Parent and caregiver journeys through the process of early neurodevelopmental follow-up for their infants – a qualitative account

Thesis submitted in accordance with the requirements of the University of Liverpool for the degree of Master of Philosophy

By Alice Fortune
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Abstract

Parent and caregiver journeys through the process of early neurodevelopmental follow-up for their infants – a qualitative account

Alice Fortune

Introduction: Early diagnosis of cerebral palsy (CP) is possible by five months corrected age for "at-risk" infants using the Hammersmith Infant Neurological Examination (HINE), Prechtl's General Movements Assessment (GMA) and MRI. As use of these tools increases, implementation issues, including how to provide appropriate information to parents, are emerging. During this uncertain and stressful time for parents, providing appropriate information and support is essential, particularly as an infant's associated developmental delay may not yet be visible to parents. Previous qualitative research into this topic is very limited and none exists within the UK.

Aims: To explore parents' views and experiences regarding the process of early neurodevelopmental follow-up for their high-risk infants in Liverpool, to provide healthcare professionals with a means of tailoring their service to the needs of these parents.

Methods: I conducted thirteen in-depth qualitative interviews with eight parents of high-risk infants (six mothers and two fathers) eligible for a new physiotherapist-led follow-up clinic at the Liverpool Women's Hospital (LWH). Interviews used a pre-piloted topic guide and took place before and after the clinic to gain an in depth understanding of parents' perspectives during this time period. Interviews were audio-recorded, transcribed verbatim and analysed using inductive coding and thematic analysis, using the framework method.

Results: Seven main themes were identified. (1) Attempting to manage uncertainty was the overwhelming theme found within parents' accounts. Other themes found were: (2) Taking priority, (3) Trusting professionals, (4) Independence in the parent role, (5) Feeling understood, (6) Patterns of care and (7) Individuality. Parents' uncertainty was related to their baby making progress, being on track and their future. A clear point of contact, regular follow-up and adequate preparation for and timing of information were vital. When uncertainty is poorly managed, parents' wellbeing suffers, and they struggle to cope. Individual parent perspectives and babies' developmental trajectories differ, creating a need for tailored information.

Conclusion: From interviews it is clear that many parents' understanding of physiotherapy and neurodevelopmental assessments is limited at this stage. This study suggests several changes to the current early neurodevelopmental follow-up process, which could improve both parents' experiences and clinic attendance rates.

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List of abbreviations

GMA	General Movements Assessments
HINE	Hammersmith Infant Neurological Examination
MRI	Magnetic resonance imaging
LWH	Liverpool Women's Hospital
AHCH	Alder Hey Children's Hospital
NICU	Neonatal intensive care unit

Chapter one

Introduction and background to the study

1.1. Cerebral palsy

‘Cerebral palsy’ is an umbrella term for a group of permanent disorders involving abnormal development of movement and posture, causing restricted activity due to non-progressive disturbances in the developing foetal or infant brain (17, 18). It is the most common motor disability in childhood, with a general population prevalence of around 1.5-2.5 cases per 1,000 live births worldwide (19, 20). Importantly, this prevalence is much higher for infants who are “at-risk” of cerebral palsy.

Cerebral palsy has various clinical presentations and aetiologies and there is a longstanding debate about how it should be defined and classified (17, 21). The Surveillance of Cerebral Palsy in Europe (SCPE) classification (**Figure 1**) published in 2007 replaced the traditional approaches by Ingram (22) and Hagberg (23), dividing cerebral palsy into spastic, dyskinetic and ataxic sub-types (24). Amongst these, the spastic sub-type is by far the most common, found to account for around 80-90% of cases (25-27). This is characterised by increased muscle tone in affected limbs, resulting in contractures, hyperreflexia and abnormal gait, typically with a scissor gait and toe-walking (17, 28). The dyskinetic sub-type involves involuntary, uncontrolled repetitive movements of the limbs with either increased or decreased muscle tone, and the ataxic sub-type predominantly affects balance and co-ordination (17, 25, 28). These sub-types are not always distinct from each other; a mixture of these can be present in some cases (24). In addition, the SCPE classifies spastic cerebral palsy as either unilateral spastic where one side of the body is affected, or bilateral spastic where both sides of the body are affected (17, 25).

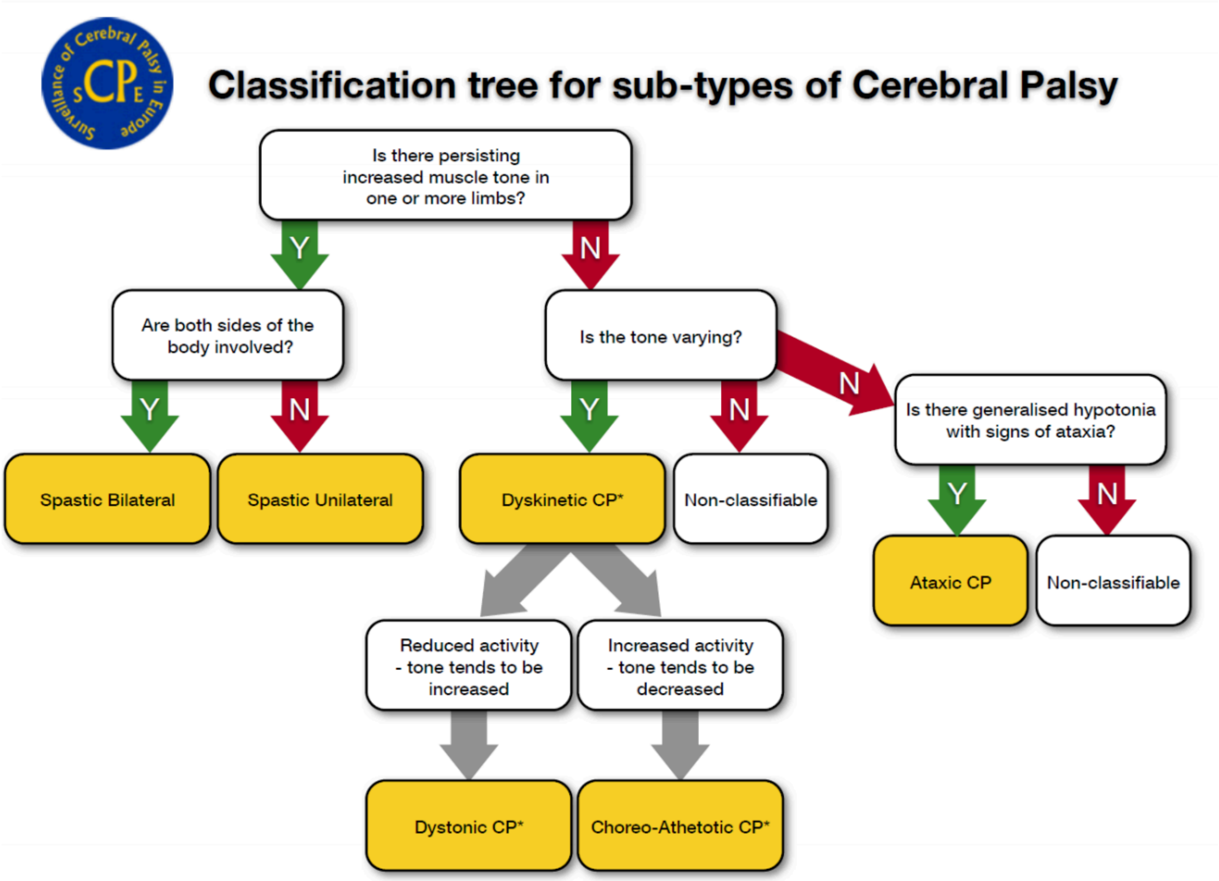


Figure 1: Surveillance of Cerebral Palsy in Europe (SCPE) classification tree for sub-types of cerebral palsy, taken from the SCPE Scientific report (1)

Motor disability due to cerebral palsy can also be classified based on severity. The Gross Motor Function Classification Scale (GMFCS) (**Figure 2**) is a widely accepted way of doing this (29). This describes each child with cerebral palsy as being at one of five levels of functional ability, designed to give families a clear idea of their child's level of functional disability and future need for mobility aids such as walking frames or wheelchairs (30, 31). There are also debates that cerebral palsy should be classified by aetiological type, using findings from magnetic resonance imaging (MRI), where these are present. The magnetic resonance imaging classification system (MRICS) has been developed which divides the brain images of children with cerebral palsy into five main groups (7).

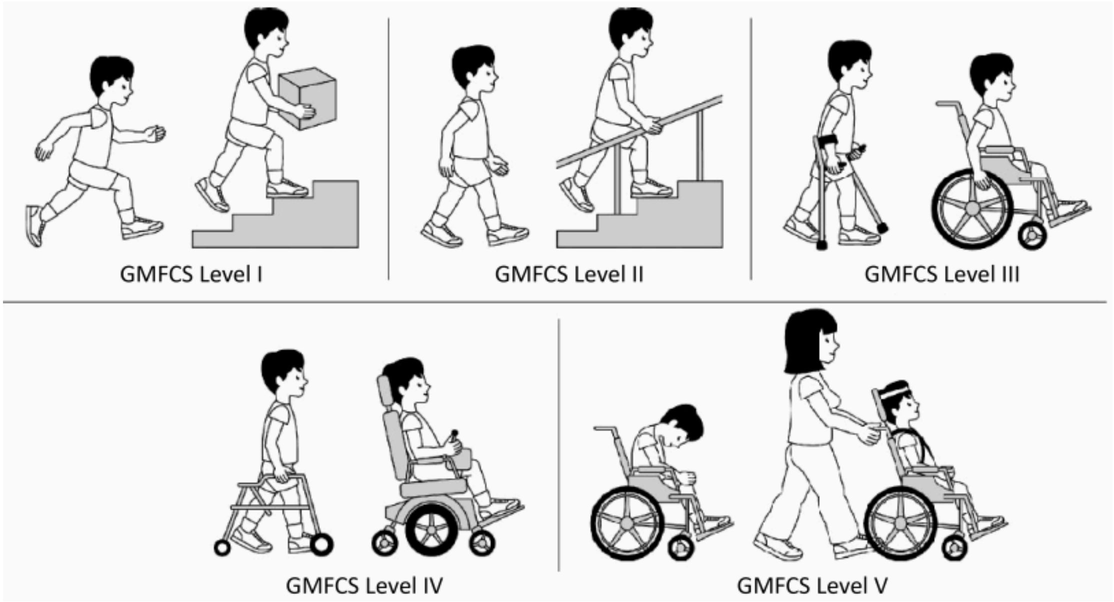


Figure 2: Levels of the Gross Motor Function Classification Scale (GMFCS) taken from Bayón (2).

Co-occurring disability is common in children with cerebral palsy. Depending on the sub-type, 25-80% of individuals have co-existing impairments, commonly epilepsy, intellectual impairment or behavioural disorders (25, 26, 32-34). One third of children with cerebral palsy are unable to walk, one quarter have impaired speech and a smaller proportion have severely impaired vision or hearing (32).

1.2. The high-risk infant

Aetiology of cerebral palsy is complex (17). The damage to the developing brain which causes cerebral palsy can occur in various ways and at different stages, either in utero, around the time of birth, in the post-neonatal period or in early childhood, usually considered as cerebral palsy if occurring before the age of two (27, 34). Of all children diagnosed with cerebral palsy, 50% have an identifiable risk factor in the neonatal period (35). These identifiable infants can be further split by those born premature, who make up 30-40% of all cerebral palsy cases, and those born at full-term and suffer neonatal encephalopathy, who make up 15-24% of all cases (35, 36).

Preterm birth

An estimated 15 million babies are born prematurely each year worldwide, and this number is rising (37). In the UK, this is 60,000 babies each year, equating to around 9.5% of all babies born (38). The World Health Organisation (WHO) define a baby as preterm if they are before a gestational age of 37 weeks (37). This is the major cause of neonatal morbidity and mortality (39) and increases these babies' risk of developmental disorders, including cerebral palsy. This risk of cerebral palsy for preterm infants increases with decreasing gestational age (9, 40, 41). Babies born before 28 weeks are classed as extremely preterm and are particularly high-risk of cerebral palsy (37), occurring in around 111 per 1000 live births (40, 42).

Low birth weight

Seven percent of babies in the UK are born with low birth weight; defined as weighing less than 2.5kg at birth (38, 43). Worldwide the prevalence is higher, estimated to be 15% to 20% of all births (44). Low birth weight is a risk factor for cerebral palsy, with particularly high risk for infants born weighing <1500g, who are described as having very low birth weight (40, 45). Rates of cerebral palsy in this group are around 70 times higher than in the group of infants born with a weight >2500g (17).

Neonatal brain injury

Another major risk factor for cerebral palsy is injury to the developing infant brain.(36) Symptoms and severity of this can vary, ranging from causing mild irritability and feeding difficulties, to coma and seizures.(46) Neonatal brain injury also has various aetiologies. A major cause is hypoxic-ischaemic damage to the brain due to birth asphyxia, causing a type of brain injury called hypoxic ischaemic encephalopathy.(36, 47) This affects full-term and late-preterm infants, increasing their risk of perinatal death and long-term neurological morbidity, particularly cerebral palsy.(47-49) Those without cerebral palsy often have another neurological disorder, making them a particularly high-risk group for abnormal neurodevelopmental outcomes.(50) Therapeutic hypothermia started within six hours of birth and continued for 72 hours has been found to reduce cerebral injury in infants with birth asphyxia.(51) This is effective in reducing the incidence of neurodevelopmental disability, however cerebral palsy still occurs in around 10% of babies affected.(36, 52)

Perinatal stroke is a common cause of neonatal brain injury, involving interruption of blood flow to an area of the brain that results in a focal or multifocal area of damaged cerebral tissue (53, 54). This usually occurs close to the time of birth and is associated with a high incidence of abnormal neurodevelopmental outcomes, including cerebral palsy (53-55). Intracerebral haemorrhage and intraventricular haemorrhage, all causes of neonatal stroke, can also increase the risk of brain injuries, most commonly white matter injuries, occurring. These all increase an infant’s risk of cerebral palsy (49, 56, 57). For infants with particularly high volumes of white matter injury, the risk of cerebral palsy can be as high as 90% (58).

Infection during the neonatal period, often caused by intrauterine exposure to maternal infection, is also a risk factor for cerebral palsy (59-61). This also increases the risk of white matter injury occurring due to exposure of immature white matter tissue to maternal or foetal inflammatory cytokines (62-64). Neonatal infections have been found to be involved in as much as 50% of cases of cerebral palsy acquired in the postnatal period (10).

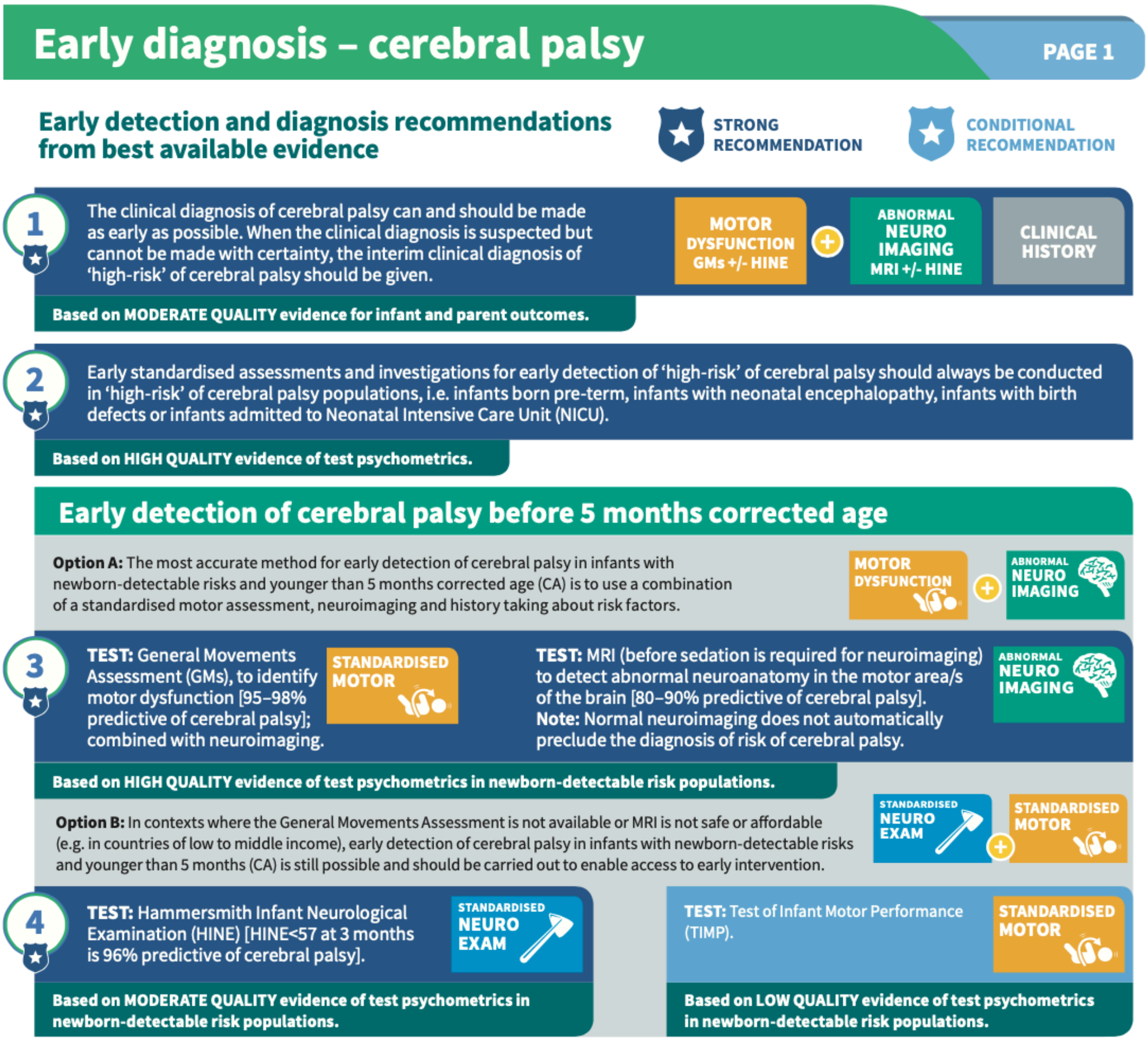
Independent risk factors for cerebral palsy are often found together and, when combined, can have a cumulative effect (10). This is often the case for preterm infants as they have greater susceptibility for both white matter injury and neonatal infection than term-born infants (62, 63, 65). A US study has demonstrated that infants before 24 weeks gestation, weighing less than 750g and with a 1-minute Apgar score (66) of 3 or less, are a particularly high-risk group, with a 30% probability of cerebral palsy (56). Furthermore, those infants who also had grade 3 or 4 intracerebral haemorrhage and periventricular leukomalacia were at even higher risk (56).

