

With your permission, we will contact you in the future to discuss your baby's progress and listen to your opinions about the care they received.

You are free to change your mind at any time and not take part; you will not need to give a reason, and it will not affect in any way the care that your baby is receiving.

What will happen to me if I take part?

If you decide to take part you will be asked to complete a questionnaire.

Information from the questionnaire will be stored anonymously.

The questionnaire can be completed on paper or via the online link provided in the questionnaire.

If you agree to be contacted later, a member of the research team (Dr Otilia Osmulikevici) will arrange a convenient time and place to meet with you and discuss the follow up and your views regarding this.

What are the potential advantages or risks to me taking part?

This study may not help you or your baby directly, but the findings of this study could help improve services in the future for premature babies and their families.

What if there is a problem?

If you have any complaints about the way you have been dealt with during the study, you can let us or the hospital know. Detailed information is given in Part 2.

Will my taking part in this study be kept confidential?

Yes. All information collected about you during this research will be kept confidential. Detailed information is given on this in Part 2.

Who can I contact for further information about the study?

You can find more information about this study on our website: neonatalresearch.net/research/followup. You can use the link provided in the questionnaire to ask questions about the study or to tell us anything you think is important.

When the study is finished you will be able to see the results on the website as well.

If you are interested in the study and would like to be contacted later, please complete the enclosed reply slip indicating that you are willing for Dr Osmulikevici to contact you. If you do not wish to be contacted, please indicate this on the reply slip and send it back to us.

This completes Part 1 of the information leaflet. If the information in Part 1 has interested you and you are considering taking part in the study, please read the additional information in Part 2 before making your final decision.

Part Two

What if there is a problem

If you have a concern about any aspect of this study you should speak to the researcher who will do their best to answer your questions. Dr Osmulikevici's email address is: O.Osmulikevici2@newcastle.ac.uk

If you wish to speak to someone other than Dr Osmulikevici, please contact a member of the research nurses team: Amanda Forster/Helena Smith, Neonatal Unit, James Cook University Hospital, Middlesbrough, Tel.: 01642854873.

Will my taking part in this study be kept confidential?

Yes. Only authorised persons (such as the research team members) will have access to information about you or your baby.

Information resulting from this study will be used in reports and publications; however it will not be possible for anyone to identify you or your baby in this way.

If we think that your baby needs help from the health point of view or in any other way, we will discuss this with you and will inform the appropriate authorities, such as your baby's general practitioner.

What happens to the results of the study?

The study will take two years to complete and is due to finish in 2019. The results of the study will be available after that. The study will also be published in scientific journals and presented at scientific conferences.

Who is organising the study?

The research is sponsored by the South Tees NHS Foundation Trust. Indemnity arrangements for the study are organised via the South Tees NHS Foundation Trust. The research is organised with the support of the Institute of Health and Society at Newcastle University.

Who has reviewed the study?

The study has been reviewed and has received ethical approval by Regional Ethics Committee.

Where can I find support and information about the NHS care I have received?

The Patients Advisory Liaison Service (PALS) provide confidential advice and support, helping you to sort out issues or concerns that you may have about any aspect of NHS care. PALS can offer independent advice to patients, their families and carers.

PALS contact details:

Freephone: 0800 0320202

Email: northoftynepals@nhct.nhs.uk

Further details can be found on their website: http://www.newcastlepct.nhs.uk/patients/pals

Thank you for taking the time to read this Parent/Carer Information Leaflet. This Leaflet is yours to keep.

………

I wish / do not wish* to take part in the above study

Signature ___________________________________ Date_____________

Print name____________________________________

Telephone number_____________________________

Other contact details_____________________________

*Please delete as appropriate

Please return this tear-off slip in the enclosed stamped addressed envelope.

Parent/Carer Information Leaflet No 2

MICB5631b -
Preterm Baby Resear

Parent/Carer Information Leaflet

'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Dear Parent/Carer,

You and your baby are invited to take part in a research study.

Before you decide whether you wish to take part, it is important for you to know why we want to carry out this research and what taking part would mean for you.

This leaflet is for you to keep. Please read it carefully and take time to decide if you want to take part in the study or not.

This leaflet is divided into two parts:

Part 1 tells you the purpose of this study and what it means for you and your baby if you take part.

Part 2 gives you more detailed information about what the study involves.

Please, feel free to ask us if there is anything you don't understand or if you would like more information.

Thank you for reading this leaflet.

PART ONE

What is the study about?

We know that having a premature baby can affect how they grow and develop, as well as many aspects of family life. We are keen to learn more about this so we can continue to improve the care we give to babies and families in the future.

For this study, we want to look at your baby's progress from birth up to two years of age. We will look at your baby's health records, the results of their routine health assessments and ask for your views by using a questionnaire, when your baby is two years old. All the information we collect will remain anonymous.

Why have I been asked to take part in the study?

You have been asked to take part because your baby was born before 28 weeks gestation.

Do I have to take part?

No, it is up to you to decide. If you decide to take part, we will contact you as detailed below.

With your permission, we will contact you in the future to discuss your baby's progress and listen to your opinions about the care received.

You are free to change your mind at any time and not take part; you will not need to give a reason, and it will not affect in any way the care that your baby is receiving.

What will happen to me if I take part?

We understand that it is not always easy to bring your baby to the hospital for follow up clinic visits. However, we are keen to find out how they are doing and whether they have any ongoing developmental or health problems. Therefore, we will contact you by phone, to try and find out what works best for you.

If you decide to take part, we can arrange for you to bring your baby to the hospital on a date that is good for you, or we will offer you a visit at home.

If you do not feel able to meet with us, we can ask you some questions over the phone.

You can also fill in the enclosed questionnaires, or do so using the internet link provided. The questionnaires should take you approximately 20 minutes to complete, and the information will be stored anonymously.

We would really value hearing from you, however if we do not hear from you, we will collect information about your baby's health from your GP, health visitor, local paediatrician or available health records.

If you agree to be contacted later, a member of the research team (Dr Otilia Osmulikevici) will arrange a convenient time and place to meet with you and discuss the follow up and your views regarding this.

What are the potential advantages or risks to me taking part?

This study may not help you or your baby directly, but the findings of this study could help improve services in the future for premature babies and their families.

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This completes Part 1 of the information leaflet. If the information in Part 1 has interested you and you are considering taking part in the study, please read the additional information in Part 2 before making your final decision.

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Information resulting from this study will be used in reports and publications; however it will not be possible for anyone to identify you or your baby in this way.

If we think that your baby needs help from the health point of view or in any other way, we will discuss this with you and will inform the appropriate authorities, such as your baby's general practitioner.

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PALS contact details:

Freephone: 0800 0320202

Email: northoftynepals@nhct.nhs.uk

Further details can be found on their website:
http://www.newcastlepct.nhs.uk/patients/pals

Thank you for taking the time to read this Parent/Carer Information Leaflet. This Leaflet is yours to keep.

……

I wish / do not wish* to take part in the above study

Signature ____________________________________ Date_____________

Print name____________________________________

Telephone number______________________________

Other contact details_____________________________

*Please delete as appropriate

Please return this tear-off slip in the enclosed stamped addressed envelope.

Annexe 2 Consent form for phase 1

CONSENT FORM

Study: 'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Hospital ………………………………Study identification number……………………………
Child's first name……………………………………………………………………………………
Child's last name……………………………………………………………………………………

Name of Chief Investigator: Dr Otilia Osmulikevici

Please, initial all boxes:

1. I confirm that I have read and understood the Parent Information Leaflet version 2 on 05/09/2017 for this study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐
2. I understand that my and my child's participation is voluntary and that I can change my mind at any time without giving any reason, and without my or their medical care or legal rights being affected. ☐
3. I understand that sections of my child's medical notes and data collected during the study may be looked at by study organisers and the research sponsor. I give permission for access to these records, where it is relevant to taking part in this research. ☐
4. I understand that information held and managed by the national neonatal database administrators and NHS bodies will be used to contact me or to provide information about my child's health. ☐
5. I agree to my child's general practitioner being informed of their participation in the study and of new concerns that have not been previously addressed. ☐
6. I agree for my child to take part in the above study. ☐
7. I am happy to be contacted later to discuss further about my child's follow up. ☐

Name of parent/guardian (in BLOCK CAPITALS)

Signature

Relationship to baby

☐☐ ☐☐ ☐☐

Name of person taking consent (in BLOCK CAPITALS)

Signature

☐☐ ☐☐ ☐☐

Annexe 3 SDQ

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2-4full.pdf

Annexe 4 Study developed parental questionnaire

Parent/Carer questionnaire

Study: 'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Study identification number …………………………………………..

Firstly, we would like to find out a little bit about you.

How would you describe yourself? (Please, circle which one applies):

- Female/Male/Would prefer not to say
- Age: <20 y………20-35 y …………>35y ………..Would prefer not to say
- Relationship to child: Mother…..Father….Grandparent….Carer….Other

Now, can you tell us about your child, please?

In terms of general health:

1. How many episodes of cough and/or wheeze that required medical attention did your child have in the last year: 0 ………<5……… 5-10 ……………>10?

2. Does your child need to use inhalers? Yes/No.

3. Was your child admitted to hospital for breathing problems in the last year? Yes/No.

If Yes, can you tell us how many times, please ……………………………………………….

4. Was your child admitted to hospital for any other reasons in the last year? Yes/No.

If Yes, can you give the reasons, please:

………

5. Was your child discharged home from the neonatal unit with oxygen treatment? Yes/No.

If Yes, what was the length of home oxygen treatment (in months) (please, circle what applies):

1 ………. 2-5………. 6-12……………. >1year ……………. Up to present…….Not applicable…………….