1.3. Early diagnosis of cerebral palsy

1.3.1. Diagnosis of cerebral palsy and new recommendations

So far, no laboratory test has been found which can confirm or rule out the presence of cerebral palsy (20). CT and MRI are useful in spotting brain injury, but there is no single pattern or group of patterns on these scans that can diagnose cerebral palsy alone. Furthermore, some children with cerebral palsy have normal findings on neuroimaging (20). Currently, therefore, cerebral palsy is diagnosed clinically based on clinical and neurological signs (3).

Until recent years, it was thought that cerebral palsy could not be diagnosed until after two years of age. This has now been updated, as assessments have been developed which can accurately diagnose cerebral palsy or “high-risk of cerebral palsy” before six months corrected age (the age corrected for the infant’s prematurity) and even as early as three months (3). A systematic review by Novak published in 2017 (3) set out these new recommendations: before five months corrected age, the Prechtl’s General Movements Assessment (GMA), the Hammersmith Infant Neurological Examination (HINE) and brain MRI are the tools with the best ability to predict cerebral palsy (shown in **Figure 3**) (3). After five months corrected age, the most accurate predictive tools are the HINE and brain MRI (3). Novak (3) recommends using a combination of assessment tools coupled with clinical judgement when making an early diagnosis of cerebral palsy, to improve accuracy and reduce the risk of a false positive result. Novak (3) also advises that clinicians use a trajectory of abnormal results from HINE and GM assessments, as this is more accurate than a single abnormal result.



Early diagnosis – cerebral palsy

PAGE 1

Early detection and diagnosis recommendations from best available evidence

STRONG RECOMMENDATION

CONDITIONAL RECOMMENDATION

1 The clinical diagnosis of cerebral palsy can and should be made as early as possible. When the clinical diagnosis is suspected but cannot be made with certainty, the interim clinical diagnosis of 'high-risk' of cerebral palsy should be given.

MOTOR DYSFUNCTION GMs +/- HINE + ABNORMAL NEURO IMAGING MRI +/- HINE CLINICAL HISTORY

Based on MODERATE QUALITY evidence for infant and parent outcomes.

2 Early standardised assessments and investigations for early detection of 'high-risk' of cerebral palsy should always be conducted in 'high-risk' of cerebral palsy populations, i.e. infants born pre-term, infants with neonatal encephalopathy, infants with birth defects or infants admitted to Neonatal Intensive Care Unit (NICU).

Based on HIGH QUALITY evidence of test psychometrics.

Early detection of cerebral palsy before 5 months corrected age

Option A: The most accurate method for early detection of cerebral palsy in infants with newborn-detectable risks and younger than 5 months corrected age (CA) is to use a combination of a standardised motor assessment, neuroimaging and history taking about risk factors.

MOTOR DYSFUNCTION + ABNORMAL NEURO IMAGING

3 **TEST:** General Movements Assessment (GMs), to identify motor dysfunction [95–98% predictive of cerebral palsy]; combined with neuroimaging.

STANDARDISED MOTOR

TEST: MRI (before sedation is required for neuroimaging) to detect abnormal neuroanatomy in the motor area/s of the brain [80–90% predictive of cerebral palsy].
Note: Normal neuroimaging does not automatically preclude the diagnosis of risk of cerebral palsy.

ABNORMAL NEURO IMAGING

Based on HIGH QUALITY evidence of test psychometrics in newborn-detectable risk populations.

Option B: In contexts where the General Movements Assessment is not available or MRI is not safe or affordable (e.g. in countries of low to middle income), early detection of cerebral palsy in infants with newborn-detectable risks and younger than 5 months (CA) is still possible and should be carried out to enable access to early intervention.

STANDARDISED NEURO EXAM + STANDARDISED MOTOR

4 **TEST:** Hammersmith Infant Neurological Examination (HINE) [HINE<57 at 3 months is 96% predictive of cerebral palsy].

STANDARDISED NEURO EXAM

Based on MODERATE QUALITY evidence of test psychometrics in newborn-detectable risk populations.

TEST: Test of Infant Motor Performance (TIMP).

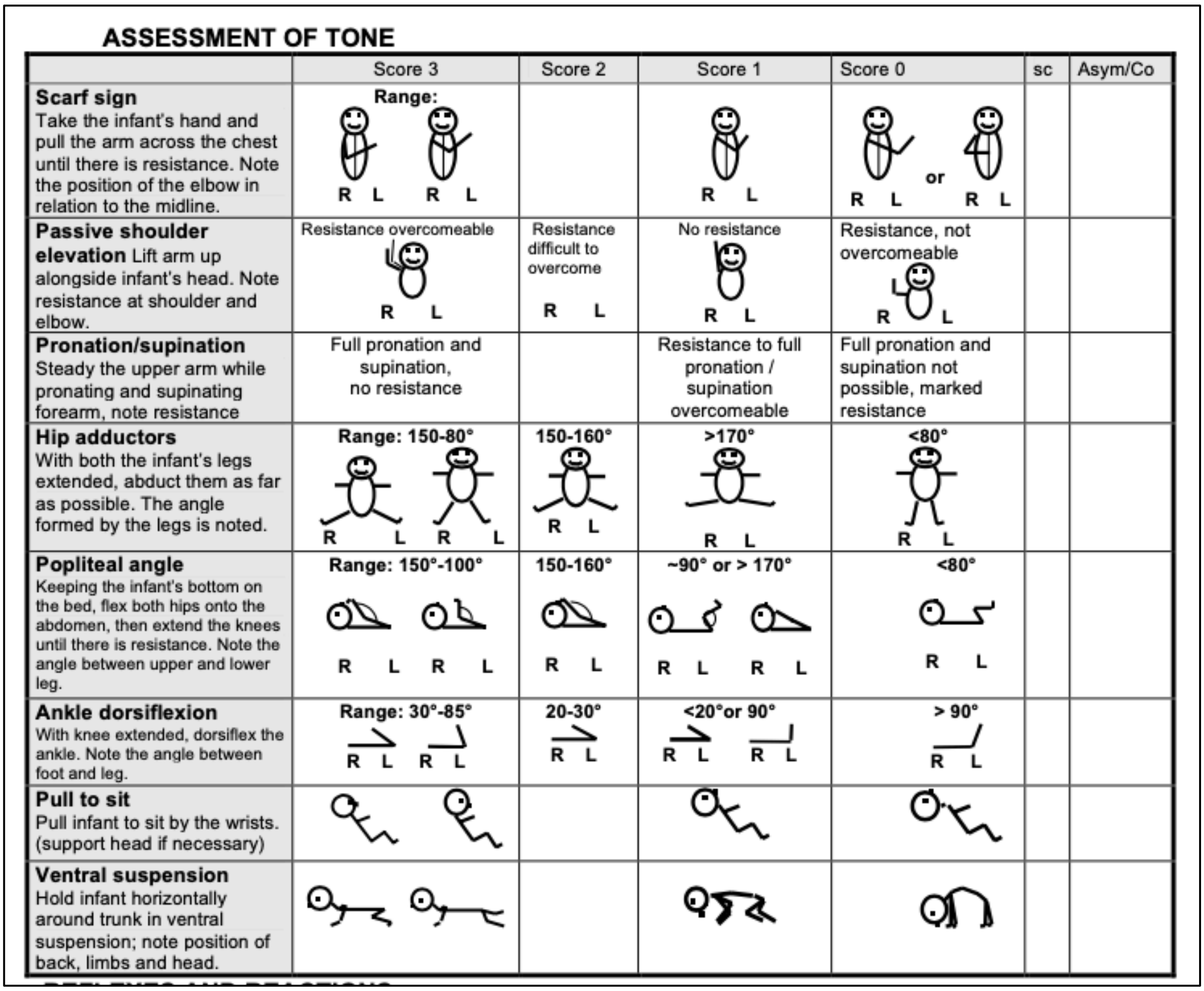
STANDARDISED MOTOR

Based on LOW QUALITY evidence of test psychometrics in newborn-detectable risk populations.

Figure 3: Part of the 'early diagnosis - cerebral palsy' fact sheet adapted from Novak (3) by the Cerebral Palsy Alliance (4).

1.3.2. Hammersmith Infant Neurological Examination (HINE)

The HINE is a simple method of scoring infants' neurological parameters and can be used to assess both preterm and full-term infants (67, 68). Invented by Lilly Dubowitz and Victor Dubowitz in 1999, it assesses various aspects of neurological function including movement, reflexes, cranial nerve function, behaviour and gross and fine motor function, using a proforma containing 26 items (**Figure 4**) (67, 69). The HINE can be used between 2 to 24 months corrected age and follows on from the Hammersmith Neonatal Neurological Examination (HNNE) used around term age (67, 70).



ASSESSMENT OF TONE

	Score 3	Score 2	Score 1	Score 0	sc	Asym/Co
Scarf sign Take the infant's hand and pull the arm across the chest until there is resistance. Note the position of the elbow in relation to the midline.	Range: R L R L		R L	R L or R L		
Passive shoulder elevation Lift arm up alongside infant's head. Note resistance at shoulder and elbow.	Resistance overcomeable R L	Resistance difficult to overcome R L	No resistance R L	Resistance, not overcomeable R L		
Pronation/supination Steady the upper arm while pronating and supinating forearm, note resistance	Full pronation and supination, no resistance		Resistance to full pronation / supination overcomeable	Full pronation and supination not possible, marked resistance		
Hip adductors With both the infant's legs extended, abduct them as far as possible. The angle formed by the legs is noted.	Range: 150-80° R L R L	150-160° R L	>170° R L	<80° R L		
Popliteal angle Keeping the infant's bottom on the bed, flex both hips onto the abdomen, then extend the knees until there is resistance. Note the angle between upper and lower leg.	Range: 150°-100° R L R L	150-160° R L	~90° or > 170° R L R L	<80° R L		
Ankle dorsiflexion With knee extended, dorsiflex the ankle. Note the angle between foot and leg.	Range: 30°-85° R L R L	20-30° R L	<20°or 90° R L R L	> 90° R L		
Pull to sit Pull infant to sit by the wrists. (support head if necessary)						
Ventral suspension Hold infant horizontally around trunk in ventral suspension; note position of back, limbs and head.						

Figure 4: Part of the Hammersmith Infant Neurological Examination (HINE) Proforma (5).

The HINE has demonstrated 90% sensitivity at predicting a diagnosis of cerebral palsy, ability to predict Gross Motor Function Classification System (GMFCS) level and strong inter-observer reliability (3, 67, 71). When judged in the clinical context and in combination with other findings, such as MRI results, HINE can also predict the severity of motor dysfunction (3). A score below 40 correlates with severe motor impairment such as inability to sit independently at two years old; between 40-60 correlates with mild to moderate motor impairment, such as ability to sit independently but not walk at 2 years old; and above 60 correlates with a normal outcome (68, 71). The HINE can also give information about aspects of the infants' neurological function other than their motor ability, such as cranial nerve function and behaviour. This allows clinicians to give parents some information about predictions of motor sequelae and overall neurological function of their child, rather than just a normal or abnormal result with no further details.

Another strength of the HINE is its accessibility for clinicians to use, as it is easy to perform, requires no specialist equipment and can be completed in 5 to 10 minutes (68). Therefore, Novak (3) recommends the use of the HINE in low- and middle-income countries, where neuroimaging is not routinely available.

1.3.3. Prechtl's General Movements Assessment (GMA)

The GMA is an assessment of the 'general movements' infants display from the early foetal period until around 20 weeks post-term (72-74). These movements reflect the functioning of the infant's developing brain, appearing 'normal' in quality if the brain is developing as it should, and 'abnormal' if the infant has an underlying brain lesion or malformation (75). Since being introduced by Heinz Prechtl in 1990 several studies have demonstrated the GMA's ability to accurately predict cerebral palsy in high-risk infants and have recommended its use within routine follow-up for these infants (76-82). After Novak (3) identified the GMA as the recommended standardised motor assessment for early identification of cerebral palsy, the Cerebral Palsy Alliance produced various user-friendly materials to inform parents and healthcare professionals about the assessment.

General movements always appear as distinct spontaneous motor patterns involving the whole body but change in a specific sequence during the postnatal period (3, 73, 74, 83). They start as 'writhing' general movements which last from birth until around 6-9 weeks when these are replaced by 'fidgety' general movements, which last up to 20 weeks corrected age (3). This shift from 'writhing' to 'fidgety' general movements at 6-9 weeks demonstrates a major reorganisation in motor output in the infant's brain at this point (84).

The GMA can be conducted between birth and 20 weeks corrected age but has the highest accuracy at predicting cerebral palsy when carried out during the 'fidgety' period, particularly between 12-16 weeks when fidgety movements are most fluent and smooth (3, 73, 85, 86). The assessment is conducted by taking a video of the infant when they are lying on their back, calm, alert and undistracted (**Figure 5**) (87). A qualified clinician observes the general movements performed by the infant in this video and assesses the presence or absence of them, and their quality (88).

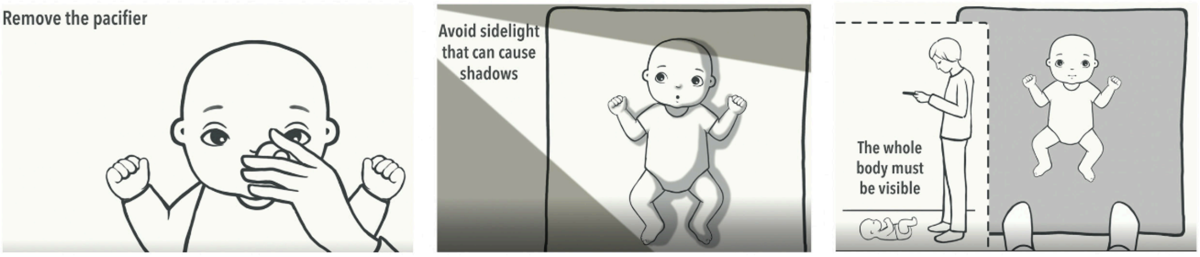


Figure 5: Screenshot of In-Motion-App instructional video for videoing a baby to perform the Prechtl's General Movements Assessment (GMA), taken from Adde (6).

Absent general movements are highly predictive of cerebral palsy and indicate need for early physiotherapeutic intervention (85). Several studies have shown the GMA to have high sensitivity for predicting cerebral palsy and long-term neurodevelopmental outcome, between 97% to 100%, as well as high specificity, between 95% to 100%, and a negative predictive value between 95% to 100% (76-78, 89-92). This has been demonstrated for assessments of infants born at various gestations (78, 80). However, there is some heterogenicity between results for different studies and presence of false positives (79, 91). Because of this, various recommendations have been created for clinicians using these tools. These include the use of a longitudinal series of assessments or combining the GMA with MRI and neurological assessments to increase predictive accuracy and reduce incidence of false positives, instead of just using an isolated GMA result (3, 79, 85, 91, 93). If this is not feasible, the second best option is a single assessment carried out around 3 months, at the 'fidgety' age (85).

1.3.4. Brain magnetic resonance imaging (MRI)

Neuroimaging can be used to identify various types of neonatal brain injury (3). Various sources recommend MRI as the gold standard imaging for this (**Figure 6**) (3, 94, 95). Brain MRI performed at term corrected age has been shown to have a sensitivity (between 86 to 100%) and specificity (between 89 to 97%) when predicting cerebral palsy (76). However, as previously discussed in this chapter, there is no single pattern or group of patterns on MRI that can diagnose cerebral palsy alone, and some children with cerebral palsy have normal MRI findings (20). Therefore, Novak (3) recommends that MRI should be used alongside GMA and HINE to increase its ability to accurately predict cerebral palsy before five months corrected age. Additionally, Novak (3) advises that clinicians should not rule out cerebral palsy in an infant with a normal MRI finding.

In countries where MRI is inaccessible, Novak (3) recommends using newborn detectable risk factors and HINE to allow identification of cerebral palsy before five months corrected age.

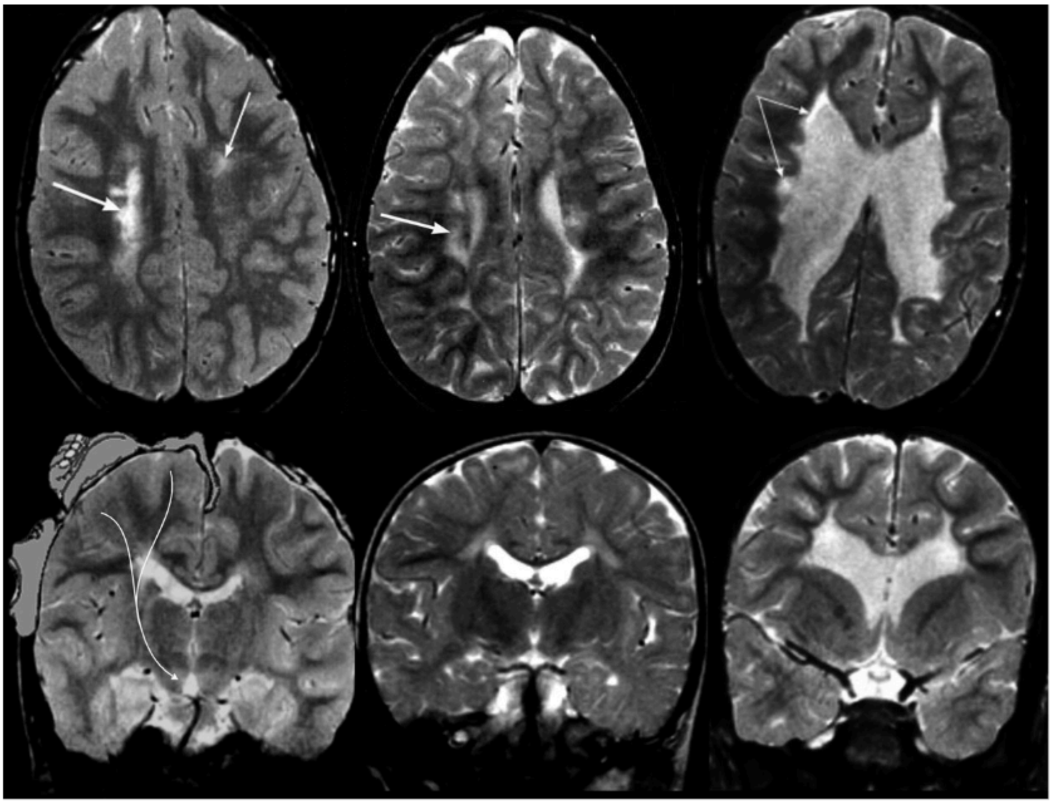


Figure 6: Examples of infant brain MRI scan images showing different types of white matter injury, taken from Himmelmann (7). Left: a mild asymmetrical brain injury involving the right motor tract only. Middle: a mild symmetrical form involving both motor tracts. Right: a severe form, causing bilateral spastic cerebral palsy with severe motor function loss. The upper row shows T2 weighted axial images. The lower row shows T2 weighted coronal images in the domain of the motor tracts (7).

1.3.5. Limitations of these tools

Whilst these assessments have strong abilities to predict cerebral palsy much earlier than has ever been possible before, they also have some limitations. Firstly, due to rapid brain growth and use-dependent reorganisation of the infant's brain as they grow older, assessments conducted before six months are limited in their ability to provide accurate information about the child's cerebral palsy sub-type or predictions for their future functional abilities and associated features (3). Whilst certain sub-types of cerebral palsy and certain co-morbidities are more likely in the presence of particular risk-factors for cerebral palsy, such as the type of brain injury shown on neuroimaging (10, 36, 41), not all children follow these patterns (41). Therefore, these predictions have limited use in generating accurate predictions about an infant's future. For example, onset of hypertonia in cerebral palsy is unpredictable and changes as the child gets older, and the Gross Motor Function Classification System (GMFCS), if performed in infancy, sees 40% of children's classification scales change when repeated after two years (3, 96). Until sub-type of cerebral palsy is known, other information about the child's future is also limited, as determining the sub-type also gives indications of the infant's likely motor function and associated co-morbidities (33, 97). Therefore, whilst parents have a desire for prognostic information to help to plan their future (98) accurate predictions are not possible at this early stage. Providing very generalised predictions may not be useful and could cause unnecessary worry for parents by leading them to expect their child to be severely disabled in the future when this may not be the case. From this, it is understandable why clinicians may be reluctant to give prognostic information at such an early stage.

Another limitation of tools for early identification of cerebral palsy is the presence of inaccurate results. Many studies demonstrate that the GMA, HINE and MRI scans have high predictive accuracy for diagnosing cerebral palsy, but there is some heterogenicity between studies and the potential for false positive and false negative results to occur (79, 93). The risk of false positives and negatives is low, (5% for false positives) when multiple assessments are used together, however it does still exist (3). Both false positive and false negative results would have damaging effects for parents; a false positive would create unnecessary anxiety and a false negative would give false reassurance. A false negative also delays early diagnosis and access to early interventions for the infant. Clinicians should be aware of the potential for these to occur, and use their clinical judgement, alongside a trajectory of abnormal scores from multiple standardised assessments to identify cerebral palsy in an infant under six months (3, 99).

1.4. The importance of early diagnosis

Advances in obstetric and neonatal care in recent decades have led to a decrease in infant mortality rates and an improvement in short term outcomes for preterm infants (39, 100). The limit of viability has decreased to below 24 weeks and more of these premature babies are surviving the neonatal period (8). However, morbidity and neurological disability rates in survivors remain high (**Figure 7**) (8, 39). Whilst overall prevalence of cerebral palsy has remained fairly constant (27, 40, 101), some studies in various countries have found rates of cerebral palsy in high-risk infants to have increased (24, 49, 102), possibly as a consequence of increasing survival rates amongst preterm infants (102). This, alongside the substantial healthcare and societal cost of neurological disability in high-risk infants emphasises the importance of strategies which reduce long-term developmental disability in these infants (8, 39, 103).

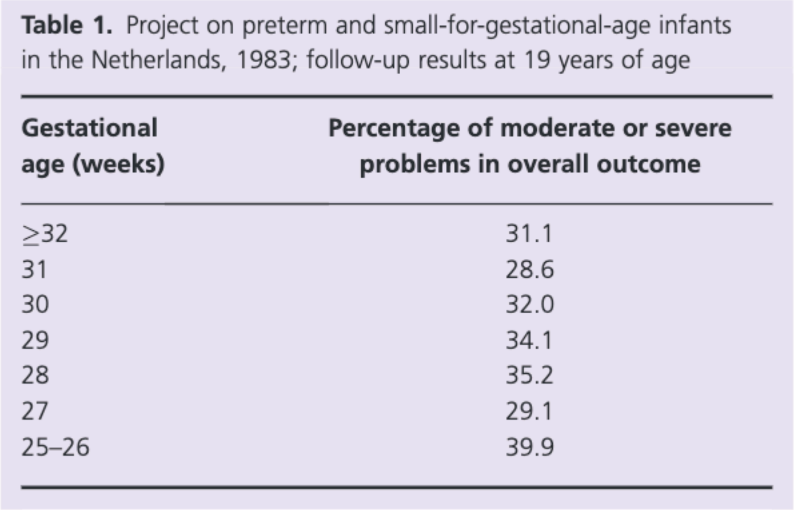


Table 1. Project on preterm and small-for-gestational-age infants in the Netherlands, 1983; follow-up results at 19 years of age

Gestational age (weeks)	Percentage of moderate or severe problems in overall outcome
≥32	31.1
31	28.6
30	32.0
29	34.1
28	35.2
27	29.1
25–26	39.9

Figure 7: Table showing percentages of moderate or severe disability outcomes for small-for-gestational-age preterm infants from a study in the Netherlands in 1983, taken from Verloove-Vanhorick (8).

1.4.1. Benefits of early diagnosis for the infant: potential for early intervention

Cerebral palsy is not curable, but many children go on to enjoy near-normal adult lives if they are provided with properly managed interventions. In general, the earlier interventions are begun, the more likely children are to overcome developmental disability (104). This is possible for the 50% of all infants with cerebral palsy who have identifiable risk factors in the neonatal period (35), as they can be diagnosed early, through early follow-up with use of the recommended tools and then referred on for these early interventions.

Neurodevelopmental outcomes in high-risk infants are mediated by the type and severity of brain injury, but also by environmental experience during early infancy which is able to impact neurodevelopment, due to considerable levels of neuroplasticity (105, 106). The highest levels of neuroplasticity in the infant brain occur from around 2 to 3 months, up to around 15 to 18 months corrected age (106). During this time, reorganisation of the brain occurs, involving activity-dependent competition for spinal synaptic space (105, 107). This may create a period of high potential for improving motor and cognitive development and reversing functional loss in infants who have suffered damage to their developing brain, through use of early interventions (105, 108-112). It is important these early interventions are activity-based, targeting the undamaged corticospinal tract, to improve brain connections to the affected limb(s) (107, 109, 112, 113). Whilst evidence around early activity-based intervention for infants with or at high-risk of cerebral palsy is limited due to a lack of high-quality trials, emerging evidence demonstrates its potential to improve both motor and cognitive outcomes (18, 114, 115). Studies have found it is task- or diagnosis-specific early intervention which leads to improved outcomes for children with cerebral palsy (116, 117). Therefore, early diagnosis of cerebral palsy is vital to allow initiation of cerebral palsy-specific early interventions (110).

1.4.2. Importance of early diagnosis for parents and carers

The vast majority of parents suspect diagnosis of cerebral palsy before it occurs (118). Late diagnosis of cerebral palsy causes parent dissatisfaction, which is associated with higher levels of mental health problems such as depression (118). Qualitative studies have found that parents strongly prefer a diagnosis of cerebral palsy in their child to be given early, often expressing anger when a delayed diagnosis is given having previously mentioned their suspicions (118, 119). Reducing the time until diagnosis has been demonstrated to increase parents' confidence in the medical team, reduce parental stress and improves satisfaction. Some papers have shown this to be correlated with a reduction in reported levels of depression and improved quality of life (118, 120). Early diagnosis has also been shown to allow parents access to early psychological support, and to begin the process of acceptance to gradually progress towards a mindset where they can begin to think about actions to help and support their child (121).

1.4.3. Implications for recommendations

The benefits of early identification, diagnosis and intervention for cerebral palsy to both the infants and their families, has led to this becoming a key focus around the world and comprising the overarching theme of new recommendations (3, 35, 122). Early identification has replaced the original "watch and wait" approach to diagnosis of cerebral palsy, in the hope that it will allow earlier access to interventions and improve the outcomes for both the infant and their families (3, 35, 122). New designs for early interventions are being produced with the aim of maximising outcomes for high-risk infants (123). Novak highlights that despite accurate classification of cerebral palsy sub-type not being possible at the time of early diagnosis, clinicians should not delay early diagnosis and instead uncouple these two processes (110). Ideally, diagnosis should occur before five months as the tools used at this stage have higher quality evidence than those after five months, and the earlier these infants are identified, the earlier they can be referred for interventions and therefore the greater the opportunity for improving their outcomes (3, 104). Novak (3) recommends that even before definitive diagnosis is given, an interim clinical diagnosis of 'high-risk of cerebral palsy' should be used so that these infants can be referred for cerebral palsy specific interventions as early as possible. Parents have been shown, in a qualitative study, to find this interim diagnosis acceptable and to understand that this would be revisited in later conversations with professionals (119). However, if an interim diagnosis is given, it is particularly important to keep parents sufficiently informed about their child's development (124).

1.5. Current use of early follow-up for identification of cerebral palsy

This section discusses current use of early follow-up for identification of cerebral palsy, including current implementation of the recommended tools for early diagnosis of cerebral palsy, globally, in the UK and in Liverpool.

1.5.1. Current follow-up globally

A few studies from the USA have demonstrated successful implementation of the new recommendations for early diagnosis of cerebral palsy, including the HINE and GMA into follow-up for high-risk infants. Byrne (125) found that implementing these into a clinic providing follow-up to high-risk infants from nine NICUs decreased the average age of diagnosis from 18 months to 13, with no significant difference in clinic attendance or decrease in parent satisfaction. Additionally, clinicians in this study reported feeling significantly more aware of the importance of assessment tools, effective interventions, early detection, improving support to parents, and optimising developmental outcomes for children (125).

Also in the US, Maitre (126) tested a design for implementing the HINE into a high-risk infant follow-up programme at one hospital, which included a training workshop and a way to record the HINE in infants' electronic medical record (126). This was successful in reducing the average age of cerebral palsy diagnosis from 27.9 months to 15.7 months, without causing 'over-diagnosis' as there was no change in the overall number of diagnoses (126). However, in this study, clinicians reported some barriers to implementing HINE, such as the additional time taken to perform the examination and some difficulty interpreting the stick figures on the HINE proforma (126), suggesting that extra time in clinic appointments and additional materials or adjustments to the HINE proforma may be required. Following this, Maitre (127) performed the first successful wide-scale implementation of the new guidelines for early diagnosis into five diverse high-risk infant follow-up clinics in the US. This led to a decrease in the average age of cerebral palsy diagnosis from 19.5 months to 9.5 months, early enough for early intervention to be initiated within the recommended timeframe (111, 127). This study reported most parents of children who received a diagnosis to have a positive perception of clinicians, and clinic attendance rates to remain constant, but that 45% of parents felt they were given insufficient information, and 28% could not understand the words used (127). Overall, this highlights feasibility of new guidelines for early diagnosis in the US, but a need for a system that is more appropriate and acceptable for parents.

Significant efforts towards an early diagnosis have taken place in Australia. In 2011, a GMA programme was implemented in New South Wales, training providers from every NICU in New South Wales in the GMA and establishing a 'rater network' to provide peer support and maintain reliability of results (89). This resulted in widespread increased use of the GMA in this region (89). The GMA and HINE are the most commonly used assessments in NICUs in Australia and New Zealand, used in 50% and 38% of NICUs respectively. However, consistency is lacking as many NICUs also use other assessments (128). In Western Australia, follow-up for high-risk infants is limited to medical reviews at 4 and 8 months, with no formal assessment until a Griffiths Scale of Child Development is conducted at one year old, and no mention of HINE or GMA (129). Overall, despite efforts to implement the new recommendations for early diagnosis in Australia and New Zealand, only 21% of infants receive a diagnosis by 6 months of age and 52% still receive a diagnosis after one year (111, 129, 130). 40% parents surveyed in New Zealand perceived a delay of over six months between being told their infant was "at-risk" and being given a definitive diagnosis (130). This delay may be explained by the inconsistent use of GMA and HINE within NICUs. Clinics following the new recommendations for early diagnosis of cerebral palsy are currently in New South Wales only, but there are plans to roll these out to other regions when funding permits (131). In addition, one third of parents surveyed about their experience of receiving a diagnosis of cerebral palsy in New Zealand reported being dissatisfied with the way the diagnosis was given (130).

The European Standards for Care of Newborn Health include a follow-up programme during the first two years for infants born preterm or with risk factors. This programme involves guidelines to ensure all responsible healthcare professionals are trained in standardised neuromotor assessments (132). For this, the GMA at three to four months corrected age is given as an example, with reference to the Novak (3) recommendations, but this is not implemented as standard practice, and the HINE is not mentioned (132).

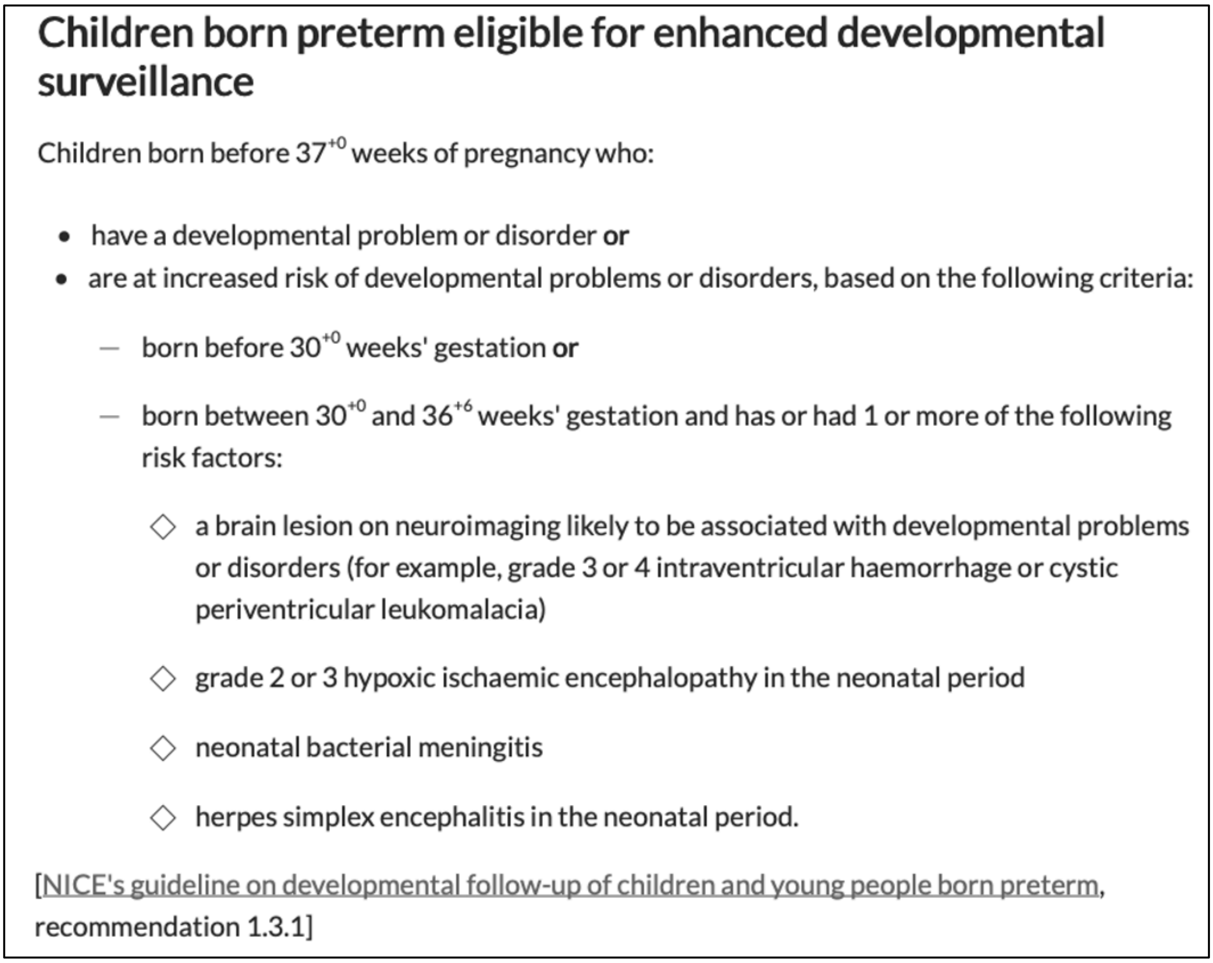
A study in Denmark reports that, for infants with cerebral palsy born between 1995 and 2003, average age of diagnosis was 11 months of age, with 21% of infants diagnosed before six months of age, and 51% before 12 months of age (133). For the time that this study was conducted, these are impressive early diagnosis rates, as the new recommendations for early diagnosis were not published until 2017. Infants appeared to be diagnosed based on presence of motor disability, found via developmental assessments, and that some infants also had abnormal cranial ultrasound findings or epilepsy which helped diagnosis be given earlier. The MRI and the GMA were rarely used but suggested by the paper as a cost-effective way to improve early diagnosis in this healthcare system. It appears that these very early cerebral palsy diagnoses may have been of a preliminary nature, as the paper describes them being given to allow infants access to healthcare, but that children were not added to the cerebral palsy register until age four to meet the criteria for a non-progressive disorder (133).