6. Does your child have a special diet? Yes/No/Don’t know.

7. Does your child need to be fed by nasogastric tube? Yes/No/Don’t know.

8. Does your child need to be fed by PEG? Yes/No/Don’t know.

9. Does your child receive parenteral nutrition? Yes/No/Don’t know.

10. Does your child need to take any regular medication? Yes/No.

If Yes – tell us what medication, please………………………………………………………………………………..

In terms of development:

1. Does your child have a diagnosis of cerebral palsy? Yes/No.

2. Does your child have seizures? Yes/No.

3. Does your child have hearing problems? Yes/No.

4. Does he/she need a hearing aid? Yes/No/ Not applicable.

5. Does your child have eye problems? Yes/No.

6. Does he/she need to wear glasses? Yes/No/Not applicable.

8. Can your child walk? Yes/No.

9. Can your child feed themselves? Yes/No.

10. Can your child say any words? Yes/No.

Thank you for completing the questionnaire. Please return this questionnaire in the enclosed stamped addressed envelope.

Annexe 5 Consent form parents phase 2

Newcastle University
Institute of Health & Society

NHS
South Tees Hospitals
NHS Foundation Trust

Parent Consent Form

Study: 'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Please initial

1. I confirm I have read and understood the information sheet for the study above. ☐
2. I understand and confirm I have had the opportunity to read the study information, ask any questions and have had my questions answered. ☐
3. I understand that my participation is voluntary and that I am free to withdraw from the research at any time, without giving any reason, without my rights being affected. ☐
4. I confirm that I agree to the interview being audio recorded. ☐
5. I am aware that the audio recording will be listened to and transcribed and after completion of the research, the audio recordings will be destroyed, but the transcripts kept (in accordance with the Data Protection Act) in a secure location for 10 years. Only members of the research team will have access to the data. ☐
6. I understand that the transcript will have no identifiable features included on it; pseudonyms (e.g. Participant 1) will be used to replace any names in transcripts, reports and publications. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Researcher
……………………………………………	……………………………………………
Date	Date
…………………………….	…………………………………………….
Signature	Signature

Annexe 6 Parents' interviews guide

Study: 'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Chief investigator: Dr Otilia Osmulikevici

Interview topic guide – parental perception on follow up

Interviewer introduces herself, outlines the study and explains that parents will receive a summary of the results if they would wish to have one. Explains about the website and the 'comments' section the parents can use; explains results will be found on the website in a couple of years.

She explains that the aim of the study is to seek the views and experiences of parents who have had a baby born preterm (before 28 weeks), in terms of the follow up care their baby received.

Interviewer explains that parents do not have to answer all questions.

She explains the use of the audio recorder – 'the interview is being audio recorded so I have an accurate account of what the participant has said and so that I don't have to take handwritten notes. Interviews will be anonymised when they are typed up prior to analysis (i.e. names and any other information that could identify you or your baby are taken out.)'

Interviewer assures parents of confidentiality and asks them to sign a consent form. She explains that the interview can be ended or postponed at any time. This will not affect their care or rights in anyway. Interviewer asks whether they have any questions about the study.

Interviewer explains that for the purpose of the interview, she cannot make any comments or give any advice; she needs to do the interview from the perspective of a lay person and ask 'silly' questions. At the end she can put back on the 'doctor hat'.

Advice for the interviewer: keep distance from the doctor role; wait for answers – the power of silence! Use probes like: is there anything else you'd like to say about this? What do you mean by…?

Topics

These are examples of the types of questions and themes that will be raised by the researcher conducting the interview.

Introduction

- How is your baby getting on?
- Tell me a little bit about their birth, please.

Questions specific for the study

- Can you tell me about your baby now, please? (Prompt - do you have any worries or concerns about how your baby is doing?)
- Looking back, how do you feel now about the fact that your baby was born early? How did it make you feel?
- How many health professionals do you see currently for your baby? (By this I mean the paediatrician, physiotherapists or any other similar staff). Probe for each appointment like: 'What do physios do? What did they say to you? ' Ask more detail about each appointment and '' what did it feel like…''' and how did this make you feel? Or 'what was about ….. that made you feel …..'?
- How many hospital appointments would you say you had to attend for your baby, in the last 6 months?
- How many times has your baby been readmitted to hospital, or seen as an emergency?
- How many times did you see you GP in the last 6 months?
- How do you feel the routine clinic appointments helped? Do you think they were important for you and your baby – in what way?
- More probing: can you tell me a little more about that? What did you understand about that?
- What do you think about the number of appointments you attended? (Prompt: Did you feel there were too many, or too few, or just about right?) Would you like to have been seen more often? (Prompt - perhaps when you first went home from hospital?).
- How long between going home and the first appointment?
- Did you have to come back to the hospital? How did that feel?
- How did it feel – was it too long between the appointments or too little time or just about right?

- Was it difficult to get to hospital appointments –in what way? (Prompt - travel, parking, need to look after other children, or work). Develop on each appointment: what it means – ‘practical issues’: work, parking, O/N stay, finance…
- Can you explain what attending an appointment involved/meant for you? How long were you in clinic for?
- How do you think that the appointments were useful? (Or targeted: How do you think that the physios were useful? How do you think that the developmental assessment was useful?)
- When you came to the hospital for the two year assessment (when they had to play with all those toys), did you have any family member with you to help?
- Can you describe how did that assessment go? (Prompt: Did your baby enjoy the play-like assessment? Did you understand what the results of the assessment were? Did your baby become unsettled towards the end? Did you have to rush through the doctor’s explanations about the results?)
- Did you know what this is for?
- Did you know what would happen?
- How do you think it went?
- How were the results communicated, was this satisfactory?
- Did you understand the results? How would you have preferred to be told the results?
- How do you think the follow up visits were important?
- When you were in hospital, what were you explained in terms of outcomes (Prompt: how will the baby be like, from the development point of view, or health…)?
- Has anyone explained about parking permit, DVLA, etc.., early in the process?
- Have you had any psychological support? Would you have liked that?
- How is your family life now? (How about earlier, maybe when they were still in oxygen?)
- Have you got any support? Do you go out at all? Do you feel tired at all?

- What about maternity leave, when did it start, how long left after discharge?
- How long have you breastfed your baby?

Aspects specific for parents who did not bring their baby to the routine appointment

- Were there any specific reasons you found it difficult to get to clinic appointments? (Prompt - travel, parking, need to look after other children, or work).
- What do you think about the fact that I contacted you and arranged for your baby to be assessed?
- Did you feel that it was helpful -why?

Aspects specific to parents of babies from multiple pregnancies (the researcher will have to be aware of the outcome of all babies and approach parents in a mindful way)

'You have more than one baby (congratulations!)'

- How do you feel about the way the follow up appointments have been organised? (Prompt: did you ever have to come to hospital twice/trice because each of them had a similar appointment, but in a different day? If yes, how did this feel?)

End of interview

- I have reached the end of my questions. Is there anything you would like to add?
- How did you feel about this interview? How did you feel (because of this…)?
- Are there any (other) questions you would like to ask me about the study?

Interviewer thanks parents for giving up their time and supporting the study.

Annexe 7 Health professionals' information leaflet

Health Professional Information Leaflet

'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England' IRAS ID 225912

Dear Colleague,

You are invited to take part in a research study of outcomes of babies born extreme preterm in the North East of England.

Before you decide whether you wish to take part, we would like to explain why we want to carry out this research and what taking part would mean for you.

This leaflet is for you to keep. Please read it carefully and take time to decide if you want to take part in the study or not.

This leaflet is divided into two parts:

Part 1 informs you about the purpose of this study and what it means for you if you take part.

Part 2 gives you more detailed information about what the study involves.

Please feel free to ask us if there is anything you don't understand or if you would like more information.

Thank you for reading this leaflet.

PART ONE

What is the study about?

The study aims to analyse short and two year outcomes of babies born before 28 weeks gestational age in the North East of England.

As part of the study, the patient's development is assessed by using the Bayley's Scales of Infant and Toddler Development (BSITD) III at two years of age, which is part of routine care for babies born extreme preterm in the North East of England. Parents are also asked to complete a questionnaire regarding their child's behaviour (the Strengths and Difficulties Questionnaire – SDQ 2-4y full).

We hope that the study will offer information about the population of babies born extreme preterm in the North East of England, in terms of disability, general and respiratory health, and behaviour. This information can be used by doctors and parents for understanding better what being born extreme preterm means and to help making decisions about the care of the babies born extreme preterm.

We aim to understand the importance of the follow up in the parents' eyes and are asking parents about their experience of the follow up offered to their children.

We consider that the viewpoint of the health professionals involved in the follow up care of babies born extreme preterm is relevant to the way that the follow up is offered. Therefore, we wish to explore the health professionals' views about the follow up offered to babies born extreme preterm, by asking them to take part in a topic guided interview.

Why have I been asked to take part in the study?

You have been asked to take part because as part of your job, you are involved in the follow up care of babies born extreme preterm.

Do I have to take part?

No, it is up to you to decide.

What will happen to me if I take part?

If you decide to take part, a member of the research team (Dr Otilia Osmulikevici) will arrange a convenient time and place to meet with you and discuss your views about the follow up care for extreme preterm babies.

This will take the form of a topic guided interview. Interviews will be anonymised when they are typed up prior to analysis and will be stored anonymously.

Will my taking part in this study be kept confidential?

Yes. All information will be kept confidential.

Who can I contact for further information about the study?

You can find more information about this study on our website: https://www.neonatalresearch.net/followup.html. When the study is finished you will be able to see the results on the website as well.

What are the potential advantages or risks to me taking part?

This study may not help you directly, but the findings from this study could help improve services in the future for premature babies and their families.

What if there is a problem?

If you have any complaints about the way you have been dealt with during the study, you can let us or the hospital know. Detailed information is given in Part 2.

Will my taking part in this study be kept confidential?

Yes. All information collected about you during this research will be kept confidential.

Part Two

What if there is a problem

If you have a concern about any aspect of this study, you should speak to the researcher who will do their best to answer your questions. Dr Osmulikevici's email address is: O.Osmulikevici2@newcastle.ac.uk

If you wish to speak to someone other than Dr Osmulikevici, please contact a member of the research nurses team: Amanda Forster/Helena Smith, Neonatal Unit, James Cook University Hospital, Middlesbrough, Tel.: 01642854873.

Will my taking part in this study be kept confidential?

Yes. Only authorised persons (such as the research team members) will have access to information about you.

Information resulting from this study will be used in reports and publications; however it will not be possible for anyone to identify you in this way.

What happens to the results of the study?

The study will take two years to complete and is due to finish in 2019. The results of the study will be available after that. The study will also be published in scientific journals and presented at scientific conferences.

Who is organising the study?

The research is sponsored by the South Tees NHS Foundation Trust. Indemnity arrangements for the study are organised via the South Tees NHS Foundation Trust. The research is organised with the support of the Institute of Health and Society at Newcastle University.

Who has reviewed the study?

The study has been reviewed and has received ethical approval by Regional Ethics Committee.

Thank you for taking the time to read this Health Professional Information Leaflet. This Leaflet is yours to keep.

……

I wish / do not wish* to take part in the above study

Signature ____________________________________ Date_____________

Print name____________________________________

Telephone number___________________________

Other contact details___________________________

*Please delete as appropriate

Please return this tear-off slip in the enclosed stamped addressed envelope.

Annexe 8 Transparency declaration

Transparency Declaration

Study title: 'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'.

IRAS 225912

South Tees Hospitals NHS Foundation Trust is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. South Tees Hospitals NHS Foundation Trust will keep identifiable information about you for 10 years after the study has finished. Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study after the data analysis has been done, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

You can find out more about how we use your information by contacting:
Mr Joe Millar
Research Manager
South Tees Hospitals NHS Foundation Trust
South Tees Institute of Learning, Research and Innovation
The James Cook University Hospital
Marton Road
Middlesbrough
TS4 3BW
stees.researchdevelopment@nhs.net
R&D tel: 01642 854089

The South Tees Hospitals NHS Foundation Trust will collect information from you for this research study in accordance with our instructions.
The South Tees Hospitals NHS Foundation Trust will use your name and contact details to contact you about the research study, and to oversee the quality of the study. Individuals from South Tees Hospitals NHS Foundation Trust and regulatory organisations may look at your research records to check the accuracy of the research study. NHS sites will pass these details to South Tees Hospitals NHS Foundation Trust along with the information collected from your research records. The only people in South Tees Hospitals NHS Foundation Trust who will have access to information that identifies you will be people

who need to contact you for the purpose of this study or audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name or contact details. South Tees Hospitals NHS Foundation Trust will keep identifiable information about you from this study for 10 years after the study has finished.

Annexe 9 Consent form health professionals

NHS
South Tees Hospitals
NHS Foundation Trust

Health Professional Consent Form

Study: 'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Please initial

1. I confirm I have read and understood the information sheet for the study above. ☐
2. I understand and confirm I have had the opportunity to read the study information, ask any questions and have had my questions answered. ☐
3. I understand that my participation is voluntary and that I am free to withdraw from the research at any time, without giving any reason, without my rights being affected. ☐
4. I confirm that I agree to the interview being audio recorded. ☐
5. I am aware that the audio recording will be listened to and transcribed by the researcher or a vetted UK transcribing company, and after completion of the research, the audio recordings will be destroyed, but the transcripts kept (in accordance with the Data Protection Act) in a secure location for 10 years. Only members of the research team will have access to the data. I agree to this. ☐
6. I understand that the transcript will have no identifiable features included on it; pseudonyms (e.g. Participant 1) will be used to replace any names in transcripts, reports and publications. ☐
7. I agree to take part in the above study. ☐

Name of Participant	Researcher
………………………………………………	……………………………………………
Date	Date
…………………………….	……………………………………………
Signature	Signature

Annexe 10 Health professionals' interviews guide

Study: 'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Chief investigator: Dr Otilia Osmulikevici

Interview topic guide – health professional perception on the follow up of extreme preterm babies

Interviewer introduces herself, outlines the study and extends a special thanks to the health professional for agreeing to take part in the research. She explains that the aim of the interview is to seek the views and experiences of health professionals involved in the follow up of extreme preterm babies.

She explains the use of the audio recorder and the fact that the interviews will be anonymised.

Interviewer assures health professional of confidentiality and asks them to sign a consent form.

Interviewer asks whether they have any questions about the study.

Topics

These are examples of the types of questions and themes that will be raised by the researcher conducting the interview.

Introduction

- What is your job role? Tell me a little bit about what it means, please.

Questions specific for the study

- What is the role of the follow up of preterm babies in your opinion? Is there any difference, depending on how preterm they are? (i.e. is it more important the more preterm they are, or not)

- What do you think that (your specific job role) does for the babies born preterm? Do you see any difference depending on the degree of prematurity? In what way do you think that the follow up is important to the babies?
- What do you think that (your specific job role) does for their parents? In what way do you think that the follow up is important to the parents?
- What do you think that the follow up of extreme preterm babies means for the NHS? Do you think that it is important for the NHS?
- What does it mean to you personally to do this job?
- Why do you think parents sometimes don’t bring their children to their NHS appointments?
- What do you think we’re doing well, as organisation?
- What would you improve? Name one change you’d like to make, please.
- How is the two year developmental follow up organised in your unit? Do you send information leaflets out to parents, prior to the appointment? If so, what do they explain? Do you think that the parents understand what this appointment means and its importance for their baby? How many appointments can you offer if the patient does not attend?
- What do you enjoy about your job?

End of interview

- I have reached the end of my questions. Is there anything you would like to add?
- How did you feel about this interview?
- Are there any (other) questions you would like to ask me about the study?

Interviewer thanks the health professional for giving up their time and supporting the study.

Annexe 11 The Tiny Lives Trust Facebook page post

Dear Parent,

Colleagues at the Royal Victoria Infirmary, Newcastle, are undertaking research regarding the follow up appointments for premature babies. They are interested to hear your views about this.

Advances in medicine mean that the survival of premature babies has increased dramatically over the last 20 years, and half of the babies born 16 weeks early now survive. The OPINE study is looking at the two year outcomes of babies born more than 12 weeks early in the North East of England. Information about the study can be found at: https://www.neonatalresearch.net/followup.html

All babies born more than 12 weeks early are offered follow up appointments, and we want to find out what parents think of these appointments.

We would be grateful if you could take a few minutes of your time, to complete this survey:

https://www.neonatalresearch.net/follow-up-survey.html

Thank you very much for your help.

Tiny Lives Trust and The Research Team

Annexe 12 The Tiny Lives Trust survey questionnaire

Survey questions

1. Was your child (were your children) born between 01/07/2015 – 30/06/2016?

Yes/No/not applicable

2. Was your child (were your children) born:
   a. Before 28 weeks completed gestation age?
   b. Between 28 and 32 weeks completed gestation age?
   c. Between 33 and 36 weeks completed gestation age?
   d. After 36 weeks completed gestation age?

3. Have you brought your child/children back to hospital for follow up appointments?

Yes/No/Not applicable

4. How many follow up appointments did your child/children have in the last two years?

None – less than 5 – between 5 and 10 – between 10 and 20 – more than 20

5. On a scale from 1 to 5, how useful did you find the appointments, where 1 is ‘not useful’ and 5 is ‘very useful’?

1 – 2 – 3 – 4 - 5

We are keen to learn more about parents' experiences of follow up clinics and would be grateful if you have any other comments you would like to share with us (comment box).

Annexe 13 REC approval

225912 Letter of HRA Approval 27.09.2017

17 – NE -0265- 225912 SA1 Fav Opinion

225912 Letter of
HRA Approval 27.09.

17-NE-0265 -
225912 - SA1 Fav Op

Annexe 14 Voice North Blog

‘The role of shared decision making in research: a new researcher's epiphany

- 31/07/2017
- Health & Social Care Research

I’ve just started my medical doctorate and I find myself in the developing phase of my project. The first few months have been a whirlwind of events, and a rather steep learning curve for me. I had never heard of Patient and Public Involvement (PPI) before, however the idea was introduced early in the project by my supervisors. I also recently attended a training session for post graduate students called ‘Developing Skills in PPI’, which was organised by the School of Primary Care Research and the Faculty of Medical Sciences Engagement team at Newcastle University.

As doctors we have the patients’ best interest at heart and we are all familiar with the idea of shared care and shared decision making. In my field of activity (children) things are even more complex because there are always others (parents) involved! Many of my patients are not at the age where they can make informed decisions for themselves, and the issues of consent and capacity are very complicated. However, any clinician will very carefully consider the wish of the child during the whole process of diagnosis and management of disease. So then, why not when it comes to research?

It felt strange for me to think that the patient’s wish may not be explored when research is conducted. Yet, I didn’t think about it until it was pointed out to me!

At the training session I met many interesting people, who helped me to understand what PPI means. I’ve also learnt how much the involvement of the patient in making decisions with regards to research can change the perception about research itself.

Following the training session I asked Voice North for their help and feedback on my study materials. Their feedback was very useful. Not only could I see what I did well, but also the areas that I could improve on. I have taken their advice and included it in my way of thinking about my study. They helped me understand my own work better!

I am really grateful to the Voice North members who took their time to help me and I am looking forward to meeting them again!