Data for age of cerebral palsy diagnosis in low- and middle- income countries is significantly lacking (134). A 2019 study in Bangladesh found diagnosis of cerebral palsy was significantly delayed, being given at five years old on average. In India, a community-based identification and intervention programme is currently underway, with a three-year observational cohort study currently being conducted to determine whether this facilitates early detection of neurological and developmental disorders and disabilities in this setting (135). The programme, called G.A.N.E.S.H (General Movement Assessment in Neonates for Early Identification and Intervention, Social Support and Health Awareness), involves implementing the GMA, which will be performed on over 2000 infants in a low-income cohort, once within two months after birth and again at three to five months (135). As of April 2020, almost 900 infants had been evaluated with the GMA as part of the G.A.N.E.S.H. programme, with 208 infants found to have abnormal or suspect GMs and referred for neuropediatric check-up (136). India and Bangladesh are both countries with particularly high prevalence of cerebral palsy, and some children never receive rehabilitation (134, 137). Improvements to services and implementing early follow-up programmes like G.A.N.E.S.H would have an enormously positive impact here (110).

Many studies have been performed testing the ability of HINE and GMA to accurately predict cerebral palsy within cohorts of infants in countries all around the world. However, few studies mention the use of these assessments within these healthcare systems outside of these studies. A 2019 study tested the predictive accuracy of the GMA performed on high-risk infants from five NICUs, three located in Norway and two in the US (93). Here, MRI was conducted for clinical purposes as part of each NICU’s guidelines, but the GMA was conducted only as part of the study’s intervention, with no mention of implementing the GMA into the healthcare systems involved.(93) There was also no mention of the HINE (93). A study investigating use of the GMA in a follow-up clinic for infants with congenital abnormalities requiring surgery in an NICU in New South Wales, Australia, did not clarify whether GMA was used as an intervention in this study or was part of the routine follow-up used here (82). However, as previously discussed, the GMA is widely used in this region of Australia, with GMA-trained assessors present at every NICU (89). In Italy, two retrospective studies conducted in the same NICU analysed the files of infants who had the HINE performed multiple times during their first year of life, suggesting that a trajectory of HINE results may have been routinely performed and recorded here (71). However, a third study in this NICU, published five years later, investigated the predictive validity of the GMA in late-preterm infants, but did not mention the HINE (80). These studies suggest that the GMA and HINE may be implemented into some healthcare systems where studies of these take place, even if this is not clarified in the paper.

1.5.2. Current follow-up in the UK

In 2017, the National Institute for Health and Care Excellence (NICE), who provide guidance for healthcare practice in the UK's National Health Service (NHS), released their first guideline for 'Developmental follow-up of children and young people born preterm' (**Figure 8**) (9). This recommends that 'high-risk' preterm infants (those born before either 30 weeks alone, or 37 weeks with an independent risk factor) are provided with developmental support and surveillance. It also recommends that clinicians provide parents with information about potential complications of preterm birth, including the risk of cerebral palsy and developmental delay.



Children born preterm eligible for enhanced developmental surveillance

Children born before 37^{+0} weeks of pregnancy who:

- have a developmental problem or disorder **or**
- are at increased risk of developmental problems or disorders, based on the following criteria:
  - born before 30^{+0} weeks' gestation **or**
  - born between 30^{+0} and 36^{+6} weeks' gestation and has or had 1 or more of the following risk factors:
    - ◇ a brain lesion on neuroimaging likely to be associated with developmental problems or disorders (for example, grade 3 or 4 intraventricular haemorrhage or cystic periventricular leukomalacia)
    - ◇ grade 2 or 3 hypoxic ischaemic encephalopathy in the neonatal period
    - ◇ neonatal bacterial meningitis
    - ◇ herpes simplex encephalitis in the neonatal period.

[NICE's guideline on developmental follow-up of children and young people born preterm, recommendation 1.3.1]

Figure 8: National Institute for Health and Care Excellence (NICE) guideline for children born preterm who are eligible for enhanced developmental surveillance taken from the 'Developmental follow-up of children and young people born preterm' NICE guideline (9).

A separate NICE guideline for ‘cerebral palsy in under 25’s’ (**Figure 9**), also recommends developmental follow-up until age two for any infant at risk of cerebral palsy, including term-born babies (10). As part of this follow-up, the guideline recommends clinicians ‘consider’ performing the GMA between 0 to 3 months.

Neither of these NICE guidelines elaborate further on use of the GMA, and HINE has no mention. There is guidance for referral to developmental services for an ‘urgent assessment’ if there are signs of abnormal development (9). One of the signs listed here is ‘unusual fidgety movements’, which would be found from a GMA. Through this, early diagnosis of cerebral palsy could be possible. However, other signs listed are abnormal motor development and persistent toe walking, which appear later than six months of age, so would not allow a diagnosis by this age. Whilst the NICE guideline states being ‘to facilitate early diagnosis and intervention’, it does not mention the potential for giving a diagnosis before six months, or in fact, by any age. MRI scans are given mention in terms of their ability to determine aetiology in infants with confirmed or suspected cerebral palsy, but it is stated that this may not be possible until two years old, which may encourage clinicians to delay giving a diagnosis until this age (10).

1.3 Looking for signs of cerebral palsy

1.3.1 Provide an enhanced clinical and developmental follow-up programme by a multidisciplinary team for children up to 2 years (corrected for gestational age) who are at increased risk of developing cerebral palsy (see recommendation 1.1.1).

1.3.2 Consider using the General Movement Assessment (GMA) during routine neonatal follow-up assessments for children between 0 and 3 months who are at increased risk of developing cerebral palsy.

1.3.3 Recognise the following as possible early motor features in the presentation of cerebral palsy:

- unusual fidgety movements or other abnormalities of movement, including asymmetry or paucity of movement
- abnormalities of tone, including hypotonia (floppiness), spasticity (stiffness) or dystonia (fluctuating tone)
- abnormal motor development, including late head control, rolling and crawling
- feeding difficulties.

1.3.4 Refer children who are at increased risk of developing cerebral palsy and who have any of the abnormal features listed in recommendation 1.3.3 to a child development service for an urgent assessment.

Figure 9: Part of the National Institute of Health and Care Excellence (NICE) guideline for looking for signs of cerebral palsy in a child, taken from the 'Cerebral palsy in under 25s' NICE guideline (10).

A 2013 survey found that 72.7% of UK neurodevelopmental follow-up programmes for high-risk infants reported using standardised assessments. Of these, 35.4% used the GMA, 22.9% used HINE and 80.9% performed assessments before three months corrected age (138). A more recent survey, performed in 2017, found that 64% of responding British neonatal intensive care units (NICU) had a dedicated neurodevelopmental follow-up service, but that there was wide geographical variation due to lack of agreed or standardised way to follow-up infants (139). The survey also found variation in timing of access to therapy, and that many units used informal screening for cerebral palsy in a general follow-up clinic, referring children on for a formal assessment only if concerns were raised (139). The 2017 survey reports Bayley III, Griffiths and the Schedule of Growing Skills being used in NICUs, but does not mention the GMA, HINE or MRI scanning (139). It is likely that use of GMA and HINE have likely increased since the 2013 study, as the new recommendations for early diagnosis were published after this. To investigate this, plans are currently underway at the University of Liverpool to carry out an update survey.

Only a few resources can be found reporting implementation of the recommendations for early diagnosis of cerebral palsy in the UK. These include resources from NICUs in Brighton and Newcastle in England and Ayrshire in Scotland which report some use of the GMA and the HINE for high-risk infants (90, 140, 141). However, the GMA and HINE are not being used everywhere; some areas use a mixture of developmental assessments, such as the Alberta Infant Motor Scale, Bayley Scales of Infant and Toddler Development and Lacey Assessment of the Preterm Infant. Introducing a nationally implemented system or guideline for early diagnosis of cerebral palsy in high-risk neurodevelopmental follow-up programmes in the UK could increase use of the HINE and GMA here and reduce the age that cerebral palsy diagnosis is given.

1.5.3. Current follow-up in Liverpool

Joint neonatal follow-up programme between hospitals

The neonatal follow-up pathway for high-risk infants in Liverpool currently consists of a joint service between the Liverpool Women's Hospital (LWH) and Alder Hey Children's Hospital (AHCH). High-risk infants are seen in clinic at the LWH at three to five months corrected age and again at twelve months corrected age, focusing on development, with both a neonatal consultant and a physiotherapist present. An additional detailed face-to-face developmental assessment is provided at two years corrected age, thereby meeting the NICE guidelines.

Babies are referred to a multidisciplinary team (MDT) NICU clinic at AHCH if they are born full-term with hypoxic ischaemic encephalopathy and an abnormal MRI, born before 28 weeks gestation with grade 3 or 4 intra-ventricular haemorrhage, or born at any age showing an abnormal neurology. In 2019-20, average age of referral to AHCH was 10 months, however it still takes additional time until a diagnosis of cerebral palsy is provided. LWH and AHCH also have a Community Neonatal Liaison Specialist (CNLS), connected to both hospitals, whose role is to ensure successful referral between the LWH and AHCH, by linking professionals at the two hospitals and maintaining regular contact with families.

Community physiotherapy

Infants discharged from the LWH NICU showing signs of abnormal development are also referred to community physiotherapists within the Liverpool region, who provide physiotherapy interventions, and a mixture of developmental assessments, including the HINE, the Alberta Infant Motor Scale (AIMS) and Bayley Scales of Infant and Toddler Development in the community. The GMA is not used, and these physiotherapists are not trained in this, as infants are usually older than three months when referred to the service. Community physiotherapists work closely with Neurodisability consultants at AHCH and feed back results from their developmental assessments on infants.

Neuroimaging

Clinicians in the LWH NICU regularly perform cranial ultrasound to look for perinatal brain injury. They use MRI here much less frequently, only for certain groups of infants, and it is not used here to diagnose cerebral palsy early.

Current age of diagnosis

In absence of routine use of HINE and the GMA between 0-3 months until recently, age of cerebral palsy diagnosis varies, and often occurs late. In general, clinicians aim to give a diagnosis of cerebral palsy before two years old, but diagnosis sometimes occurs after this. Some babies who have obvious clinical signs present from an early age receive a diagnosis before one year old. For some infants with suspected cerebral palsy, their diagnosis is confirmed at two years of age via a confirmatory MRI scan.

New pilot physiotherapist-led early follow-up

In the past year, the HNNE, HINE and GMA have started being performed on high-risk infants in the NICU and physiotherapist-led follow up clinics, by a physiotherapist trained in these assessments. The clinics are still in their pilot phase, and only one physiotherapist is trained in the assessments, so capacity is currently limited to only high-risk babies from Liverpool and South Sefton areas.

Support for parents

A counsellor is based at the LWH NICU who parents can access during their baby's stay if they wish. At AHCH, a child health psychology team conducts sessions and provides support to parents and carers with babies seen at AHCH with various health conditions, including cerebral palsy. However, there is currently no counsellor or therapy service available for parents once they have been discharged from the LWH NICU and are undergoing early follow-up, before being referred to AHCH.

1.5.4. Discussion of current use of early follow-up for identification of cerebral palsy

Despite substantial evidence for the ability of recommended tools to accurately predict cerebral palsy by six months (3), and their feasibility for use within clinical practice (127), these tools are not yet implemented in all healthcare systems, and diagnosis still occurs late (142). This may be due to barriers which limit their implementation. In the UK, lack of funding and availability of staff with sufficient training are limitations to providing neurodevelopmental follow-up (138, 139). Training opportunities are available, with courses held around the world suggesting that insufficient funding may be a key constraint (143).

Where funding and numbers of adequately trained staff are limited, and where geographical constraints exist, at-home videoing by parents for remote GMA is a possibility, to increase accessibility to early diagnosis. Ricci (144) trialled at-home videoing for GMA in the US, however, this was unsuccessful as parents were not able to transfer videos to clinicians. A parent-friendly method for providing videos to clinicians, including providing written instructions for parents, may improve the implementation of at-home videoing for the GMA in this setting. The 'Baby Moves' and 'In-Motion' smartphone apps have been designed and trialled in Australia and Northern Europe, respectively (6, 112). These allow parents to video their baby at home and upload this for a trained professional to then assess remotely. Both apps have been trialled with large numbers of parents and found to be user-friendly, with most parents successfully providing scorable video (6, 145). Whilst the 'In-Motion' app trial did not find the app to increase parents' worry about their child's development, surveys in the 'Baby Moves' App trial found parents with an extremely preterm or extremely low birth weight infant did feel more worried when using this (6, 145). These parents also had a lower response rate than others, a higher preference for face-to-face assessments, compared to those with a full-term baby (145). A method of using this app which is acceptable for this group of parents is needed. Various attempts are also currently being made to develop artificial intelligence for computerised analysis of videos for GMA, which would reduce the time and cost of using the GMA by removing the need for staff to manually assess the videos (146, 147). However, these are not yet ready to be implemented into large scale practice (146). Whilst these apps and computerised analysis technology have great potential for reducing the staffing resources required for performing the GMA, face-to-face consultations would still be required to provide any diagnosis compassionately.

Another set of barriers lies in healthcare professionals' decisions to use developmental assessments and perform early diagnosis (148). Healthcare professionals' use of assessments varies but, interestingly, increases where professionals feel they create a positive connection with the parents (119). Some professionals report struggling to explain assessments in a way that parents understand, and do not use assessments as they feel they do not fit into the family-centred care approach (148). Therefore, there is a need for a parent-friendly method, to increase parent satisfaction with assessments, and thereby promote the professionals' use of these assessments. Whilst other factors also contribute to professionals' hesitancy in providing early diagnosis, such as the lack of a single definitive aetiology for cerebral palsy and the limited ability to predict prognosis (35), parents' preferences and developing a parent-friendly method would certainly improve clinicians' confidence in using developmental assessments and providing an early diagnosis.

1.6. The need for a parent-friendly method for diagnosing cerebral palsy early

Receiving a diagnosis of cerebral palsy for your child is understandably a sad, stressful, and worrying time, and can impact negatively on parents' wellbeing (118, 149-151). This impact is made worse when parents feel dissatisfied with the way a diagnosis is given: higher levels of dissatisfaction have been correlated with higher levels of depression in mothers (118). Positive parent-infant interactions are well known to promote early infant development (152-154); and there is substantial evidence showing that parental depression negatively affects these interactions and can increase an infant's risk of developmental delay (155). There is a need for professionals to provide appropriate information and emotional support to parents during this time, and to provide a diagnosis in a way which is acceptable for parents (151).

Explaining the importance of early identification to parents effectively and prepare parents for receiving a diagnosis is essential. Parents have the right to refuse screening for their infants if they do not agree with it and may not attend follow-up appointments for developmental assessments of their infant if they do not understand their importance (156). Parents are also shocked and overwhelmed when unprepared for a diagnosis, and this can delay their adjustment to the diagnosis (151), and, in turn, limit their engagement in interventions for their child (157).

Parental empowerment and motivation, and a positive, trusting relationship between parents and professionals are also important for parent-delivered interventions for a baby diagnosed with cerebral palsy to be successful (158). Parental empowerment is influenced by their views of the healthcare system, and parents' motivation is dependent on receiving adequate support (3, 159). If support systems are poor, emotional burden can accumulate for parents with an infant with cerebral palsy (149). Some parents are dissatisfied with the way a diagnosis is given and experience long-lasting anger and bitterness with the healthcare system (160). This all highlights the need to provide a diagnosis in a way that parents find acceptable.

1.7. Rationale for the study

Increasingly, infants born prematurely and with birth complications such as hypoxic ischaemic encephalopathy are surviving the neonatal period due to advancing medical technologies and improved care within NICUs (8, 39, 100). However, rates of neurological disability, such as cerebral palsy, in survivors remain high (8, 39). For the 50% of infants diagnosed with cerebral palsy who have identifiable risk factors in the neonatal period, accurate early diagnosis before six months is possible, and this can benefit both the infants' outcomes and their parents' wellbeing (35). This has led to early identification of cerebral palsy becoming a key focus worldwide, with the aim of reducing the age at diagnosis (3, 35). Early diagnosis has been found to be feasible in some healthcare settings, however, not all parents are satisfied with the way that diagnosis is given (126, 127, 161).

As previously discussed, ensuring parents are satisfied and well supported during the time they receive a diagnosis is crucial. Whilst we know that parents want an early diagnosis and sufficient information explaining this (118, 119), we do not know how to do this specifically within the setting of an early diagnosis provided before six months using the GMA and HINE. Additionally, some professionals remain reluctant to provide an early diagnosis, or even use these assessments, due to the lack of a parent-friendly method for these (119, 148). This delays diagnosis and access to early cerebral palsy-specific interventions for the child, which may negatively impact their outcomes. There is a need for improvements to the process of identification of cerebral palsy in high-risk infants within the healthcare system, to make this appropriate and acceptable for parents. To achieve this, clinicians need to understand what it is that parents of these high-risk infants want; what they expect from follow-up for their infants; what information and support they prefer when receiving a diagnosis; and their perspectives on what could be improved in the current system.

Few studies have been conducted exploring parents' and carers' experiences during the process of early identification of cerebral palsy. In those which exist, very few specifically explore parents' experiences specifically with early diagnosis using the recommended assessments, the HINE and GMA. Currently, only one qualitative study exists which specifically explores parents' experiences regarding diagnosis of cerebral palsy using HINE and GMA, and this was conducted outside the UK (119). Additionally, previous research has been largely cross-sectional, and there is a need for longitudinal studies to understand how parents' views and perspectives change over time (162).

Therefore, the current study has been designed, which aims to undertake this research and fill this gap.

1.8. Research question

What are parents' and caregivers' views and experiences during their journey through early neurodevelopmental follow-up for their high-risk infants?

1.9. Aims and objectives of this thesis

Primary objective

To explore parents' and caregivers' views and experiences regarding the process of early neurodevelopmental follow-up for their high-risk infants in Liverpool, to provide healthcare professionals with a means of tailoring their service to the needs of these parents.

Secondary objectives

Objective 1: To review the literature which identifies current views and experiences of parents and caregivers regarding the process of neurodevelopmental follow-up and identification of cerebral palsy in their infants.

Objective 2: To understand, through a 'parent journey' style data collection process, using in-depth interviews and focus groups, the perspectives of parents and caregivers with high-risk babies who are undergoing the process of early neurodevelopmental follow-up for identification of cerebral palsy in Liverpool.

Aims of this thesis

Chapter Two: to review the literature which explores parents' and caregivers' views and experiences of their infants stay on an NICU and follow-up for diagnosis of neurodevelopmental disorders, as well as receiving a diagnosis of cerebral palsy or another condition diagnosed in early childhood.