Dr Otilia Osmulikevici
Postgraduate Research Student
Institute of Health and Society
Newcastle University'

Annexe 15 Lay Summary

Study: 'Population-based study of two year outcomes in very preterm babies - a regional cohort in the North East of England'

Advances in medicine mean that the survival of premature babies has increased dramatically over the last 20 years. Half of the babies born more than 16 weeks early now survive. Whilst most go on to lead happy and healthy lives some have longer term problems, such as physical difficulties, slower learning, or medical problems. We want to determine two year outcomes of babies born more than 12 weeks early in the North East of England. This information is important for babies and families; it may help nurses and doctors to improve care, and is also important for the NHS to plan its resources.

The study will identify babies by using existing NHS records. We will collect existing information about disability, general health, any problems with breathing, and the baby's behaviour, and also about the care the baby received whilst in hospital, and during follow up visits to hospital, using medical notes. We will also ask parents to complete a questionnaire. Parents will be informed about the study at the time of the routine hospital visit when their baby is aged two years, and can choose if they wish to be involved in the study.

Although all babies born more than 12 weeks early are offered a follow up appointment, some are not brought to the hospital. We want to understand the reasons for this. We think it is important to collect the outcomes for every baby, so we will contact parents who do not bring their baby to the routine follow up appointment directly (by letter and/or phone), after having checked how the baby is doing with their general practitioner. We will offer to collect follow up information by arranging a home visit if families find it difficult to get to the hospital, by questionnaire or telephone.

Annexe 16 List of presentations

Neonatal follow up: a literature review on parental perceptions; Neonatal Network Research Conference, Boldon, September 2018

Neonatal follow up and the transition to paediatric services; 25th August 2020 Great North Children Hospital, 25th September 2020 Neonatal Network Research Meeting; 18th November 2020 Sunderland Royal Hospital

Abstract submission to the European Academy of Paediatric Societies Conference 2020

'A Qualitative Study of the Journey of a Preterm Baby; Parents' perspectives'

Abstract

Background and aims: Previous literature exploring parents' views and perceptions related to the birth of their preterm baby, the care offered and the neonatal follow up suggests that parents' ongoing engagement with health services is influenced by their existing experiences. We undertook a qualitative study aimed to improve our understanding of how parents engage with health professionals following hospital discharge.

Methods: Qualitative study involving one-to-one semi-structured interviews. Parents were recruited following their babies' attendance for the 2-year routine neurodevelopmental follow up. 17 interviews were carried out with 23 parents of babies born before 28 completed weeks of gestation. Interview data was analysed using thematic analysis.

Results: The analysis of the parents' interviews identified two key themes: 'Emotions' and 'Here and now'. The first theme, 'Emotions', included three subthemes: 'The emotions related to the preterm birth – a rollercoaster', 'The post-traumatic stress syndrome' and 'The overprotective parent'. The second theme, 'Here and now', included four subthemes: 'The storytelling', 'The coping mechanism', 'The impact of being born early' and 'The value of the follow up'.

Conclusions: Findings from this research provide insight into the views and experiences of parents of preterm babies, highlighting that there is a specific set of issues for parents of preterm babies. Our results will help to inform health care planning around neonatal follow up. Relatively small changes in practice can improve the parents' experience, their engagement with the follow up, and therefore their babies' outcomes.

Key words: preterm, follow up, parents' experience

Abstract submission to the European Academy of Paediatric Societies Conference 2020

‘A Qualitative Study of Health Professionals’ Views of the Neonatal Follow Up’

Abstract

Background and aims: Previous research on barriers and facilitators to neonatal follow up emphasised the importance of effective communication between parents and health professionals, with poor communication increasing parental stress levels. Studies underlined the relevance of the relationships established between parents and neonatal staff to their engagement further with the health services. We undertook a qualitative study to explore health professionals’ views on neonatal follow up.

Methods: This was a qualitative study involving one-to-one semi-structured interviews, with health professionals involved in the follow up care of preterm (<28 weeks) babies.

Interviews were carried out with 20 health professionals, including neonatologists and community paediatricians, community nurses, physiotherapists, health visitors, speech and language therapists and dieticians. Interview data was analysed using thematic analysis.

Results: The analysis of the health professionals’ interviews identified two key themes: ‘Communication’ and ‘The Child Not Brought’. The two themes included five subthemes: ‘The Journey’ and ‘The multi-disciplinary team post discharge’, and respectively ‘The impact on the baby’, ‘The NHS point of view’ and ‘Why do parents not attend?’.

Conclusions: Health professionals describe the birth and follow up of a preterm baby as a journey. The continuity of care and good communication contribute to improving this journey for parents and health professionals. Due to the complexity of the team involved in the follow up of the preterm baby, communication may suffer at different levels. Improving communication will have a positive impact on the parents’ and their babies’ journey, and therefore on the babies’ outcomes.

Key words: preterm, follow up, health professionals

OPINE

Annexe 17 COREQ criteria

Item	Description	Reported on page
Domain 1: Research team and reflexivity		
1. Inter viewer/facilitator	Which author/s conducted the interview?	
2. Credentials	What were the researcher's credentials?	
3. Occupation	What was their occupation at the time of the study?	
4. Gender	Was the researcher male or female?	
5.Experience and training	What experience or training did the researcher have?	
6. Relationship with participants established	Was a relationship established prior to study commencement?	
7. Participant knowledge of the interviewer	What did the participants know about the researcher?	
8. Interviewer characteristics	What characteristics were reported about the inter viewer/facilitator?	
Domain 2: study design		
9 . Methodological orientation and Theory	What methodological orientation was stated to underpin the study?	
10.Sampling	How were participants selected?	
11.Method of approach	How were participants approached?	
12.Sample size	How many participants were in the study?	
13.Non-participation	How many people refused to participate or dropped out? Reasons?	
14.Setting of data collection	Where was the data collected?	
15.Presence of non-participants	Was anyone else present besides the participants and researchers?	
16.Description of sample	What are the important characteristics of the sample?	
17.Interview guide	Were questions, prompts, guides provided by the authors?	

18.Repeat interviews	Were repeat interviews carried out?	
19.Audio/visual recording	Did the research use audio or visual recording to collect the data?	
20.Field notes	Were field notes made during and/or 10after the interview?	
21.Duration	What was the duration of the interviews	
22.Data saturation	Was data saturation discussed?	
23.Transcripts returned	Were transcripts returned to participants for comment and/or correction?	
Domain 3: analysis and findings		
24.Number of data coders	How many data coders coded the data?	
25.Description of the coding tree	Did authors provide a description of the coding tree?	
26.Derivation of themes	Were themes identified in advance or derived from the data?	
27.Software	What software, if applicable, was used to manage the data?	
28.Participant checking	Did participants provide feedback on the findings?	
29.Quotations presented	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified?	
30.Data and findings consistent	Was there consistency between the data presented and the findings?	
31.Clarity of major themes	Were major themes clearly presented in the findings?	
32.Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	

Annexe 18 Sample interviews

Parent interview

M mum I interviewer (.) episodes of play

I: So, how is she doing?

M: She's fine, yeah… obviously she's small, smaller than what she would be like, again, like someone like her… like not a prem… she's alright, she just started like speaking words in the last couple of months, she was late to start talking. Not a very good eater, but other than that she's fine.

I: … do you have any worries about her, any concerns at all?

M: Not yet, I don't think … there's no point in worrying yet, I think when she gets to school, they said she might have like concentration problems, with like mathematics and writing, English, listening, but until then… I don't know, just enjoy her, the way she is...

I: It makes a lot of sense…

M: Aha…

I: Ok… and tell me a little bit about her birth …

M: Horrible, traumatic, horrible… me waters broke at the (shopping centre) … at the big shopping centre and I started contracting straight away, but I didn't tell me husband that, cause obviously we got a ... an older boy … an older boy, he's seven at the end of the month, so I knew I was in labour when me waters went, then it was like the perfect … almost the perfect labour, just 15 weeks too early… horrible, they couldn't stop it, I only had time for one steroid, horrible… but having her naturally, that was the only kind of good thing about it…

I: Right…

M: Really horrible …

I: And, where was she born?

M: (tertiary centre).

I: She was at the (tertiary centre) … Were you booked there?

M: No.

I: Did you just get transferred there?

M: No, I was at the shopping centre …

I: Just ‘cause you were… right!

M: … so, in my mind I knew they had a special care baby unit... but I didn’t realise until after I had her I was in the right place at the right time. My local hospital wouldn’t have been able to have her… wouldn’t have been able to have her there and she would have get transferred, they’re not like a high level… a neonatal intensive care unit, so I could have had a completely different outcome if I hadn’t been there at that time…

I: You think?

M: Aha, I’ve been told, yeah … I was told (local hospital) don’t take babies from that early on…

I: I see...

M: And when I was there, she did a month there, I’ve seen like a little one being born, they’ve had to just… the doctors on call there were intubating and getting ready to transfer a baby, I was just glad that wasn’t me. I’m just glad I had her in one place, and she went straight in the incubator, and went straight into breathing support and ventilating, and that’s where we were for like eight weeks, whatever it was, yeah…

I: Did anyone get to explain anything to you before she was born?

M: Baby doctors came in, but in my mind I was just in total denial, even though she was like right down there… I'm thinking, no, I won't be having her… they're bringing in the resuscitaire thing, baby doctors … I was like… yeah, yeah, that's nice, I won't need you… I was just like in total denial, I was like, no, I won't have her, this isn't happening, babies that little don't survive, I'm not having her… they were like, oh, if we can stop your labour, we'll keep you coming into clinic, just to check you, you can go on without waters… that wasn't gonna happen ... and I had her.

I: Right… and how soon did you get to see her, after she was born?

M: I can't remember… I had a picture straight away…

I: Would you say within twelve hours…

M: I think so. They took us round to the intensive care area within twelve hours I think, but I've no recollection of like time for the first couple of days…

I: Right...

M: It was a bit like a blur really, but...

I: Why do you think that that was?

M: There was just lots of people, I had my obviously … my visitors, me husband, getting moved around on the ward, onto like a bay with women that didn't have the babies with them, lots of people coming in, asking us to take part in studies …

I: Was that hard?

M: No, I was just … I just agreed to everything, it was a situation that you just can’t pre-empt, horrible, but very real, all the same, yeah…

I: And, how did we explain to you when you were there, about outcomes, what we think it’s gonna happen, how she’s gonna be like… did we tell you this kind of things?

M: Mhm, I think so, yeah …

I: And did it help?

M: Yeah, I mean what I can remember, yeah… I did like me own research as well and… obviously, with her like being like a very premature, you could kind of… obviously you talk to other parents on the unit, and you could see those ahead of you, kind of how they were progressing, and yeah, she only had like a couple of setbacks, like blood transfusions, and a … a sodium correction… really, she followed a basic… straightforward …

I: Was it helpful to see other parents and other…

M: Yeah, definitely, definitely ...

I: In what way?

M: That gives you hope and that, like, if you think of it like a journey, ours like at the beginning, and you can see people like going home with their babies, so that gives you hope. You’re born that early, you don’t really expect to survive. And obviously, when we were in there, you’d see a baby’s name on the board, and then next time you go in, baby’s name not on the board, they had her moved to another bay, so that was very real, you see life and death just like that. That scary!

I: Would it worry you?

M: Oh, it was the scariest thing in the world! Oh, yeah!

I: The moving of the name on the board?

M: Oh, yeah! Horrible… What's happened with that baby?! Horrid, awful!

I: And was it only for (child's name), or was it if you'd seen anyone, that you'd...

M: Just anyone! You're worried for that baby, worried for my baby… oh, my God! babies this small don't survive… and … yeah. But you just keep going…

(.)

I: I see… and you know, looking back, how do you fell now about the fact that she was born early?

M: Guilty!

I: Guilty?

M: Mhm… my body had to do one thing, carry her for approximately nine months, me body did not do that!

I: Right...

M: So therefore, I kind of feel … but in a way it did the right thing by having her that early, 'cause it was confirmed to have a placental abruption. Had that completely come away, they said she would have died… so really my body did the right thing. Just 15 weeks too early…. So, I've got to like hold on to that and just remember that it did the right thing ultimately…

I: Yeah!

M: Yeah …

I: And are you ok with this?

M: Yeah…

I: … with this sort of feeling…

M: Yeah, I mean … it will be there me whole life, but yeah …

I: Right, ok… (.) And, at the moment, how many health professionals do you see for her?

M: Well, when she turned… when she had like her 2-year checks, they discharged us from me local community paediatrician, we had the (tertiary centre) check, who then referred us back to the community paediatrician and until she reaches school age, but I've had no appointments since the two years check, I just wait for people to write to me now. Me own (health) visitor wanted to do like a two year check on her, but I'd already had that at the (tertiary centre), like a Bayley 3 assessment, that was very, very in depth and would have been more than what my health visitor one was, so I told my health visitor, I don't want that check, cause she goes to nursery now, so she's got like professional early years, people there are keeping an eye on her. I said to my health visitor, don't contact us until like she's ready to hand over to the school nurse, 'cause I think there's a big … what I would say a big overlap between services getting in touch and it does not seem to be much communication between (local neonatal unit), (tertiary centre) and just (local hospital), between my three. I know it's probably because she was born in the county that she's not registered at, that's the only big criticism that I have…

I: so, what actually happens, in what way?

M: Like, I'll have three people all writing us with 2-year checks in the same … it seems really is a big duplication of everything… one single appointment would be absolutely fine, but me, I don't feel the need for me own local health visitor to come round and for her to get to (tertiary unit) to get weighed, to (local hospital) to get weighed, to (local neonatal unit) to get weighed, it’s just a lot of unnecessary appointments, I think.

I: And is it just for the 2-year one that it happened or was it before?

M: Oh, for the 1-year one, and the 12-weeks one, and… yeah, hopefully that would be it for now, but obviously six monthly you tend to get three other places…

I: Really...

M: Yeah… I know… very, very busy at some point… when all the appointments come through...

I: So, apart from the community paeds, neonates, health visitor… anyone else you’ve seen since she was discharged?

M: Just hospitals when we’ve had to go in when she’s had like... when she had … she was really badly sick for like a full week, didn’t eat anything… just hospitals…

I: Did she just go once, did she get admitted?

M: We went twice… one for like a respiratory... breathing, I can’t remember even what it was… I couldn’t get her temperature down below 40, it was, I couldn’t get it down … and once she was just like sick for like a whole week, she wasn’t eating… anything, couldn’t keep nothing down, for that … and first thing they say to you there, when they’re checking her in… so, was she straightforward birth, was she born on time? … ‘no! she wasn’t’, just look at… is there no computer you can look at, recalling all?!... she’s really not … just having to repeat that whole thing every time, and … when they see like a long line scar, or the scar off like a canula, there’s like… what’s that… what’s that… what’s that… I feel like they should have had the information in front of them…

I: Was this in (local neonatal unit)?

M: Yeah… that's off (local neonatal unit) yeah… I mean she stayed, she was at (local neonatal unit) for like a month… month and a bit…

I: Really?

M: Yeah, on her… when she got transferred from the (tertiary centre) … to (local neonatal unit), she was there just for like feeding and growing.

I: so, she was there…

M: Yeah, she was on like a few meters down the corridor, so you'd think they'd be able to recall like her file... whatever, but no…

I: Right… and, apart from them, you've not seen anyone like physios or eyes or...

M: Oh, yeah, she had physio out for a little bit, like the first year, no concerns, didn't really need it… and she went to get her eyes checked… they were meant to write to us again in January this year, but they didn't, but I've had no concerns about her no more, she had a really good check, fine… when she's tired one kind of like drifts to the side a bit, but her vision's absolutely fine, so I don't think we see those people no more.

I: I see… so, in the last six months how many appointments do you think you had?

M: One for speech and language, but that was instigated by me… I had… 'cause she wasn't talking… and the (tertiary centre) agreed that she wasn't talking like … a nine month old for her speech, so they did a referral for us. But she started talking like a couple of days just before we had that (laughs), so they've seen her … just speech and language down the road… they've seen her once and they didn't wanna see her again…

I: Right…

M: … that's one less appointment out of the way as well… so yeah, we don't see anyone regularly now… there's nothing that she needs, which is nice…

I: Do you see your GP at all, or have you seen them?

M: Hardly ever! Just if she's had… she had a couple of ear infections, couple of years ago… just for antibiotics for that, nothing… nothing really…

I: I see… and did she go home in oxygen?

M: No, no, she was off that.

I: And the first appointment after you were discharged from (local neonatal unit), how long was it between that and the first appointment?

M: I think it was … ahem… either in the January or the February… like within a couple of months of being home…

I: Do you know where it was, was it in the (tertiary unit)?

M: It was the (tertiary centre), I'm sure, it was like a 12-week appointment or something…

I: And how was it to go back there?

M: It was alright...that was fine….

I: Yeah?

M: Yeah…

I: Was it hard for you to get to the appointments in terms of traveling there?

M: No, we drive, I was on the maternity leave at the time, it was good … gave us something to do, I don’t mind that (laughs)…

I: Yeah... how do you feel that the routine appointments helped?

M: Ahem… for like reassurance. Ahem... I don’t know really…like reassuring that she was under some form of care, you’re not just left to go home and like struggle yourself, it's nice to always… it was nice to always, like, have like an appointment, to get checked and just to make sure she’s doing what she should be doing, and that she’s like healthy enough.

(.)

I: Do you think they were important for her?

M: Yeah… they were routine, they were all over quick, she was like a good patient I would say, I don’t think I had a lot of worries, we’re quite calm about everything… she was doing what she should be doing. Yeah… fine…

I: And … I mean you did say that in terms of how many they were, they were kind of overlapping… but thinking just of the ones you had in the (tertiary centre) for example, were they too many, if you think just of those? Leaving the overlapping aside…

M: They were just the right amount … just the right amount…

I: Ok … how often would you go?

M: At first it was… I think it was like six-monthly until she was one, yeah… and then we waited … it was like a full year, it was like a one year up to when she was one, and then they didn’t see her until she was two.

I: And was that ok?

M: Ah, yeah, brilliant, like a relief, like yeah… good! Great! I don’t have to come through… just go away and be a mum now… yes, good (laughs) …

I: I see… and when you came for the two year one, how did that go?

M: Oh, we liked that one! Very, very good, well structured, followed like guidance and checks and she performed well on the day, we were happy with that it was a true reflection, a true score of how she was at the time. It was very good, it worked well, with like the doctor and the physio being there. I’ve met them both before… it was very good, just the right amount of time as well. A long appointment obviously, for the assessment, but really good, aha...

I: And did you get all the explanations you wanted?

M: Aha…

I: You found that you had time to ask questions…

M: Yeah, had all of that, very good …

I: Did you know what the appointment was for before going… did you?

M: Yeah, mhm ...

I: How did you know?

M: I think they told us at the appointment before that she would be due…

I: ... another one…

M: … this at the time, and when I rang to make the appointment, they told us how long it would take anyway, so I knew in my mind… I thought…

I: I see… and practicalities wise, you said you drive… is it ... going to the appointments, what does it mean for you?

M: It's fine. You have a baby that early, you know you're gonna have appointments, absolutely fine, happy, more than happy…

I: And did anyone tell you about parking and stuff, anything… parking permit when you were in the (tertiary centre) for example …

M: We had a parking pass…

I: Mhm… how does that work?