Chapter Three: to discuss the methodological approaches and methods available to use in this study, describe the chosen study design and methods and justify the reasons for selecting these, as well as describe the study setting and discuss ethical considerations, reflexivity and my positionality as a researcher.

Chapter Four: to present the findings from the thirteen interviews with parents within themes and sub-themes produced from thematic analysis, alongside illustrative quotes from these interviews.

Chapter Five: to discuss the relevance of this study’s findings and the extent to which they agree or disagree with previous research on this topic. This chapter also aims to discuss the strengths and limitations of this study and present my recommendations for clinic practice and for further research.

Chapter two

Literature review

2.1. Introduction

To aid the design of this study, a literature review was undertaken to identify the most up to date evidence on the views of parents regarding the process of identification of cerebral palsy and similar conditions which are identified early in childhood. This chapter presents this literature review.

A month was allocated for this literature review and therefore a pragmatic approach to reviewing the literature was deemed to be the most appropriate. In essence this meant that not all relevant literature was reviewed and the technique for reviewing the literature did not meet the requirements of a systematic review. In the next sections I will describe the purpose and scope of this review.

2.2. Purpose

In this review, I aimed to identify, critically review and summarise the literature which explores the views and experiences of parents and caregivers regarding the process of identification of cerebral palsy in their infants, as well as other conditions identified in early childhood. I identified areas which have already been explored and demonstrated the gaps in the evidence base which require further research, allowing informed generation of the research question and justification of the need for this research. I also reviewed the study designs and methods which have previously been used to study this specific research area, to guide my selection of research methods for this study.

2.3. Scope of this review

I identified qualitative and quantitative studies that investigate parents' and caregivers' experiences before, during and after follow-up assessments for their child screening for cerebral palsy or neurodevelopmental delay. To encompass these different components, I conducted separate searches to look independently for literature exploring parents' experiences at each stage of the process of diagnosing cerebral palsy. As the HINE and GMA are the recommended assessment tools for early diagnosis of cerebral palsy, I also conducted an independent search to identify any papers which investigate parent experiences of these specific tools.

Additionally, for my study, I felt that an insight into the 'bigger picture' surrounding the follow-up and process of diagnosis for cerebral palsy would be beneficial and so I widened the scope of this review to search for literature which identifies parents' experiences of other disorders diagnosed in early childhood and included some of these in this review. I hoped this would give me a broader understanding of this phenomenon and highlight issues which run in parallel to issues within the process of diagnosing cerebral palsy.

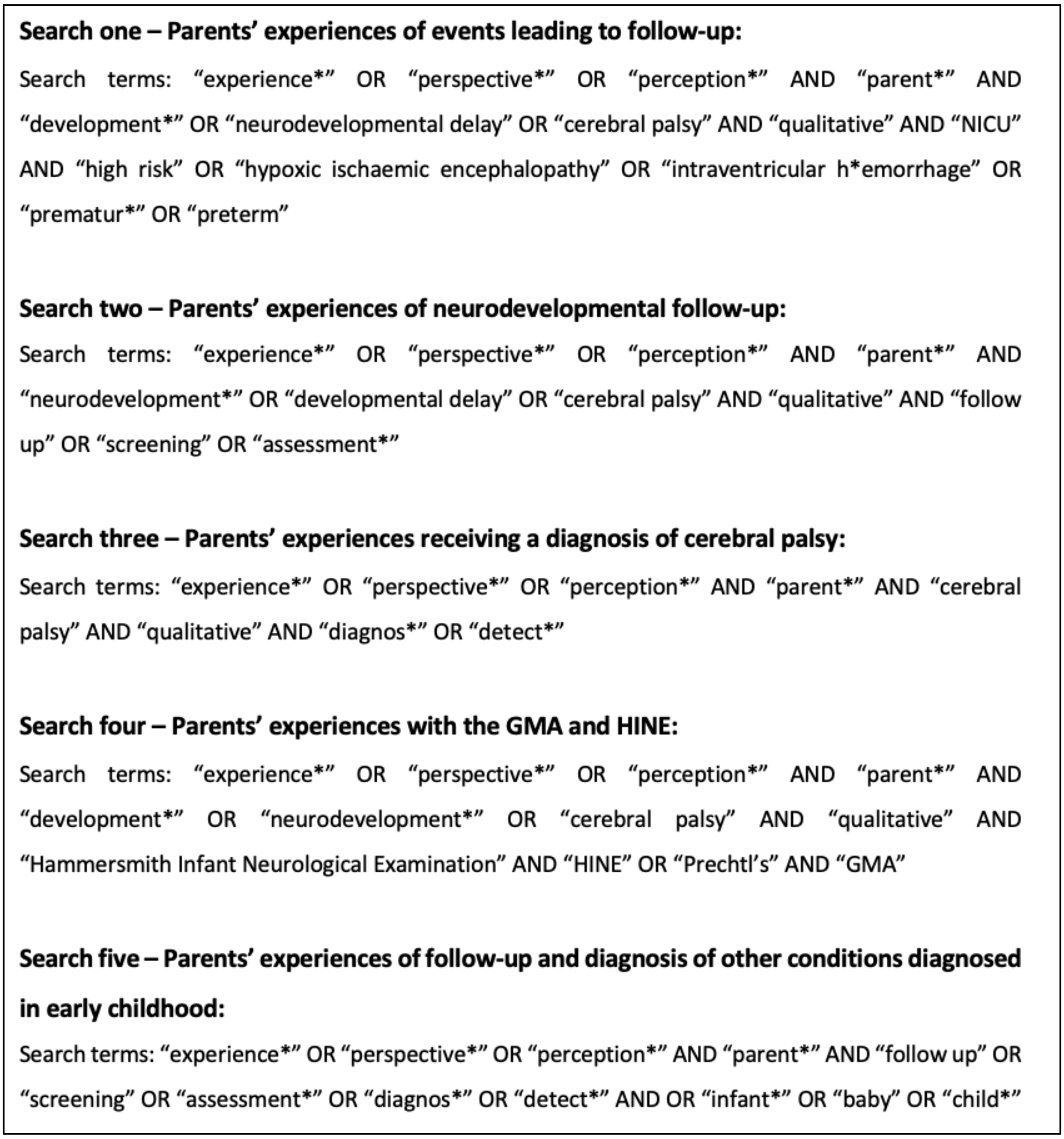
2.4. Search process

Search design

To undertake this review, I searched the databases PubMed, Scopus and Web of Science for all papers containing the key terms and following the inclusion and exclusion criteria that are detailed below. I used the Boolean operators “AND” and “OR” between key terms to retrieve relevant results. I used wildcards to include results containing either the English or American spelling of words, for example ‘haemorrhage’ and ‘hemorrhage’. I also used truncations for key terms which had various endings, for example ‘experience’ may also be ‘experienced’ or ‘experiences’, to include papers containing these words in any of these forms. For PubMed searches, the term “cerebral palsy” was searched for in the form of the MeSH term “cerebral palsy”.

I applied filters so that only studies in the English language, completed between January 2000 until October 2020 were included.

Figure 10 below shows the searches I conducted on all three databases, to identify papers:



Search one – Parents' experiences of events leading to follow-up:

Search terms: "experience*" OR "perspective*" OR "perception*" AND "parent*" AND "development*" OR "neurodevelopmental delay" OR "cerebral palsy" AND "qualitative" AND "NICU" AND "high risk" OR "hypoxic ischaemic encephalopathy" OR "intraventricular h*emorrhage" OR "prematur*" OR "preterm"

Search two – Parents' experiences of neurodevelopmental follow-up:

Search terms: "experience*" OR "perspective*" OR "perception*" AND "parent*" AND "neurodevelopment*" OR "developmental delay" OR "cerebral palsy" AND "qualitative" AND "follow up" OR "screening" OR "assessment*"

Search three – Parents' experiences receiving a diagnosis of cerebral palsy:

Search terms: "experience*" OR "perspective*" OR "perception*" AND "parent*" AND "cerebral palsy" AND "qualitative" AND "diagnos*" OR "detect*"

Search four – Parents' experiences with the GMA and HINE:

Search terms: "experience*" OR "perspective*" OR "perception*" AND "parent*" AND "development*" OR "neurodevelopment*" OR "cerebral palsy" AND "qualitative" AND "Hammersmith Infant Neurological Examination" AND "HINE" OR "Prechtl's" AND "GMA"

Search five – Parents' experiences of follow-up and diagnosis of other conditions diagnosed in early childhood:

Search terms: "experience*" OR "perspective*" OR "perception*" AND "parent*" AND "follow up" OR "screening" OR "assessment*" OR "diagnos*" OR "detect*" AND OR "infant*" OR "baby" OR "child*"

Figure 10: Search criteria for the five searches conducted in three databases to identify literature for the literature review

I reviewed all papers that came up in response to these searches and filtered out those that were not relevant to the topics I aimed to review, so that only relevant papers were included. As well as conducting database searches, a small number of additional relevant papers were also identified through snowballing. In total, 46 studies were included in this literature review.

2.5. Evaluation of literature

I read the relevant papers identified for this review and evaluated their relevance and contributions to this research area, based on the content and quality of their findings, and their use of research methods. From this, I identified gaps in the current evidence available, and used these to inform the generation of my study's aim. I also considered which methods may be most appropriate to use in my research.

2.5.1. Part one: Parents' experiences of events before follow-up

First, I will review papers exploring parents' experiences with a high-risk infant in an NICU. This area has been researched thoroughly using qualitative methods. The majority of studies used interviews as their primary method. A few used a mixture of qualitative and quantitative methods. Most often, the parents in studies were recruited due to their infant being born preterm to a given extent. However, some studies excluded certain high-risk infants. For example, Provenzi (163) included only parents of infants with neonatal or postnatal complications or injuries and Guillaume (164) excluded parents of infants with any recent severe clinical aggravation or abnormal development patterns. This means that views of some parents whose infants were high risk for cerebral palsy and may go on to receive a diagnosis of this were not included in these studies. Some studies' samples were homogenous in terms of parent characteristics, such as ethnicity and socioeconomic status, which may limit the transferability of their findings to other parent populations (165-167). Others had more heterogenous study samples, achieved by recruiting parents speaking one of multiple languages (168, 169) or from multiple NICUs (164, 166, 170, 171) which will likely increase their transferability.

There are certain themes of note, which frequently recur in these studies, regardless of study settings and parent or baby demographics. These are discussed below.

(1) Parent involvement and empowerment

Provenzi (172), in their systematic review of studies exploring fathers' experiences with a preterm infant, report fathers often describe feeling a need to be involved by professionals. In a similar sense, Ballantyne (173) found in their scoping review of qualitative studies that parents experienced stress when they were not involved or informed about their premature baby. Hoogen (167) reported that parents with an extremely premature baby had different views on being involved in their baby's care and decision-making: some felt empowered by this, some felt a barrier to being involved in that they had to try and 'make it work in the context of their lives', and others felt being involved was 'their responsibility'. This study referred to development specifically, stating that parents responded positively to a programme of structured meetings with NICU staff involving discussions about developmental care for their extremely preterm infants (167).

(2) Impacts on mental health and emotions

Several studies reported parents to describe the NICU experience as an 'emotional rollercoaster' (166, 167, 174, 175). Nylund (175) performed a detailed analysis of interviews performed with parents about their experiences feeding their extremely preterm infants on a Swedish NICU and found that parents also described the emotional impacts of the general NICU experience; reporting that they were thrown between 'hope' and 'despair' depending on their baby's wellbeing. However, these researchers did not state how they sampled parents for this study (175). Arnold (166) interviewed a sample of mainly white ethnicity, married or co-habiting parents and found they felt a wide range mixture of emotions, from feeling elated to devastated, as well as guilty and confused at times. Their homogenous study sample may have been caused by their recruitment achieving only a 32% response rate. Other studies conducted with parents from Canada, Sweden and Iran also reported that parents described a range of emotions relating to their child's stay on the NICU, including shock, denial, loss, anxiety, anger and helplessness (165, 168, 175).

Granrud (170) used two researchers to interview a sample of parents with a preterm infant staying in one of two NICUs in Sweden. They found that parents experienced strong anxiety about 'something happening to the baby' which continued throughout the entire hospital stay. Harvey (176) also found anxiety was expressed in parents of a very preterm baby staying in a UK NICU. This study specifically explored how parents experience information and communication about brain imaging and neurological prognosis in the NICU, so has greater relevance to the topic of neurodevelopment than most other studies reviewed. In this study, parents' anxiety related to their baby's diagnosis, prognosis and long-term development. Rossman (174) was the only other study reviewed to also link parental mental health and emotions to their child's neurodevelopmental risk. This study found that a sample of mainly low income, single mothers reported that the 'grim prognoses' from brain ultrasound results contributed to the 'rollercoaster' of emotions they experienced and for one mother, caused her to feel depressed.

(3) Coping mechanisms

Rossman (177) studied an ethnically diverse sample of mothers with a very-low-birth-weight infant in a US NICU, and found these mothers often coped by taking it one day at a time. Harvey (176) reported this same finding but this time in fathers with a very preterm infant in a UK NICU. Wakely (178) found that a small sample of parents in rural Australia reported 'thinking optimistically' as a way of coping with having a premature baby. However, this study interviewed parents up to seven years after leaving the NICU and so the findings may not reflect how parents perceived these experiences at the time they happened. A similar finding was reported by Amorim (179) that some parents in their purposively sampled cohort handled their fear for the future for their extremely preterm infants by 'choosing to think positive', despite being scared. This study used qualitative interviews to expand or validate findings from quantitative surveys. It performed a thorough investigation into parents' experiences at a set point in time, interviewing 26 couples all at 4 months after childbirth.

In terms of parents' ways of coping with their child's high neurodevelopmental risk specifically whilst in the NICU, there is limited mention in the studies reviewed. Amorim (179) was one of the very few to do this, reporting that parents found it helpful to reframe their expectations of their infant's current and future development by taking their prematurity into account. One parent in this study stated: 'we can't expect that he, [at] 4 months [old], matches a 4-month term baby' (179). Arnolds (180) was another study to explore how parents coped with disability and developmental delay, finding that parents often displayed optimism and hope as well as appreciation for the care team. They recruited parents from two NICUs in the USA and aimed to perform two interviews with each parent at different time points, however, several parents were lost due to follow-up at the second interview, and not all parents in this study had an infant who was high-risk for cerebral palsy.

(4) Becoming a parent to their infant

Ardal (168) found that an initial 'dislocation of the parental role' was expressed during in-depth interviews with mothers with a very-low-birth-weight infant who spoke a range of languages. One mother in this study described how only 'after two or three months passed, you started feeling like you are a real mother.' This study provides unique insight, as often parents who do not speak the native language are not included in qualitative studies due to the difficulties with translating and interpreting during interviews. The transition to 'feeling like a parent' was a common theme amongst papers; experienced both by parents with a preterm infant, who felt the unexpected early delivery changed their anticipated roles and relationships with their infants (168), and those with a term-born infant with birth asphyxia, who felt that their bonding with their baby had been affected by them undergoing hypothermia as it created an 'involuntary parent-infant separation' during the first few days after birth (181). In the latter study, parents were recruited from an NICU in Sweden and interviewed about their experience of becoming a parent to a child with birth asphyxia. Detailed thematic analysis of these interviews found these parents described a 'feeling of inadequacy' due to not being able to take care of their child themselves (181). Similarly, Guillaume (164) interviewed a sample of 60 parents about their experiences during the first month of their preterm baby's life in one of three NICUs in France. For these parents, feeling dependent on NICU staff to care for their baby was described as leaving them feeling disempowered. This study's sample size is relatively large for a study performing qualitative interviews. However, this does not necessarily make the author's comparisons between mothers and fathers, and between parents of different demographics, valid in terms of generalising these findings, as the sample is not representative of the population from which it was recruited (164).

Few studies report parents relating their perceptions of 'becoming a parent' to a high-risk infant to their infant's development or neurodevelopmental risk. Øberg (182) is the only study found to link these, by exploring parents' experiences carrying out a motor intervention in the NICU involving handling and moving their preterm infant and finding that this made parents feel more 'empowered' as they were able to contribute to their infant's development. This suggests that parents can have positive experiences relating to their baby's development in the NICU despite the knowledge that their baby may have an abnormal developmental outcome. However, the relevance of the study remains limited, as it only explores parents' experiences with a motor intervention, with no mention of experiences relating to the process of screening for neurodevelopmental disorders.

(5) Fear and uncertainty for the future

Some papers reported parents to feel uncertainty and fear for the future for their high-risk infants including uncertainty and fear for future diagnoses (165, 169, 173). These may include future diagnoses of neurodevelopmental disorders; however, these papers did not mention these specifically. Craig (183) conducted focus groups to explore parents' experiences of therapeutic hypothermia for their baby with hypoxic ischaemic encephalopathy and in their inductive approach to thematic analysis found that some parents had concerns specifically relating their baby's high risk of being diagnosed with cerebral palsy. However, these focus groups were conducted over two years after parents' babies underwent therapeutic hypothermia, and so their experiences shared may differ from those that would have been collected had focus groups been conducted closer to the time of these events. Heringhaus (181) reported parents' experiences waiting for MRI results in the NICU; here, some parents described the MRI result as 'one of the most important milestones in the child's hospital stay' and felt this was important to make them 'more prepared for their future family life', demonstrating that receiving information which can give some indication about their baby's future neurodevelopmental outcome was important to parents at this time. However, no further experiences relating to the process of identifying neurodevelopmental risk were discussed in these papers.

(6) Information and communication needs

Papers exploring parents' experiences with a high-risk infant often discussed the information and communication needs of these parents. Most explored this in relation to parents' general needs and did not refer to parents' needs for information and communication about their infants' neurodevelopmental risk or development specifically. For example, Guillaume (164) reported how parents 'stressed the importance of always giving news' and Nylund (175) described parents' need for tailored information to increase their satisfaction. A few studies did explore parents' need for information and communication relating to their baby's neurodevelopmental risk. One of these was Harvey (176), which found that almost all parents worried about their preterm baby's long term developmental outcomes, and that some parents had concern specifically relating to their baby having brain damage or severe disabilities in later life. This demonstrates parents having a level of understanding of their baby's neurodevelopmental risk whilst in the NICU.