M: It was just like… you know when the machine gives you like a card, in the car park, I think you just put it in the thing, you didn't have to pay… we just kept hold of that until someone higher priority or further away…

I: I see…

M: … had it… (laughs) but there was no one further away than us at the time!

I: Yeah, it would be hard… (laughs)

M: So, we were commuting from here, so I got like discharged after like a day or two, 'cause I was physically absolutely fine, what with having just a natural birth, so pretty much it was like… we would travel like a thousand miles a month going through there like two or three times a day...

I: And how did you feel to be discharged, was that ok?

M: Oh, I was fine, I think I got an extra day out with them cause me blood count was low, but it was fine… just so I could go and see her through the night in the intensive care unit and that… it was fine… better. Cause obviously I got an older boy, that had just started school… he'd been in school two weeks and I had her… so, it was good to like, drop him into school, get him to routine, stay with her all day, come back… it was good, it was fine, fit into routine very quick…

I: Yeah… did the routine help, you think?

M: Did what?

I: … having a routine, in terms of …

M: Yes! Yeah, just constantly keeping your mind busy with what you're doing and that … I was obviously expressing all her milk around the clock as well, so even though I was home, it was three-hourly getting up through the night to express milk, but just knowing that you can do that for her, even though I wasn't with her, I'm doing something for her, which was nice I think, which helps as a mum…

I: Yeah... in what way?

M: Just … ahem… obviously, I'm feeding her… I'm giving the best thing…that she can get really… there wasn't a lot else I could do for her… other than express milk, but that's what I did and I got loads and loads and loads…

I: How long did she have breast milk?

M: Sixteen weeks …

I: Did she go at the breast at all?

M: A little bit when we got home, but because I couldn't stay with her at (local neonatal unit) and through the night they had to cup feed her, to avoid like nipple confusion… I was not ok with that! with her spilling all the milk down and they having to like sit her up, cup feeding her…oh… but they were like, you'll get her home quicker if we just put her milk in a bottle and feed her and we did… we did got her home quicker, so she was still having like breast milk …

I: But in the bottle…

M: But in the bottle, fine… but I did feed her a couple of times when she was home, but I was expressing that much … I had that much milk, and she had reflux, it was just chocking her! I had … I had supply for like a nine pound baby … she was like five pound when she got back… she was just… it was laughable (laughs)… it was just like … 'ch, ch, ch, ch' (makes chocking noises) like that, bless her… but she had a little go and … which is obviously… I like to think she benefited from it…

I: Absolutely! pretty sure, yeah...

M: Mhm …

I: Ok… and were you working at the time when you had her?

M: Mhm, I was full time…

I: And did you get maternity pay and stuff like that?

M: Yeah, straight away, very good, it was for a utility company, at the time… but it was just bad that it started the day after I had her… obviously it starts straight away the maternity pay, which was fine…

I: But in what ways bad like…

M: I had to go back too early...

I: How long has she been home before you had to go back?

M: Really… three or four… about four months I would have had to go back.

I: Right …

M: … which was a lot longer than what some companies offer… but I would have had to go back in the March...

I: And was she home already?

M: oh, yeah ... she came …. she got out … like, I would have been 37 weeks pregnant…

I: Right, ok…

M: But obviously the first three months of her life were practically like just in hospital, and that's how my maternity leave was spent just sitting and watching the incubator... watching her grow… that… that was my maternity leave, sitting there, expressing milk and watching her in a plastic … box …. (laughs)

I: Was it… how was it?

M: All right, I used to like knit … clothes and hats for her, ahem… obviously express milk, it was just like ground hog day... just traveling there, being with her all day, come home, express through the night, go again, it was just…

I: Same…

M: The same, the same, the same!

I: Right…

M: And I never asked them when can she come home, cause I knew no one will be able to tell us, that's the one thing I did not ask, cause I knew they would have been like, oh, we don't know and… couldn’t … I wouldn’t have been happy with whatever answer they’d said.

I: Really?

M: (laughs) it was obvious like, yeah ... babies that big, there’s no point in asking…

I: And so, did you go back to work after she came home?

M: No, redundancies came up, and I’ve been with the company for like 14 years, so I got a good redundancy, let us stay off a little bit longer and then I got a different job after that, yeah... so I work early mornings, and then I can spend time with the kids which is… it’s all worked out very, very good, I’ve been lucky in that respect. Yeah...

I: Good, right… and do you have any support at all with her, do you have any family… anyone?

M: A little bit, she goes to nursery for three half days, a week… husband… and she's got a big brother… grandparents that sometimes see her for about few hours a week.

I: Do you guys get to do anything… do you go out to… do you go out with her?

M: Ah, with her, all the time… oh, yeah, we’ve got loads of friends and we do loads, yeah, she’s wild, she’s very much an outside person, we’re always out, every day I was out with her… yeah, she likes running around and she’s active and jumping and ...

(.)

I: I see… and how do you think that follow up visits were important overall?

M: Which visits?

I: The appointments, the visits to hospital, the …

M: Ok… I think we were lucky because she was kind of discharged with not many issues, so really it was just like a tick in the box, like... yeah, she's doing alright… and like kind of just… like a sign off kind of process. Like definitely needed the ... just of any concerns that I might have that she might be showing, but luckily, she ultimately didn't really need many of them I would have said, but absolutely fine.

I: And when she was there, 'cause you said you asked questions… did we explain about things, did you feel like you had all the information you needed?

M: Yeah, I felt like I was very much a part of the decisions for her care, I did feel like her voice, and I was never made to feel like I was in the wrong for doing that. Obviously, like when we had like ward rounds, I would ensure I was there for that, doctors would keep us informed exactly of what was happening, I could read through her notes that were like by her bed and that, so that was fine, yeah, very much kept informed with what any next steps of medications, scans, checks and everything. It was fine, mhm ...

I: In what way was this good?

M: … cause kind of when you see like a… what was it? like an x-ray machine, getting put next to your baby, that could be quite worrying…

I: Mhm… how?

M: Like, if you didn't know… you might not have known it was an x-ray machine, you might not have known what they were getting done, I think as a parent you could get worried. For example when she had like a distended stomach, for like when they suspected NEC, they had to do like an abdominal scan on her, that was within … within the doctors seeing her and that happening was pretty much straight away… it was like ‘get everyone out of the room!’, and when the doctor’s at your baby, that could be frightening… if I just… if I didn’t know that was gonna happen and I walked into that, I would have just been like, oh, no!… what… what’s happening… it was really an x-ray machine… but yeah … so, I knew that was gonna happen, so that was fine, and it was over and done with quick…

I: Yeah… I see… so did you find it scary when you saw doctors there like?

M: Nah, it’s a hospital, so…

I: We’re supposed to be there…

M: Yeah (laugh) … that’s one place where you wanna see doctors, in a hospital…

I: It probably would have been scary if you weren’t …

M: the more the better! (laughs). No, they’re all nice…

I: These are kind of my questions, is there something that you would like to say?

M: I don’t think so, no… I had like a birth debriefing…

I: you had?

M: I had that, yeah, … only had that maybe about a year ago...

I: So, about a year after she was born…

M: Yeah, just like a debrief, just to find out the reason why I delivered early, ‘cause I didn’t really know… and it was on there that I found I had like a placental abruption…

I: Yeah… did that help?

M: Yeah, I think so…

I: Yeah…

M: cause like other people like ask you… ‘oh, why was she born early’?

(.)

M: … cause everyone’s always nosy when you have a baby that early, they’re always like… oh, why did you have early, and would you have any more, and that… it’s always a topic of conversation, wherever you go, so yeah, it was good to say 'cause people always assume they know everything… I was like actually, no, I had a placental abruption and it’s just … it’s just good for her, just good to know…

I: You did say it did help with that feeling of guilt, isn’t it, which…

M: Oh, yeah!

I: Yeah…. And the debrief was with the midwife, was it? Or…

M: Yeah… it was with a midwife at the birthing centre.

I: Right, ok ... and do you think something similar would help, talking about her with one of the neonatal people?

M: Oh, definitely …

I: Do you think that would be something perhaps to… would you’ve liked to?

M: I think so, yeah, I think that would have been good, yeah. I think we went to a support group there, we went to one … that would… yeah… we did go to one…

I: Who was in the support group?

M: I can’t remember… it was a couple of nurses that were on, when she was there, cause we went quite quickly after her discharge, within a couple of months after… so we found that beneficial…

I: Mhm… and what were the topics you talked about… what did you talk about?

M: It was just open conversation, it was just all ages of babies there, some like obviously nursery and school age, it was just good to see (.) … like bigger babies and that and was like oh, she is gonna grow up! Like a good insight into … actually, she might be all right after all…

I: And the way you had the debrief with the midwifes, would it help to have a debrief with one of us as well?

M: Ahem...

I: … would it make any difference at all?

M: Possibly not for me, ‘cause I didn’t have any questions around her care or anything, cause I’m there all day, could just … you just ask all day when you’re there. I think you’re just glad to be … personally I was just glad to be out of there…

I: Really…

M: Yeah, it gets just a bit like … (sighs) … too much really… I just wanted to be out and home with her and just start life at home really… but yeah, when you’re there there’s always someone there to ask things anyway…

I: Right… and how did you feel about this interview?

M: Fine.

I: Was it ok?

M: Yeah, absolutely fine cause we hadn’t had any appointments or anything for a while, so… it’s good cause like, when you’re involved in like all these studies like … as soon as she was born… it’s nice that they wanna continue reviewing when she’s like two, three-year old nearly, so I think that’s good that they do follow them through a certain length of time, not just when they’re born as babies and that.

I: Thank you.

Health professional interview

I Interviewer. HP Health professional

I: Thank you for taking part.