A few studies also reported parents' information needs relating to neuroimaging. Guillaume (164) found some parents of a preterm infant expressed a need to 'not be kept waiting' about results from ultrasound scans. Craig (183) found some parents with a term-born infant who suffered hypoxic ischaemic encephalopathy had expectations of the ability of tests such as MRI scans to give definitive prognostic information about neurodevelopmental outcome in the neonatal, and that these expectations were not met. Hoogen (167) reports findings from interviews with parents about their experiences undergoing personalised training with physio- or occupational therapists to learn how to observe their baby's behaviour. This study reports that parents described this experience positively and found it 'motivating'. These studies give some limited insight into parents' needs for information about their baby's neurodevelopmental risk and outcomes.

(7) Support

Hoogen (167) found that parents interviewed often described staff as being a major source of emotional support. This was also reported by Nelson (184), who studied a small convenience sample of mothers, some of whom felt the nurses in the NICU caring for their preterm baby came to feel like 'friends' or 'extended family' who looked out for both the mothers and their infants. However, other studies found parents struggled to access emotional support from staff as staff were too busy to provide this or that parents preferred to seek emotional support from others, such as their partner, other relatives and other parents on the NICU (167, 175, 185). Lakshmanan (169) used typical-case purposive sampling to achieve a sample of mainly Hispanic parents recruited from an urban high-risk follow-up clinic in the USA. In interviews, they found some parents had an unfilled need for a 'support group' where they could share their experiences with other parents. This study used medical professionals involved in clinical care to act as interviewers which is likely to have affected the openness and honesty of responses from parents, particularly their responses regarding negative experiences. The studies reviewed usually referred to support in general, without specifying the area that support was provided for, and with very limited mention of parents' support needs relating specifically to their infants' development or potential for abnormal neurodevelopmental outcomes.

(8) Comparing to 'normal' babies

Parents with a high-risk infant often compared their child to 'normal' babies during their time in the NICU. Ireland (185) found from thematic analysis of interviews that some parents compared the appearance of their baby to that of 'normal' babies in terms of colour and size, recognising that their preterm baby looked different. Arnold (166) reported some parents comparing holding their preterm baby as different to holding babies born full-term. Studies often reported parents to refer specifically to developmental delay when discussing this theme. Lakshmanan (169) described how some parents in their mainly ethnic minority sample recruited from a high-risk follow-up clinic felt concerns about their baby's development being 'behind' and were 'afraid that he might not catch up', which caused them great anxiety and stress. Wakely (178) found that some parents in their small sample reported 'striving for normal' with their baby and feeling 'happiness when a child achieved a new goal.'

Conclusion to part one

When combined, the studies exploring parents' experiences with a high-risk infant in an NICU provide a solid evidence base. Studies have been conducted in a wide range of settings, with parents of various demographics. However, most studies' findings do not shed much light on the topic of development as they explore parents' general experiences during the NICU, or a specific area such as feeding (175) or skin-to-skin contact (171), with only a few studies giving mention to how parents perceive their infants' development and neurodevelopmental risk during this time. Therefore, from the current evidence base, there is a lack of in-depth understanding regarding the way parents conceptualise their infants' developmental risk at this early stage. Additionally, several studies conducted interviews or focus groups with parents several years after their infants left the NICU, limiting the evidence that currently exists reporting parents' experiences and perspectives gathered close to the time of these experiences. This is relevant as the way parents recall these experiences from this later time point may differ from how they would have described the experiences if interviewed closer to the time.

2.5.2. Part two: Parents' experiences of neurodevelopmental follow-up and assessments

Next, I will review the papers identified from my searches which explore parents' experiences of neurodevelopmental follow-up and assessments.

A handful of studies have been conducted; these use a mixture of qualitative and quantitative methods. All study the experiences of both mothers and fathers, rather than one group alone. Sample sizes were generally large, and studies commonly used either qualitative or quantitative surveys to collect parents' experiences, although interviews and focus groups were also used.

Dorner (186) explored the views of a convenience sample of 19 parents with a preterm infant regarding early neurodevelopmental screening. These parents' infants were reported to be 'relatively low risk from a neurological standpoint' and had not yet had any developmental screening, instead this study provided a 'theoretical example of a non-invasive non-painful test' as a 'proxy' for the GMA to enable discussion. Parents interviewed described seeing benefits in early screening for neurodevelopmental disorders as it would give them 'more information' and an early awareness so that they could begin to plan for various aspects of their family's future. Parents found the idea of a false-positive result distressing but feel the negative aspects of screening were 'outweighed by the potential benefit of early intervention'. Whilst this study provides a useful perspective, it does not study parents whose infants have actually undergone screening, whose views would likely differ from this and provide a more accurate way of understanding parents' experiences with screening (186).

Some studies explore parents' experiences of their infant undergoing follow-up to identify a neurodevelopmental disorder, but do not give details of the follow-up that was provided, or what parents' views were of this. Raspa (187) retrospectively explored the experiences of a large, diverse sample of parents during the time leading up to identification of a developmental delay in their infant, using focus groups conducted with parents from three states in the USA. This study's findings provide insight which is helpful for understanding some general themes about identification of children. It found that usually the parents were the first to express concerns about their infant's development, and that this mostly stemmed from their infant having delayed speech, or by noticing differences when comparing their child's development to that of other children. Parents also described experiencing denial and depression in the period before they approached professionals about their concerns. As these researchers asked parents to reflect on their experiences years after these occurred, their responses in focus groups may have differed from those they would have given had data collection occurred closer to the time these experiences occurred (187).

Some studies explore parents' experiences of their child undergoing follow-up for identification of a neurodevelopmental disorders, using assessments other than the HINE and GMA. Martin (188) presents a single case study of a 40-year-old mother's experiences with her extremely preterm infant who was found to have motor delays when scored at various points during their first 10 months of life using the Test of Infant Motor Performance (TIMP) and the Alberta Infant Motor Scale (AIMS). When interviewed at the infant's 10-month follow-up visit, this mother described constantly questioning whether her daughter was 'where she should be' with her development and anxiety created by her daughter's motor delays. This mother also reported 'overcoming obstacles' by doing what she described as making the 'best of a bad situation' and having 'low expectations' by taking her daughter's extreme prematurity into consideration. However, as this is a single case study, the range and transferability of findings are limited (188). Danguecan (189) performed a mixed-methods study of a large sample of parents with a child with hypoxic ischaemic encephalopathy, recruited from neurodevelopmental follow-up programmes in Canada. The researchers collected open-text survey responses from 54 parents during the time that their infant was underdoing neurodevelopmental follow-up. The responses provide useful insight into how these parents felt about their child's developmental outcome during this time, such as that some parents felt their baby 'was going to be okay', but others felt a lot of uncertainty about the potential for a range of outcomes, such as cerebral palsy. However, these qualitative findings are limited. The study reports children undergoing the Bayley's scales of infant and toddler development and two child behaviour assessments during follow-up, as well as MRI scans performed within one week after birth, however, the findings provide no insight into parents' experiences or views of these (189).

Another qualitative study by Komoriyama (190) explored the experiences of a purposively sampled group of parents during neonatal follow-up for their high-risk infant in Liverpool. Parents' infants were either born preterm or with hypoxic ischaemic encephalopathy, allowing insight into the views of both these parent groups. Interviews with these parents found some wanted clear information about their child's prognosis, often feeling frustrated at not receiving this earlier than they did. Thematic analysis identified that some parents viewed the follow-up pathways as unclear or did not recognise the need for them, as they had received little information about it during their time in the NICU. Parents' understanding about their child's developmental risk and future prognosis was also found to vary greatly. These findings provide useful, in-depth insight into parents' views and experiences of follow-up, but this follow-up did not involve the HINE or GMA (190). Since this study, the neonatal follow-up system for high-risk infants in Liverpool has undergone changes to introduce new physiotherapist follow-up clinics for screening of high-risk infants with the HINE and GMA, to enable earlier diagnosis of cerebral palsy.

Some studies which explored parents' experiences before neurodevelopmental follow-up, in the NICU, also explored parents' experiences during follow-up. Craig (183) found that parents with an infant treated with therapeutic hypothermia had persistent fears about their infant's long-term prognosis and outcomes such as cerebral palsy or autism, during neurology follow-up appointments at 3, 6 and 12 months. Nylund (175), whilst mainly focusing on parents' experiences feeding their extremely preterm infants whilst on a Swedish NICU, also found the parents interviewed described their views of the follow-up provided to their baby after discharge from the NICU. Some parents expressed their views that the general follow-up by child health services offered to all children aged 0-5 were 'a waste of time', but that the check-ups carried out within the neonatal follow-up programme after discharge from the NICU were beneficial as they increased the parents' confidence (175). Similarly, Heringhaus (181) found that parents with infants born at full-term with birth asphyxia 'felt safe' during the follow-up visits to the doctor after discharge from the NICU as they had the opportunity to ask questions and their baby's development was being checked. Wakely (178) reported findings from interviews with a small sample of parents of a preterm infant and gave brief mention to parents' experiences of follow-up, stating that parents felt regular developmental monitoring through their child's first year helped them to set new developmental goals as well as giving them reassurance that their child was making progress. These studies did not, however, define what this follow-up involved, such as what assessments were performed, and gave limited insight into parents' experiences with neurodevelopmental follow-up as their primary aims were to explore other topics.

A few studies have explored parents' experiences with the HINE and GMA. Byrne (125) tested the implementation of new infrastructure and assessments, including the GMA and HINE, into follow-up clinics for diagnosis of cerebral palsy in the USA. The researchers collected views of over 300 parents using quantitative questionnaires distributed before and after implementing the new infrastructure and assessments. These found that parents' overall satisfaction with the follow-up clinic remained high and unchanged, with almost 100% of parents feeling the healthcare professionals had concern for their worries and questions (125). These findings give limited insight into parents' experiences, however, shortly after, Byrne (119) performed focus groups to gather parents' experiences of their child being assessed using the HINE and GMA and subsequently diagnosed with cerebral palsy. They found that parents had a need to know the name and purpose of assessments and be given a description during the assessment followed by a summary at the end. MRI scans were also discussed during focus groups, which the parents were reported to prefer these to be done as early as possible (119). This gives a valuable insight into parents' experiences with the HINE and GMA assessments; however, performing a deductive analysis with pre-determined themes will have prevented the study from uncovering issues experienced by parents that were not anticipated by the researchers (119). Kwong (145) distributed quantitative surveys to around 200 parents with either an extremely preterm (EP) or extremely low birth weight (ELBW) infant, asking about their views of providing home-recorded videos of their infants' movements for the GMA, via a smartphone app. Survey results showed that most parents found the app user-friendly. The researchers also found that compared to a 'control' group of 200 parents with a full-term infant, the parents with an EP or ELBW infant described a higher preference for face-to-face assessments and experienced greater worry when using the app (145). This provides some useful insight into parents' experiences of at-home videoing for the GMA, however studies using qualitative methods are needed to provide a more in-depth understanding.

Conclusion to part two

I have reviewed the literature on parents' experiences of follow-up and assessments for identifying neurodevelopmental disorders. Most studies identified have been conducted outside of the UK and may not be transferable to a study within Liverpool. Also, some studies used quantitative methods, producing superficial findings, rather than an in-depth understanding, as they conducted only a limited exploration into parents' experiences. Of studies that explored parents' experiences in depth, only Byrne (119) included parents' experiences regarding early follow-up for diagnosis of cerebral palsy using the HINE and GMA. This study was performed in the USA and performed a deductive analysis with pre-determined themes. This meant that the findings did not include any issues these parents experienced that were not anticipated by the researchers. Komoriyama (190) studied parents' experiences of neurodevelopmental follow-up for their high-risk infants in Liverpool, but since this, the follow-up system has changed and the HINE and GMA have been introduced. Therefore, a gap remained for a study in the UK, which takes an inductive approach and provides an in-depth insight into parents' views and experiences during early neurodevelopmental follow-up for their high-risk infants, using the HINE and GMA.

2.5.3. Part three: Parents' experiences receiving a cerebral palsy diagnosis

Next, I will review studies which shed light on how parents experience or perceive receiving a diagnosis of cerebral palsy in their child. I identified a handful of studies exploring this which were conducted in various countries around the world using a mixture of qualitative and quantitative methods.

Several studies provide insight into parents' perceptions and emotions relating to their infant receiving a diagnosis of cerebral palsy. Fernandez-Alcantara (151) studied a sample of 24 parents with a child aged between five months and six years old, who had been diagnosed with cerebral palsy and was receiving treatment at a hospital in Spain. Parents were purposively selected to achieve diversity in their children's age and severity of their diagnosis. During interviews, some parents shared that before receiving the diagnosis, they were aware of the possibility of cerebral palsy, but for most it was unexpected news. Some of the parents described the experience of receiving the diagnosis as a 'struggle' or 'battle' and having feelings of loss, anger and helplessness; some also expressed concern about how their infant's cerebral palsy would develop. Based on the ages of infants at the time of recruitment to the study, it is clear that at least some received an early diagnosis of cerebral palsy, and the study gives detailed insight into parents' perceptions of this (151). Similarly, Whittingham (150) found some parents in their focus groups were already expecting a diagnosis of cerebral palsy in their child when it was given as they were aware of the possibility for an abnormal developmental outcome since birth. These studies both demonstrate how much parents' perspectives of receiving a diagnosis vary greatly depending on their prior awareness of their infant's risk of having cerebral palsy. Whittingham (150) studied a small sample of highly educated parents in Australia, most of whom were married or living with a partner. This study described parents' views years after their child had received a diagnosis and so their accounts may not reflect how they perceived receiving the diagnosis closer to the time it happened (150).

Knis-Matthews (191) aimed to explore four parents' experiences with movement therapy for their child with cerebral palsy in the USA, however, parents also described their experiences receiving their child's diagnosis of cerebral palsy in the interviews. Some of these parents expressed having a lack of information at the time of diagnosis and finding it very hard to fulfil this information gap. Some also described that having a 'strong support system' was highly important to help them deal with what they described as an extraordinarily stressful situation. However, the results in this study are limited, as its aim was to explore another area of parents' experiences (191). Huang (192) conducted long, in-depth interviews with a purposive sample of Taiwanese mothers', to explore their experiences receiving a diagnosis of cerebral palsy in their child aged between 0-18 at the time of the study.

Analysis of interviews found some similar findings to studies performed with parents in western cultures, such as feelings of loss and being helpless or out of control. Unique themes were also found by the researchers, including feeling self-blame or experiencing blame from others due to 'violating the foetal God' or breaking traditional Chinese taboos (192).

Some studies which explored parents' perspectives of neurodevelopmental follow-up also explored parents' experiences of receiving a diagnosis of cerebral palsy. Byrne (119) found that during focus groups with parents whose children had been diagnosed with cerebral palsy after being assessed using the HINE and GMA, the parents expressed their views that receiving an early diagnosis, or 'high risk of cerebral palsy', was important to them. This study also found that many parents wanted honest, detailed and positively phrased information and wanted more education and resources (119). Komoriyama (190) found some of their 27 parents interviewed expressed anger and regret in not having had an earlier diagnosis or at least a discussion with professionals about these diagnoses. Both these studies provide useful insight as, unlike others, they shed light on the parents' experiences and views of the way that the diagnosis cerebral palsy in their child was communicated to them by professionals. This is helpful for understanding how this experience could be improved for parents.

Baird (118) also provides useful insight into parents' perceptions of receiving a diagnosis of cerebral palsy in their findings from semi-structured interviews with a large sample of mainly white British parents with an infant with cerebral palsy in the UK. Unfortunately, these interviews were not analysed in depth, but the researchers did find from them that many of these parents felt angry at the delay in being given a diagnosis after they had mentioned their suspicions. This study also used questionnaires, completed by parents, which found that when parents were more dissatisfied with the way the diagnosis was given, they were more likely to feel depressed following the diagnosis (118).

Maitre (127) explored a large group of parents' views and experiences during a follow-up clinic visit in the USA, where they were provided with an early diagnosis of cerebral palsy in their high-risk infant, after being assessed with the GMA and HINE. Findings from quantitative questionnaires completed by parents after the clinic visit show that 55% of parents felt information about the diagnosis was sufficient in content, 72% found the words used understandable, 70% felt the professional giving the diagnosis showed warmth or support (127). As these researchers used quantitative questionnaires alone, the insight provided into parents' experiences lacks depth, and so qualitative methods are needed to understand the perspectives of parents more fully.

Conclusion to part three

Of the papers reviewed which explore parents’ experiences of receiving a diagnosis of cerebral palsy in their infant, many of these focus on how the diagnosis made the parents feel and how it impacted their lives. Of the studies which did explore parents’ perceptions of the way the diagnosis was provided to them, only two involved the infant being given an early diagnosis of cerebral palsy after being assessed with the HINE and GMA (119, 127). These two studies used either quantitative methods, or qualitative methods but using a deductive approach. Therefore, there is a gap remaining for an in-depth, qualitative study using an inductive approach to explore the experiences of parents receiving an early diagnosis of cerebral palsy in their high-risk infant, performed using the HINE and GMA. This research is required to inform healthcare providers how they can improve this process for parents.

2.5.4. Part four: Parents’ experiences of follow-up and diagnosis for other conditions diagnosed in early childhood

I will now review the studies I collected which explore parents’ experiences and view of follow-up and diagnosis of a range of conditions in their young children or infants.

Similarly to part three of this literature review, some studies retrieved from database searches only provide insight into parents’ reactions to being given a diagnosis, such as how they feel about the diagnosis itself, rather than their views of the way it was given. Hamilton (193) aimed to explore cultural differences in receiving a diagnosis of neurodevelopmental delay, by studying a small purposive sampled cohort of Aboriginal and non-Aboriginal caregivers of infants diagnosed with neurodevelopmental delay or foetal alcohol spectrum disorder in Australia. Caregivers’ responses were found to be mixed: some described being unsurprised by the diagnosis as it did not tell them anything new, but just confirmed their own observations of their child; one mother felt the diagnosis was positive as it provided her with new information; another mother was visibly upset by the diagnosis (193). Klein (194) produced similar findings, from analysis of interviews with 18 parents about their perceptions of receiving a diagnosis of autism spectrum disorder (ASD) or global developmental delay in their infant: some parents expected the diagnosis as they felt it was simply a confirmation of what they already knew, whereas others did not, and found it overwhelming, describing that their feelings [were] ‘still raw’ (194). DeLuca (195) used longitudinal interviewing to explore the perceptions of a diverse sample of parents regarding the experience of their baby undergoing newborn screening in the USA. Qualitative content analysis of these interviews found that some of these parents described feeling shocked due to receiving abnormal results from screening and underwent what they described to be an ‘urgent and often frustrating’ process of searching for information. The researchers also found that the parents reported inaccurate ideas about the disorders despite exposure to ‘large amounts of information’, suggesting parents may not have understood the information they were given, or had not been able to take it in at the time it was provided (195).