Would you like to tell me a little bit about what your job role is and what does it mean?

HP: I’m a (…), which means I see children with developmental problems and with disabilities, in particular neurodisabilities. So, I see quite a lot of complex children.

What it entails is I do clinics, where I see children in the child development clinic, which is based here at the …. I do that on a weekly basis.

I also see children in special schools. I go out to those schools. (…)

Again, on a weekly basis I will go to one of those schools and see children there with a wide range of developmental problems and disabilities essentially.

Basically I'm there to oversee their health and deal with any health concerns. I'm there to help coordinate their care as well within the multidisciplinary team, because I work within a team. I'm there to generally support families really as well. That’s what I do.

I also attend many meetings, multi-professional meetings, because that makes it easier to coordinate the care of the children that really can be quite complex.

I: Do you see a lot of ex-preterm babies?

HP: I do.

There is a proportion in my caseload of the children that I see that have been born preterm.

Some of them extreme preterm, others not so preterm, but yes, absolutely.

There’s quite a range that I see.

I: What do you think is the role of following up those preterm babies?

HP: The role, I always tell everyone, and I've kind of just gone through it briefly there, is threefold.

It’s to address any health needs as well as monitoring their development essentially.

To refer to all the appropriate services within the team in the community, such as physiotherapy, speech and language therapy, dieticians if needed, a social worker if needed.

Who else is in the team? There are a lot more people in the team.

There’s the early learning team as well.

Then to also help coordinate the care with education and with the schools really.

The third thing is really providing a means of support for these families, because the children often have quite complex disabilities and it can be very challenging for the families to manage the children. It’s being there along their journey, essentially, and helping them through that.

I: Taking them one by one or just separating a bit, what do you think the follow-up does for the children themselves?

HP: Follow up for the child? Obviously addressing any health needs for the child. Ensuring they're on appropriate medications for whatever their health concerns might be. Talking through their development and observing their development when they come along to clinic. Do a developmental assessment for the child. That’s mainly it.

Then ensuring that they get the right education as well. Obviously, I'm there really for that child, to recommend, and to help the parents decide as well, so they can make an informed decision about where their child goes to school, depending on their disabilities really.

I: Mainstream school or…?

HP: Mainstream versus a special school. Education setting. I just discuss through my experiences with the children that I see. Where has worked best for certain children that I see essentially. It’s not my job as such to say, “I would recommend they go to that school.” I just share experiences.

I also help to form what’s called an education health and care plan, which outlines a child’s difficulties and disabilities and what they would need in an education setting. And that really dictates where that child goes. The local authority make that decision depending on the information that they gather in that education health and care plan.

I: How early do you tend to talk about education, recommend education? How old?

HP: I talk about it from preschool years, essentially, because of course a child with a disability is entitled to an educational placement from the age of two. Some families choose to send them to nursery earlier, but I would always recommend it from the age of two. Alongside the early education team, we help support the families to make a decision on nurseries.

I: What kind of children go in that category of children who could use some extra help from age two? What do you have to do or to be like, in terms of disability, to warrant that sort of help?

HP: You're right. There are criteria. It's those children that have any kind of delay in their development. I don't think it just has to be a global developmental delay. I think it can be things like an isolated developmental delay, such as just as speech delay, that kind of thing. Or it's the families that are from an underprivileged background that are entitled to a nursery place from the age of two. I think that's the criteria.

I: So it doesn’t matter whether they've got a background of being extreme preterm? It’s either they have a…

HP: Yes, the background doesn’t matter.

I: How delayed do you have to be to get the extra support? Is there a cut-off of development?

HP: No, I don’t think there is. I don’t think it’s that precise with their cut-off. They don’t have to have a background of prematurity. Although, as you know, those children that are born extreme preterm are in that high-risk category of having developmental problems, but it doesn’t have to be that severe. It can just be a mild developmental delay that gives them that entitlement to a nursery place.

Actually, we would encourage it too, because we often see that it does promote a child’s development when they're in education and in a setting where they're with a peer group that are developmentally normal. So, the majority of the time they would go into a normal mainstream nursery, and it does really help promote development.

I: Do you think the importance of the follow up is different depending on how preterm you were?

HP: I do, yes. Obviously, the more extreme prematurity the more likely they are to have health problems and developmental problems, and of course all the studies show that, don't they? All the outcomes, like the EPICure studies, all those show that they're the high-risk group.

Although, saying that, there are some of those that aren't that extreme preterm that also have developmental problems and health needs. So generally I think the prematurity does dictate how often you're seeing them or whether they actually do need to be seen in clinic, but it's not always the case.

I: In what way do you think that the follow-up is important for the parents?

HP: Follow-up for the parents? Because they often have needs that need addressing. They have concerns.

A lot of these parents are extremely anxious, because they've gone through such a journey, through the neonatal intensive care unit, special care baby unit, then follow-up initially with the neonatal team, and then moving on to see us.

It's a huge journey, and it's very anxiety provoking, and they've often been through a rollercoaster of a journey really with health problems.

I think the means of support that they need, so they know someone is there to help them with their health concerns, with their developmental concerns. Someone is there to discuss through maybe what's happened in the past, what's happening now. There are all sorts of issues can arise really.

I'm seeing one particular child at the minute whose mum is extremely anxious. I think she's needing a high level of support with things like weaning her child off oxygen at home. She’s finding that really difficult, because she’s almost used to that now and thinks that her child should remain on the oxygen, otherwise something bad is going to happen to him.

They do become very reliant on medical equipment and professionals. I think we’re there as a means of reassurance and to provide information about health and knowledge, what we know.

In his particular case I've been there to really optimise his treatment for his chest. So we have been able to wean him off his oxygen. That kind of thing really.

I find that more with the preterm children. That the parental anxiety is a lot higher than in other families. Because I think they’ve just been through such a journey, and often these children and babies have been…

Not that every child isn’t a precious child, but a lot of the time they’ve been a precious child in terms of they might have been difficult to conceive. They may have well been through some IVF treatment. Obviously, the journey during the pregnancy has been difficult and then has ultimately led to a preterm delivery.

So there’s all of that in the mix as well, that means that it’s really helpful for a health professional to be there to support the family.

I: You mentioned the journey. Is there a process of transition from neonates to community? What’s that like?

HP: Yes, it is. I hear different stories from families, and perhaps we could be better at doing the transition really. Because I think the families feel like they've established a really good relationship, and they've really got to know the neonatal team.

Particularly when they're in hospital it's a very intense environment. There's a huge level of support there from the nursing staff, and from all the doctors, and everybody involved there.

Then I think they're discharged home with a community nursing team, who again provide an intense support. Then seeing the neonatal consultant on a regular basis for follow-ups.

Then they get their developmental follow ups in the Bayley's clinic, if they're born extremely preterm. Some of the times a lot of the issues are addressed. They come to us then, into community paediatrics.

There's not a transitional clinic, which I think might be a downfall for these families. Because, as I say, they have developed that relationship with the neonatal team, and then moving on to us things work slightly differently in community paediatrics. Although we're there to support, we're perhaps not seen as much as they saw professionals in the past.

If the health needs are mainly addressed and it's mainly a developmental follow up, that will be on a six-monthly basis, unless there are meetings between the clinic appointments. So we won't see them perhaps as regularly as what they were in the past. So perhaps the transition.

I always outline that to families when I first see them, but perhaps that’s a shock to families in that transition, moving over, that actually they feel that somebody is not there for them as much perhaps as they were in the initial stages. Some of them say they feel like they're just left to get on with it.

Perhaps we could do this differently and listen more to the families about what it is that they would like and what they need at that time, but we don’t.

The transition is a referral letter to community paediatrics, which comes into our referrals meeting. Then patients get allocated to a consultant. Then there might be a little bit of a lag between seeing the neonatal team and seeing us. Yes, I don’t think it’s perfect really.

I: Why do you think that sometimes parents don’t bring their children to the appointments? I don’t know if you have this problem in community. Do they not come?

HP: Occasionally, yes, I do have this problem.

I: Why?

HP: Possibly we might not be that accessible. Community sounds like you do your clinics out in the community. We don’t do that much anymore, apart from the clinics I do in my special schools, which generally I will know the families well by the time they’ve got into the special school. We do the clinics here at the hospital. Perhaps the hospital clinics aren’t accessible to some families.

Obviously, the families that are dealing with children with complex disabilities it can be hard to get out of the house and get to an appointment. It can be quite stressful for them to bring all the equipment they need and then get the transport and get here.

And my clinics run in the morning, so sometimes the appointment is quite early. Nine o'clock is my first appointment. Some families just can't get here for that time, and I don't think we give them leeway in that respect.

Perhaps it's not really outlined to them how important it is to continue to see a health professional.

Perhaps there are other things going on in the family as well. Obviously, we just cover the area. That's our patch. But there are mixed cultures and backgrounds to the families as well. I don't know. Perhaps a lack of understanding. Or they feel isolated and not able to come along. We do book interpreters as they're needed and when that's highlighted to us, but that can be a barrier as well, communication.

I think there are a number of reasons, and it's quite complex why patients don't attend, but we see it like everybody else does.

In some circumstances, if it becomes such an issue and I know the child needs seeing, I will go out and do a home visit to try and reach that child.

Or we will work with the professionals that know the family well. Say if the health visitor knows them well, or if one of our children's community nurses know them well, they will try and support the family and bring them along, come along with them. Or a family support worker, for example, bringing them along to the appointment or joining them at the appointment, to try and encourage them to come.

I: In those cases, what did you find was the main reason why they weren't coming? When you had to go to the home.

HP: Again, I don't think there's one particular reason. I think there are a multitude of things.