Other studies present findings which shed light on parents’ views of the way that a diagnosis is provided in their child. Jashar (196) conducted a mixed methods study to explore parents’ satisfaction with a neurodevelopmental evaluation conducted on their infants who were high risk of autism, which was used to give a same-day diagnosis. Qualitative findings included parents describing their appreciation when a diagnosis was given in a direct, concrete and honest manner and the clinician being patient, sensitive and friendly (196). Klein (194) found that some parents, when interviewed about the experience of their infant being diagnosed with autism spectrum disorder or global developmental delay described the diagnostic assessment process as ‘emotional and anxiety provoking,’ and explained this as being due to receiving little prior information about what the process would involve. Russ (197) asked parents to complete a semi-structured questionnaire shortly after their infant was diagnosed with permanent congenital hearing loss, to explore their experiences of receiving this diagnosis. Two-thirds of parents who were asked to complete this questionnaire, did so. The findings showed that some of these parents felt shocked and frustrated due to delays in receiving the diagnosis and communication difficulties with professionals. Parents’ views of screening for congenital hearing loss were also collected, and the findings showed that the parents of one child had received a false negative result, and that they found this experience distressing (197).

Smith (198) gained some limited insight into 50 Irish parents’ experiences with diagnosis of their baby with Down’s syndrome through quantitative surveys. Only 8% of parents who completed the survey reported having a discussion with a professional about Down’s syndrome antenatally, 42% felt they were provided with too little information when given the diagnosis and 38% of parents felt their first discussion of the diagnosis was ‘negative/very negative’ (198). Sices (199) achieved a more in-depth findings by conducting focus groups with a large sample of mothers in the USA, exploring their preferences during conversations with healthcare professionals about their child’s developmental delay. Thematic analysis, conducted by multiple researchers, found that mothers’ preferences differed: most mothers expressed their preference for what the study refers to as a ‘non-alarmist’ style of communication when developmental delays are suspected; however, some preferred a more direct style, including professionals using medical labels to help them understand their child’s development.(199) Cunningham (200) conducted interview surveys with the parents of 59 infants who had been diagnosed with Down's syndrome in the UK between one week and eight months previously. From quantitative analysis of the findings, these researchers report that some parents in interview surveys reported positive views of receiving the diagnosis from a healthcare professional they already knew well. Almost all parents were in couples, and many reported their preference to receive the diagnosis together, rather than it be given to only one parent (200).

Some studies explored how parents' general experiences around the time of receiving a diagnosis in their young child could be improved. Rahi (201) conducted a mixed methods study exploring the views of a large sample of parents regarding a service run by professionals in London, UK, which aimed to meet parents' needs around the time of diagnosis of visual impairment in their child at around two years old. In the qualitative component of the study, a purposive sample of parents were interviewed, and during this reported that the service benefitted them during the time of diagnosis by providing emotional and information support through discussions with professionals and helped them to access further services through this such as referrals and benefit services (201).

Conclusion to part four

As there are only a handful of papers which discuss parents' experiences of follow-up for and diagnosis of cerebral palsy, these studies provide a useful 'wider picture' of the research that has been conducted into parents' experiences and views of follow-up and diagnosis of a range of disorders in their young child. As most studies in this literature review have explored parents' experiences of communication with healthcare professionals about their child, many studies in this part of the literature review draw parallels to findings in studies in parts two and three. However, as the findings from these studies can not necessarily be transferred to other study settings and populations, the gaps, previously discussed in this chapter, remain.

2.6. Conclusion

Many studies have been conducted exploring parents' experiences around the time of follow-up and diagnosis of cerebral palsy in their high-risk infant. It is important to note that the term 'parents' is often used to report on studies that primarily, and sometimes solely, report on mothers' perspectives and experiences.

The topic of parents' experiences with a neurodevelopmentally "at-risk" infant staying in an NICU has been particularly thoroughly researched, and provides a solid evidence base, however it largely focuses on general experiences during the NICU stay, rather than development specifically. A smaller number of studies have been conducted exploring parents' experiences with follow-up for their high-risk infant, including experiences of developmental assessments, and parents' experiences receiving a diagnosis of cerebral palsy in their high-risk infant. Whilst the 'wider picture' provided by studies reporting parents' experiences of follow-up and diagnosis of other disorders in their young child is useful, it does not fill the gaps that currently exist. Only one qualitative study has been conducted which provides an in-depth insight into parents' experiences during follow-up, using the GMA and HINE, and receiving a diagnosis of cerebral palsy following this. However, this study took a deductive approach, preventing issues that are experienced by parents but were not anticipated by the researchers from being uncovered in the analysis, and this study was also conducted outside of the UK. There is a gap in the current evidence base for a study that provides an in-depth understanding regarding the way parents conceptualise their infants' developmental risk whilst in the NICU. There is also a gap in the literature for a study in the UK that takes an inductive approach and provides an in-depth insight into parents' views and experiences during early neurodevelopmental follow-up and diagnosis of cerebral palsy in their high-risk infants, using the HINE and GMA. This research is required to inform healthcare providers about how they can improve this process for parents.

Additionally, previous research has often collected parents' accounts of events and experiences with their infant that happened several years previously, limiting the evidence that currently exists reporting parents' experiences and perspectives gathered close to the time of such experiences. This is relevant, as qualitative accounts from parents differ depending on the time point that they are collected in, and so a study that collects parents' experiences and perspectives close to the time that early neurodevelopmental follow-up and diagnosis of cerebral palsy occur would be valuable.

Chapter three

Methodology and study methods

3.1. Introduction

In this chapter I will discuss the various methodological approaches and study methods available to use for this research. During this, I will evaluate the opportunities and challenges that different methods and approaches present, and their appropriateness for this research. I will also describe the decision-making processes that led to development of the study design for this research, and a detailed description of this study design including the methodological approach, fieldwork, sampling and recruiting methods, study settings and set up, ethical considerations, data collection procedures and analytical approach. This will make it clear how this research was designed and carried out, and why it will be done in this way. Reflexive remarks will also be made, discussing my positionality and how this may have influenced the research.

3.2. Methodological approach

3.2.1. Importance of defining a methodological approach

To establish the methodological approach I would use to underpin this research, I began by questioning ‘how do I see the world?’, ‘what is the reality that I am studying?’, and ‘what is the nature of this reality?’ (202). Through defining how I see the world, and the assumptions I made when approaching this research, I could determine how it should be studied. This then influenced the way I conducted this research (203).

By identifying my methodological approach, this also allows the reader to understand this, to then critique the research and make use of its results (12).

3.2.2. Positivist vs interpretivist paradigms

Qualitative and quantitative research methods are often considered dichotomic, as they generally represent two opposing paradigms (204). The paradigm usually associated with quantitative research is positivism (12). The ontological stance here is that there is a stable, constant reality ‘out there’ which can be studied objectively (205). Empiricism is a key idea of positivism: the idea that only phenomena which can be studied through observation can be counted as knowledge (12). In positivist research, data is ‘objective’, and the researcher attempts to distance themselves from any influences which might create bias - this being anything causing deviation from studying the single, fixed reality (12, 205). This produces what positivists call ‘value-free inquiry’, meaning that this observed data is held as objective, rational and neutral (205).

Interpretivism, the paradigm often associated with qualitative research, is described as opposing positivist ideas. It was first developed by Immanuel Kant (1724-1804) who argued that there are ways of knowing about the world other than direct observation. He said perception relates not only to the senses but also to human interpretations of what our senses tell us, and knowledge of the world is based on subjective 'understanding' which arises from thinking about what happens to us, not just simply from having had particular experiences (12, 206). Theorists argue that interpretivism is more suitable for the study of social phenomena because of the complexity of these phenomena (205).

3.2.3. Selecting an interpretivist, qualitative approach

I chose to locate my approach to this research within the interpretivist paradigm as I felt this was best suited to the study aims - to explore the views and experiences of individuals. Through my belief that people interact with their worlds and produce a subjective interpreted ‘reality’, resulting in multiple realities, rather than a single, fixed, external reality, I feel an interpretivist paradigm is appropriate. Within this research topic, there are clearly many complex, interpreted variables at play, which cannot be controlled or measured objectively, making a positivist epistemology unsuitable (13). Parents’ and carers’ experiences are not visible in a naturally occurring form which can be ‘observed’ experimentally. Instead, these experiences were brought out by means of language and conversation, in order to be understood.

Whilst qualitative research is often viewed as less important than quantitative research due to some fundamental differences between the two approaches, it is clearly vital to explore complex phenomena which are not amenable to counting or measuring, such as those in this study (11, 207). Qualitative methods can access complex phenomena, such as the meaning people ascribe to their experiences and why people have particular views, as well as many everyday questions in healthcare, in ways that quantitative research cannot (204, 207, 208). Because of the growing complexity of healthcare systems, use of qualitative methods in healthcare research is becoming increasingly important (15). Studies researching healthcare service quality, such as this one, can no longer be done only through monitoring and counting variables, but also requires exploration of attitudes, meanings and experiences associated with healthcare services, enabling a broader and deeper understanding (15, 209). Parents’ views and experiences cannot be studied in their full complexity by simply counting how many people had certain views or experiences, as in a quantitative study (11). Whilst quantitative surveys can obtain some data regarding the experiences and views of participants, they are criticised as over-simplifying individual’s experiences through production of aggregate data, and so would not have allowed a full understanding of the phenomenon studied in this research (13).

A qualitative approach was highly appropriate to use for this study as its aims and approaches fit well with those of this research. Like this study, qualitative research aims to understand the complexity of people's experiences and to generate knowledge grounded in human experience (16). Additionally, this study and qualitative methods both aim to give emphasis to meaning, views and experiences from the point of view of those involved and understanding how these individuals interpret, experience and make sense of social phenomena (15, 207, 208). Qualitative methods can give insight into various issues in healthcare, such as attitudes and beliefs to health, living with and managing disease, and factors affecting access to healthcare (16, 204). My aim for this study was to explore parents' views and experiences with all these issues, particularly those relating to their baby undergoing early neurodevelopmental follow-up. Qualitative methods are also able to help me in reaching my end-goal to provide healthcare professionals with a means of tailoring their service to the needs of parents with infants at risk of cerebral palsy in Liverpool. This is due to their ability to give insight into the process of policy implementation; identifying where and why implementation is successful, uncovering implementation issues and suggesting solutions (15).

3.2.4. Selecting an inductive approach

Because of the complex nature of social phenomena, when researchers invite people to talk about their experiences, they can learn more than they initially expected (204). This was the case in this study: some aspects of parents' experiences, or factors affecting their experiences, could be predicted, but others were unknown. Therefore, an inductive approach was appropriate to gain an understanding of these experiences through this research. A deductive approach whereby a hypothesis is formulated and tested would not have been appropriate for this research as, for this, all the factors affecting parents' experiences must have been known in advance, which was not the case.

3.2.5. Qualitative traditions

Within qualitative research, there are several traditions or methodologies. I will now discuss a few of these, however there are many others which are outside the scope of this thesis.

Phenomenology

Phenomenology was established by the German philosopher, Edmund Husserl (1859-1938) (210, 211). This overlaps with many interpretivist ideas, where phenomena are seen as socially produced through the interpretative process of interaction of an individual with their world (206). Husserl argued that all objects in the external world are subject to the act of perception, so cannot exist independently of an individual’s consciousness (205, 212). In order to understand the ‘essence’ of these objects, one has to understand how the ‘everyday world which we experience and take for granted’ (the ‘life-world’) is directly experienced, in other words, how objects are subjectively perceived and experienced (205).

Alfred Schutz (1899-1959), a German sociologist, is associated with bringing Husserl’s philosophical ideas into sociology. He focused on the ways in which the ‘life-world’ was actively constituted by ‘members’ - social actors within this world (205). The focus of phenomenological research is to understand how people experience and ascribe meaning to their world, from the perspective of those experiencing it (11, 202, 213). Both Husserl and Schutz followed the idea of the researcher ‘bracketing off’ their personal judgements and assumptions, to gain insight into direct experience of phenomena (205).

Social constructivism

Social constructionism offers another approach to understanding the world. Introduced into the social sciences by Peter Berger and Thomas Luckmann, the key belief underpinning this is that reality is socially constructed (214). Therefore, the focus is on analysing and understanding how phenomena are socially constructed (205, 214). Ideas which commonly concern a researcher undertaking the social constructionist approach are ‘what are the different varieties of knowledge?’, and ‘what are the processes by which any of this knowledge comes to be socially established as reality?’. In this approach, reality and knowledge of everyday life are seen to vary depending on the specific social context (214).

Pragmatism

As methods have evolved, researchers have begun to take a more pragmatic approach to research, subsiding the opposing epistemological underpinnings of qualitative and quantitative methods and selecting that which allows the most effective exploration of a research question (207). The argument for this is to allow selection of the most appropriate design for the research, whereas a purist approach to epistemology may prevent this (12). Challenging this dichotomy between qualitative and quantitative methods, in favour of pragmatism, has led to introduction of ‘mixed-methods’ studies which use both methods in combination. This remains an area of ongoing controversy (203, 204). Ritchie (12) with her background in psychology and policy research adopts this pragmatic approach to undertaking social research, with the aim to produce rigorously collected and analysed data that can support wider inference (12).

3.2.6. Selecting a pragmatic approach

The goal of this research was to understand the knowledge and experiences parents and carers have regarding the process which identifies cerebral palsy in high-risk infants in Liverpool, to identify ways that this can be improved for parents and carers. This goal fits with the pragmatic approach taken to research for policy purposes by Ritchie (12) where the aim is to produce rigorous, valid evidence and outcomes for service delivery. In terms of ontology and epistemology, I proposed to adopt the pragmatic approach described by Ritchie (12), 'borrowing' from different qualitative traditions. As discussed above, I located this approach within the interpretivist tradition for the purposes of this research.

My decision to adopt this pragmatic, interpretivist approach had implications for the nature of inquiry in this study. Different parents and carers have different experiences, views and perspectives, based on their unique context, and their interactions with the NICU and its healthcare staff, other parents and their own families. Therefore, exploring the views and experiences of a range of parents, using my approach taken, was valuable in providing insight into the different 'realities' that exist and the different ways that parents experience the phenomenon studied. Parents of a high-risk infant are 'experts by experience' as they hold a level of knowledge of the process of early neurodevelopmental follow-up which is heavily rooted in their direct experience of this (215). This level of knowledge was accessed through the data collection.

A comment on reflectivity

Although I aimed to produce research located in the worlds of the individuals I interviewed, I recognised that my own background and beliefs would influence the research to some extent (12). To counteract the possible effects of this I ensured two things. Firstly, transparency throughout this entire research process, by providing a clear, detailed account of the planning, decision-making and conducting of all stages of this research within this thesis. Secondly, I undertook reflexivity throughout the research process, by identifying my presumptions and beliefs, reflecting on these and considering how my influence on the research could be minimised. These reflexive remarks are provided in section 3.10 of this chapter.

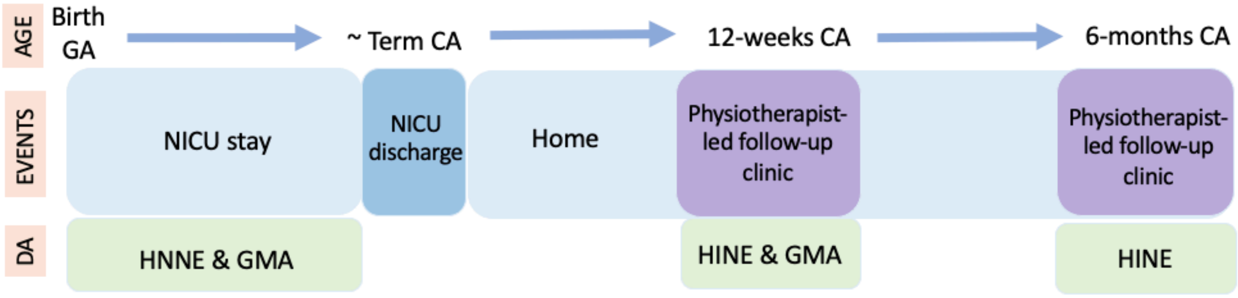
In the next section I will begin to describe the way in which this study was set up.

3.3. Study set up and approvals

3.3.1. *Study settings*

This study was based at the LWH in Liverpool, UK. This is a tertiary hospital which admits over 1,000 babies per year, from various locations across the country, in need of specialist neonatal care (216). A physiotherapist-led clinic was recently introduced at this hospital and is currently being piloted within the follow-up services that the LWH provides for developmentally at-risk infants discharged from the LWH NICU. Infants are eligible for this physiotherapist-led clinic if they are considered 'high risk' of neurodevelopmental disorders, due to being born either before 28 weeks gestational age, or after 28 weeks with one of the following: grade 2 or 3 Hypoxic Ischaemic Encephalopathy in the neonatal period, a brain lesion on neuroimaging likely to be associated with developmental problems or disorders, neonatal stroke, neonatal bacterial meningitis, or herpes simplex encephalitis in the neonatal period. As the clinic is currently being run as a pilot by a single physiotherapist, the capacity is limited and only families living in the Liverpool and Sefton areas are currently being invited.

Parents and carers are invited to an appointment at the clinic with their baby at 12 weeks' corrected age and again at 6 months of age. At 12 weeks the HINE and GMA are performed, and at 6 months, HINE is repeated. Additionally, before attending this clinic, whilst inpatients on the NICU, high-risk babies are assessed with the Hammersmith Neonatal Neurological Examination (HNNE) and GMA and parents are provided with information about their baby's development (**Figure 11)**.