Actually, with another family, this wasn't a preterm child, but one mother told me that she has her own mental health problems and anxieties. She finds it so difficult to leave the house. We don't appreciate that. We think it's fine. We leave the house every day. But for some people it's really difficult.

So there are all those different reasons that I've already mentioned. I don't think there's one particular reason over any of the others. It's different in every case. And it can just be all of them together that can mean they don't attend the appointments.

But if it's highlighted that the family do DNA frequently then if one of the community nurses is involved I will ask them to try and bring them along to the appointment. Or at least attend with them to encourage them to come.

Then I will often visit and ensure they've written a date down for the family and the time, and keep reminding them that, "This is when the appointment is." That's really helpful.

I: What do you think the follow-up of extreme preterm babies means for the NHS? Is it important, and in what way, for the NHS?

HP: For the NHS is it important? It's important, I suppose, so we don't miss anything.

I suppose you could look at it from a research point of view, a statistical point of view, and what the outcomes are. Obviously, I don't directly do the formal developmental assessments like the Bayley's. That's the neonatal team here, as you know, that do those. That's very useful for research and statistical purposes.

What else for the NHS? Just early intervention. We're there to promote health promotion, health prevention, all that. We do a lot of that in community paediatrics, and for the NHS it could be a cost saving thing for the future. If their health needs are addressed earlier, or the family are supported and the child is supported in the right way, then in the future it could save the NHS money.

Certainly it could save the burden of perhaps future problems in the child, such as mental health problems. Because if things haven't been addressed early on in education, for example if they have a learning disability, then that can have worse outcomes later on and be more of a cost burden on the NHS.

I: In terms of the assessment at four years of age, do we have a formal framework for that? Do we do anything specific for that, or is it just as it goes and depending on…? For babies born at less than 28 weeks.

HP: No, we don't have anything formal at the minute. I think we're going to be possibly moving towards that, but we have no formal developmental assessment. We just have ongoing follow-up in the community, doing developmental assessments as we go along. But we don’t do the formal Bayleys, Griffiths, any of those, because they're so time consuming.

I: Do you follow up all ex-28-weekers or just those who get referred to you?

HP: Just the ones that get referred to us. I do know, because recently we’ve been looking at this because of the NICE guidance and things, that some of those I don’t think there’s a need to refer them. So I think some don’t get seen, just because they haven’t been referred essentially.

I know the odd case that I have seen and actually they’ve been spot on and following their developmental trajectory nicely, so there hasn’t been a need to continue follow-up.

There’s the odd, certainly one if not two on my caseload, where I've seen them once or twice and then discharged in the preschool years.

But I always do highlight that, “I can’t predict at this stage what the prematurity is going to mean for your child going through the school years, so I would always be happy to see them again. And do see the GP early, or the school nurse or whatever, and get a referral back if concerns are highlighted.”

I: Do you find that they just spring out from school with behaviour problems or not really? It’s not something that you would have seen?

HP: There can be. There can be the odd one. You mean referred back to us because of behavioural issues?

I: Yes.

HP: Yes, there can be the odd one.

I: I'm thinking more in terms of extreme preterms.

HP: The extreme preterm ones generally remain with us, because they normally show these signs earlier on. They're normally showing neuro developmental problems from an earlier age. Or there have been other issues that’s meant they’ve been kept under review really.

We don’t see many that come back to us. That’s just from my experiences, so perhaps it’s different from others, but I wouldn’t say there’s a huge amount that that happens to.

I: If you were to think of one thing that we do well as an organisation, and I'm thinking the hospital at this point, what would it be? What do you think we’re doing well?

HP: For preterms?

I: Yes. For follow up.

HP: For follow up? What are we doing well? Good question. See, I can think of all the things that we’re perhaps not doing so well. It’s always the way, isn’t it?

I: Well, that’s my next question. (Laughter)

HP: What are we doing well at the minute? I must think of some good things, what we’re doing well.

Well, we are a big team, and we do provide… I think the team work well together in some respects, because if a child has got complex needs they will come together and work together in trying to do their best for that child.

But then that could be done better. Although we know each other in the team, and we all communicate well together, there’s perhaps a more efficient way that we could do that – I'm moving on now to what we don’t do so well – in that the child development clinics could be run more as multidisciplinary clinics, and they're not.

Generally, unless one of the other professionals comes along, we just see them as a community paediatrician. We’re there just to see them, without any of the other team there.

It would be nicer, in a way, if we had a proper, established child development centre, where all the community professionals work from, because at the minute we’re based all over the place. That we’re all in one building, so that we can really work better together. More collaborative working. And that we’re more easily accessible that way, because…

I: Like an outreach location out of the hospital sort of thing?

HP: Yes, I think so. I think that’s what we all want as a team of community paediatricians really. And that would really help this group of children and other children as well with developmental problems. That is a huge downfall really of our service.

I: What do you enjoy about your job? What does it mean to you personally?

HP: The job is hugely rewarding, because despite the long list of problems that a lot of these children have…

You might look at a clinic letter before you meet the child and think, “Crikey, this is horrendous. They’ve been through so much. Look at all these problems they have.”

But they always come through that door, most of the time, smiling and happy, and what we try and do is promote all their abilities, not the disabilities. And obviously try and include them in everything that’s going on in the city, in the hospital, everything like that.

And they're so motivated. They're such a motivated group of children. And that is really rewarding. That actually all the hard work that’s been done by the neonatal team, not by us really, it’s hugely rewarding for us to see that you’ve achieved such a huge amount.

And for families to be happy that they have their child home. A lot of the time, regardless of their disabilities, they're just happy they’ve got their child home and alive, and that they’ve got all that support from the professionals there.

And in the children that we see sometimes just the small changes and the small things we do can hugely matter for the family. That’s a massive thing for me. That even though we’re only, say, tweaking a dose of something or recommending something it can mean a massive thing for a family. I think that’s really hugely rewarding.

The schools I go to where I see children, a proportion of the children that have been born extremely preterm go, they're amazing schools. It’s lovely to see how happy the children are there too, and that the staff are really enthusiastic, motivating. You would never go in there and see that anybody is really upset. Everybody, the staff and the children, always have a smile on their face. It’s such a happy place to go.

That’s what I always tell people. Because I think some people are really reserved to send their child to a special school, but when they see it they just see how amazing the service is and that it is perhaps the right place for the child. It’s not for all children, but a lot of the extreme preterm children that have been affected a lot by their prematurity it is the right place for them.

I: Do you find that children with multiple disabilities go to mainstream schools and do well? Or do they tend…

HP: Some children do.

I: On what does it depend? Is there a medical reason to go to either one of the schools, or is it preference of how…?

HP: I would generally say those children that have perhaps only

– only sounds awful – got a unilateral, say, cerebral palsy as a result of their prematurity, often their cognition isn’t all that bad, so they do go to mainstream school, and their disabilities don’t really hold them back. Things are adapted according to what they need at the school, and that is definitely the right thing for them.

Actually, children without developmental problems at mainstream schools, I find more and more nowadays that they're just accepting of children with disabilities and are actually really quite caring towards a child with disabilities. That’s what I hear, and that’s what I see as well happen, which is really nice.

Yes, I think a child with motor problems can go to mainstream school. Saying that, some children with bilateral cerebral palsy, if their cognition is quite good, then again mainstream school is the right place for them, definitely. But everything has to be taken into consideration, obviously.

I: Those were my questions. Is there anything else you would like to add?

HP: I don’t think so. We’ve talked about transition, haven’t we? I don’t think so. Have I covered most things that you wanted me to cover, do you think? Is that generally what you want to hear?

I: Yes.

HP: I'm just thinking of the preterm group in particular.

I suppose the only other thing is obviously within our team the children’s community nursing team get to know the children, the ex-preterms, earlier than what we do, because as soon as they're discharged from the neonatal unit they get referred to the…

Well, if they're on oxygen with chronic lung disease they obviously get referred to the community nursing team, and they're involved in providing all the equipment and support around that. Feeding perhaps as well at times. Then weaning off the oxygen and things.

Actually, it might be easier for us to get involved sooner than what we do, because then it’s not so much of a shock for the families. That might be something that needs to be looked at and that could be done differently.

The other thing is often around the diagnosis of cerebral palsy. In the first year of life, obviously, the child may start to show signs of developing cerebral palsy, but then with the transition often the label has not been given, or the diagnosis has not been given, of cerebral palsy.

Then it’s a really awkward time. They transition to us. They meet us for the first time. Here are we, and we tell them that their child has cerebral palsy. And that’s not right, because they meet us for the first time and hear bad news. It’s almost like they kind of know but no-one has told them.

I've done that recently with a family, actually, and I felt terrible. They were fine about it. They seemed fine about it. But I did worry that it might affect our relationship. I think that’s an issue.

I: Yes. And you will have a relationship with them for a long time.

HP: Yes. I think they kind of knew deep down. Things had been mentioned but no diagnosis as such given.

It was unfair of me to hold that back, when I clearly see in a child that they’ve got cerebral palsy. I think that’s unfair for me to hold the diagnosis back. I want to be honest right from the start about what’s happening, and what to expect, and what we need to do.

So I think that’s another thing that perhaps could be worked on, and is a downside perhaps of the transitional process, because perhaps we don’t have an understanding of what we’re each doing and whose role it will be to do that.

Don’t get me wrong. It’s not all the cases. Sometimes the children will be transitioned through and they’ve already got a diagnosis of cerebral palsy. But yes, I think that’s something that could be looked at.

I don’t think there’s anything else. I think that’s it. I will probably think of loads of things now. (Laughter)

I: If you want, I can come back, if there’s anything else.

HP: Yes.

I: But thank you. Was the interview okay?

HP: Yes. Absolutely fine. I just hope I've given you enough information and not gone off on a tangent.

I: No, absolutely not. Thank you very much.