GMA = general movements assessment, HINE = Hammersmith infant neurological examination,
GA = gestational age, CA = corrected age, DA = developmental assessments

Figure 11: Diagram showing the timing of new physiotherapist-led early neurodevelopmental follow-up and assessments within infants' NICU stay and discharge home

3.3.2. Study approvals

I applied for sponsorship from the University of Liverpool and received confirmation of this on 5th August 2020 (Sponsor ID: UoL001556 7880). I then submitted my application for ethical approval from the Liverpool central research ethics committee on 19th October 2020 (IRAS project ID: 285643) and after one re-submission of the application with amendments on 4th December, received a favourable opinion on 10th December 2020. Details of the ethical considerations made throughout this study can be found in section 3.7 of this chapter. The study received approval from the Health Research Authority (HRA) and Health and Care Research Wale (HCRW) on 23rd December 2020 (see Appendix F). Permission to proceed with recruitment from the sponsor was then achieved on 2nd February 2021.

3.4. Selecting fieldwork methods

Data produced by qualitative methods can be divided into two types: naturally occurring data, which exists in a naturally occurring form that can be directly accessed, such as within or by observational methods, and generated data, which must be generated through language or other means, to be accessed (12). As previously discussed, this study aimed to collect parents' views and which are not visible in a naturally occurring form which can be 'observed' but must instead be 'generated' through language and conversation between the researcher and parent, in order to be 'seen' and understood. Therefore, this study collected generated data, consisting of a verbal recounting of parents' and carers' experiences.

3.4.1. Generated data

Interviews and focus groups are the most common methods of data collection in qualitative research (217). They are especially helpful in allowing assess to views service users have of healthcare services (15), as this study aimed to do.

3.4.1.1. Interviews

Qualitative interviews are a powerful method for data-collection and can be used in a range of methodological approaches (218). They allow researchers the opportunity to explore the views, experiences and beliefs of individuals and gain a detailed understanding of how phenomena are experienced (217). Individual interviews are particularly appropriate for exploring sensitive topics, where participants may not want to talk about such issues in a group environment (217). It is important to note that these only give access to an account of participants' experiences, constructed through language, not the direct experiences themselves (219).

Although qualitative interviews can vary in their level of structure (which will shortly be discussed), most are open-ended and flexible in nature. This does not mean that they are unstructured, but that the structure of the interview is shaped as it is being conducted, as the researcher listens to and analyses the participant's responses (220).

Types of interviews

There are different types of qualitative interview. Two types are semi-structured interviews and in-depth interviews (15, 205). Other authors refer to structured, semi-structured and open or unstructured interviews(218, 221), and terms are not always used consistently - what some authors consider a semi-structured to be, others may consider in-depth (12). The different categories of interviews also overlap, creating a continuum, from the most exploratory, open, unstructured interviews where the participant's narrative is followed entirely, to the most fixed, structured interview where a pre-determined list of questions is asked in the exact same way to each participant (12, 215, 219).

The most structured interviews are relatively quick and easy to administer. However, they only allow for limited responses from participants, and take a deductive approach as there is no scope for probing or follow-up questions (217), so would not be suitable for this research. The most unstructured interviews are performed with no preconceived ideas or theories and no topic guide, but simply begin with an opening question, and then progress based, mainly, upon the initial response (215, 217). These are time consuming, and the lack of predetermined questions may mean that participants feel unguided and confused on what to talk about (217), so I feel these would not be the most appropriate method for this study.

Semi-structured interviews

Semi-structured interviews balance standardisation of questions with flexibility, usually based on a topic guide with pre-determined, open-ended questions that are asked by the interviewer in the same way each time (222). They have some scope for follow-up questions to participants' responses, allowing the discovery of information that is important to participants but may not have been previously considered by the researchers (223). When the aim of the research is to focus on a specific area, rather than explore individuals' experiences holistically, or when there are a very large number of participants, these are a highly appropriate method and can make analysis more manageable (223). However, they allow less flexibility and probing by the interviewer compared to in-depth interviews (12).

In-depth interviews

In-depth interviews also involve open-ended questions but have less structure than semi-structured interviews and allow a greater degree of flexibility to understand participants' experiences or views in greater depth and detail (221). Probing questions are used more extensively, to gain additional elaboration and clarification about participants' responses and questions do not need to be phrased in the same way or asked in the same order to each interviewee (12, 224). This allows greater opportunity for issues which are important to the participant, but which the researcher may not have previously contemplated, to be uncovered and explored (205). These qualities also mean that in-depth interviews allow more detailed exploration of participants' experiences and views than semi-structured interviews.

The method selected for this research

As this research aimed to gain an understanding of parents' views and experiences through a method that allows collection of rich, descriptive data and involves exploring the phenomenon through language, I decided that in-depth interviewing would be most appropriate as my primary data collection method. I felt in-depth interviews were more appropriate to use than semi-structured interviews because they would allow a more inductive, flexible approach, and allow me to gain greater depth from participants about their views and experiences, to help fulfil the study objective (15).

3.4.1.2. Focus groups

Focus groups have previously been used successfully with both patients and providers in research aiming to improve the quality of healthcare services (15). Like interviews, they are useful in generating a rich understanding of participants' perspectives and views about social issues and the meaning behind these (217, 225). However, they also allow insight into shared views of phenomena and the way individuals interact with each other as they involve discussion between a group of participants (226). Part of the researcher's role is therefore to encourage discussion between individuals (227). Other parts of their role are to ensure all participants have sufficient opportunity to contribute to the discussion, so that a range of views are heard and preventing one participant's narrative from dominating the discussion (12, 228). Achieving this can be challenging. Rosenthal (224) suggests that novice researchers should not undertake focus groups in a first attempt to conduct qualitative research.

Focus groups can be used as a stand-alone method, or alongside others, as a way of triangulating data (204). For example, performing focus groups after in-depth interviews allows the interview data to be challenged, verified and any incomplete pieces of data to be expanded on or clarified (12, 217). In the context of this study, focus groups appear to offer an opportunity for parents and caregivers to discuss their experiences of the process of identification of cerebral palsy in a group. However, exploring this phenomenon may lead to discussing sensitive issues with participants, and for this, individual interviews are more suitable as participants may feel uncomfortable discussing these in front of a group (12, 224). Additionally, parents whose infants are undergoing early neurodevelopmental follow-up have different levels of understanding regarding the possibility for their infant to be diagnosed with a neurodevelopmental disorder, such as cerebral palsy. Therefore, a focus group discussion would have been inappropriate, as parents may have been shocked or distressed by comments they heard from other parents. On balance, and as this was my first time conducting qualitative research, I decided that focus groups were not the most appropriate method to use.

3.4.1.3. Questionnaires

Questionnaires can be used to collect both quantitative and qualitative data depending on whether closed or open questions are used (229). Qualitative questionnaires using open questions could have been used for this research, however, these would have likely limited the quantity of in-depth data participants provided, and limited my ability to take a flexible approach, probing further into participants' responses to gain enough clarification and detail to allow a complete understanding of their experiences and views. However, questionnaires can be used to generate key demographic data, allowing some understanding of the context to participants' situations (215). Therefore, I proposed to utilise a questionnaire containing structured demographics questions, to collect some key demographic data about participants, to help understand the contexts of their responses and make comparisons between individuals during the analysis stage.

3.4.2. Naturally occurring data

The collection of naturally occurring data such as observational, conversational, discourse and documentary, have produced a whole cadre of research methods (205). These allow everyday behaviour to be analysed without a researcher intervening to create the data, so enable data to show what people actually do, rather than just what they said they do (15, 230). As previously discussed, parents' experiences and views of early neurodevelopmental follow-up are not present in a naturally occurring form, so cannot be collected using these methods alone. However, naturally occurring data can emerge alongside data generated in interviews, consisting of the researcher's observations of participants' physical appearance, non-verbal communication, surroundings if the interview takes place in the participant's home, and the researcher's thoughts and ideas about the interview (215, 225). These can be helpful observations to note down and use during the analysis, for example, in understanding the meaning behind verbal responses through the emotions, mood and character participants display within their physical appearance and non-verbal communication (217). Therefore, I decided to utilise this opportunity, by proposing to record my observations immediately after each interview, in this study.

3.5. Recruitment and sampling methods

3.5.1. Sample size and saturation

Selecting an appropriate sample size in qualitative research is a complex task, but I felt that the most appropriate criterion to guide my decision was saturation (231, 232). Although the concept of saturation is challenged by arguments that further interviews will always provide new insights, and so complete saturation is not a feasible target, I felt that it was a valuable concept to guide my sample size decisions as it would allow my sample to provide enough data to fulfil my research objective (217, 233). It would also demonstrate the breadth of issues highlighted by the findings and allow the work to be considered higher quality (231, 234).

I decided that recruitment of new participants should cease beyond reaching saturation for two reasons: firstly, due to an ethical consideration, which is explained in section 3.7 of this chapter, and secondly, qualitative interviewing very rapidly produces a large quantity of unwieldy data (218). Continuing to interview beyond saturation would produce a greater volume of data to be analysed, with no benefit to the study's findings, as there would be no additional codes or themes produced.

Deciding the exact point at which I would consider my data 'saturated' was challenging, as saturation can be conceptualised in different ways, and there is a lack of specific guidance as few authors state how they assess saturation in their studies (233). After reading various literature on this, I chose to follow guidance by Hennink (231), and aim for two points of saturation: code saturation, the point where no new issues are being identified; and meaning saturation, the point where enough data has been collected to fully understand these issues. I felt reaching meaning saturation was important as it demonstrates the depth required in the data before interviewing could cease (232). Additionally, as recommended by Morse (234) I aimed to continue interviewing until the 'negative cases' - these being perspectives which contradict the main body of current findings – were saturated, so that the range of different views and experiences parents have would be fully explored. However, I expected that the small study population in my study setting and limited time available could limit this. To try and counteract this, I selected a longitudinal study design, and a sampling method which would ensure only parents who had direct experience of the phenomenon being studied were recruited, as these design features can maximise the quantity of relevant data collected from each participant, and so can reduce the number of participants required in the study sample before saturation is reached (235). Both of these design features are explored in greater detail later in this chapter.

Overall, determining my sample size would be a pragmatic exercise (233). The level of saturation that was reached is explained in chapter five.

3.5.2. Qualitative sampling methods

Qualitative researchers aim to produce rich, detailed and holistic representations of phenomena, and so aim to obtain as wide a range of views and perspectives of the phenomenon as possible (15, 231). However, unlike in quantitative research, there is no requirement for this sample to be statically representative of the population from which it was drawn (15, 236). There are various approaches to qualitative sampling. I will now discuss these, and their appropriateness to this study.

Purposive sampling

Purposive sampling is arguably the most important and frequently sampling method in qualitative research (213, 236, 237). It involves deliberately selecting participants who have direct experience of the phenomenon being studied so they can provide data which will shed the most light on this, and be most useful for fulfilling the research objective (13, 213, 215, 217, 224). Participants with particular characteristics such as age, gender and socioeconomic status can be selected if these are believed to enhance these individuals' contributions to the study (213, 237). A purposive sampling framework is often used, containing details of any pre-selected characteristics which the sample must possess. For recruitment using purposive sampling methods to be successful, the study population must be large enough, and accessible enough, so that a sufficient number of participants can be recruited to fill the sampling framework.

Convenience sampling

Convenience sampling involves selecting potential participants simply on the basis that they are the most easily accessible to the researcher (12, 237). This is less expensive and requires less time and effort than other methods (237). However, the individuals who are most available to be interviewed may not be those who can be shed light on the phenomenon being studied, and so the sample produced may lead to poor data. Additionally, this method may exclude individuals who possess certain characteristics that make them less readily available to be interviewed, meaning the views of these individuals are not explored in the study. Because of this, convenience sampling is considered to lack rigour, and potentially damage the credibility of the data (237).

Opportunistic sampling

In this approach, the researcher samples in a flexible way, taking advantage of unforeseen opportunities for data collection during the duration of the fieldwork (12, 237). The sample moulds itself around the fieldwork context as this unfolds and so is most appropriate for exploratory field research where little is known about the research setting (12, 237).

3.5.3. The sampling design in this study

I was aware that the parents in Liverpool with direct experience of early neurodevelopmental follow-up, during the time of my study, were those whose infants were being seen at the new physiotherapist-led follow-up clinic at the LWH. Therefore, these were the parents I aimed to recruit, as they would be the best positioned to provide the most useful data for fulfilling the research objective (215).

Recruiting from this specific group of parents meant that my study population was very small. Because of this, I felt that purposive sampling, with a defined sampling framework, would not be a suitable approach as selecting only individuals with specific characteristics, whilst also aiming to achieve a study sample large enough to achieve saturation (as detailed in section 3.5.1), was unlikely to be feasible. Additionally, selecting appropriate characteristics to have within a sampling framework would have been difficult as I was unaware of the characteristics that would lead to differences in the data. Rather, this is what I aimed to find out. Therefore, I selected a convenience sampling approach. I aimed to recruit every parent whose baby was being invited to a physiotherapist-led follow-up clinic during the data collection period, and who was willing to participate. Despite not defining any specific characteristics which participants must have, the group of participants would be naturally stratified, containing parents with different characteristics (such as various ages, gender and postcode) and with babies who are high risk for different reasons. Whilst convenience sampling has limitations, as discussion in section 3.5.2, it can be a suitable and successful approach in certain circumstances. I felt that in my study setting, with a limited study population size, it was the most appropriate sampling method to use. Here, convenience sampling allowed me to recruit as many parents as possible, helping with my goal to reach saturation.

I proposed to collect basic demographic information for all parents (and their infants) who were approached for this study, to provide a record of who accepted and declined participation in the study. This was to make me aware of any sub-groups who were not included in the study, to highlight any further research that may be needed after this study to gain the perspectives of sub-groups of parents who were not included. This demographic data also allowed me to clearly see who the study findings applied to and who they did not, to help judge the dependability and transferability of the findings (14).

Next, I will give details of how I planned to recruit parents and carers to this study.

3.5.4. Recruiting procedures

When designing recruiting procedures, I focused on making the study appropriate, accessible and convenient for parents, to maximise the number of who agreed to participate. Some matters I considered were the timing of recruitment and the type of communication used to invite potential participants to take part. There were only a limited range of options for the timing of recruitment, as I was interested in exploring the level of understanding parents and carers had of early neurodevelopmental follow-up, and their baby's developmental risk, before attending the 12-week follow-up clinic, meaning parents needed to be recruited before they attended this. The ability to recruit parents face-to-face was also limited by this study taking place during the COVID-19 pandemic, when restrictions were limiting face-to-face interactions in healthcare services.

As most infants are discharged from the NICU around term corrected age, around three months before they attend a 12-week follow-up clinic, parents and carers would most likely be living at home with their infant at the time they were invited to take part in the study. Therefore, I planned for my study recruiters to contact eligible parents and carers by phone, or alternatively face-to-face providing a recruiter happened to have contact with an eligible parent or carer in-person, for reasons outside of this study. I believed inviting parents and carers to take part face-to-face could be more successful in recruiting parents than telephone invitations, but this was made challenging by parents being at home with their baby at this time, rather than in the NICU, and because of the COVID-19 restrictions in place.

I designed a participant information sheet (Appendix A) to inform parents and carers about the study and prepare them for interviews (12, 238). As planned, this participant information sheet was provided to all parents and carers by a recruiter when invited to take part in the study. If a parent or carer was happy to be contacted at this point, their phone number was passed on to me by the recruiter, and I contacted them to ask whether they would like to participate. The decision to use recruiters to first introduce the study to parents and carers was due to an ethical consideration, explained in section 3.7 of this chapter.

I planned to contact each parent or carer up to three times, as beyond this I could risk annoying or harassing them. To maximise the likelihood that parents would answer my call, I planned to phone at different times of day and on different days of the week (e.g both during and outside of standard working hours) each time I attempted to contact them. I also prepared a script for leaving messages on answerphone, which included providing information about who I was, why I was calling and when I would next attempt to contact them (239). Fortunately, parents usually answered my call on the first, or if not second, attempt.

3.6. Designing fieldwork methods

3.6.1. Content of the interviews

The aim of interviews in this study were to understand the knowledge, views and experiences parents and caregivers have of the process of early neurodevelopmental follow-up for their high-risk infants, and the information and support they have received during this time, relating to this follow-up and their infants' development. Therefore, open-ended questions posed to participants in interviews related to this subject. I aimed to understand not only the information that parents and carers had received, but also their subjective understanding of this information, through their interpretation of it. Following my inductive approach, I also planned to allow participants to bring up issues which they felt were important to them, relating to the research topic,

3.6.2. Location of interviews

Due to COVID-19 restrictions, interviews had to take place virtually. I planned that this would either be over the phone or using the online communication platform 'Zoom', until restrictions lifted. Whilst the interview location was pre-decided due to COVID-19 restrictions, it was still important that I reflected on and considered the ways that this location might help or hinder open, in-depth discussion during interviews.

One challenge of remote interviewing is that it is more difficult to establish rapport, particularly where the interviewer and interviewee cannot see each other, such as in telephone interviews (239). Therefore, I planned to make use of other opportunities to develop rapport. The participant information sheet would allow participants to develop a level of trust through understanding who I am and what the purpose of the study was, and at least one phone conversation would take place during the recruiting and consenting process (218). These would allow some initial rapport to develop before the first interview. I would develop further rapport through some informal conversation at the beginning of each interview. Where it was the participants' preference, interviews would take place over an online communication platform using webcams, allowing parents and I to see each other, which would also help to develop rapport.

'Zoom' has been widely used in previous research and found to be a successful medium for qualitative interviews (240, 241). As the University of Liverpool's recommended online communication platform, I have access to calls of unlimited length, allowing the length of interviews conducted using this platform to be unrestricted. 'Zoom' also has the benefit over some other online communication platforms such as not requiring participants to have an account to take part in a call, which may make it appear more convenient and appealing to participants. Therefore, I chose 'Zoom' as the online communication platform that interviews would take place on if parents opted for this, over a phone interview.

If participants opted for a telephone interview, it would not be possible to develop rapport through the participant and I being able to see each other, or for me to make observations about physical appearance or non-verbal communication to aid interpretation of verbal responses. In the past telephone in-depth interviews have been criticised for these reasons (242). However, there is currently little evidence to show that the interpretation and quality of data collected over the phone is different to that collected in-person (243). Where I cannot respond to visual cues, there may instead be instances where I can respond to both their narrative or and tone of voice instead (239). I felt that as not all participants may have access to the technology for an interview using 'Zoom', it was important to provide the option for a telephone interview to make the study more accessible to a wider range of individuals (244).

Interviews were conducted at times that were most suitable for participants (217). Remote interviewing also made it easier for interviews to be convenient for participants, as there was no requirement to travel to any location for a face-to-face interview (245). As this research was my primary commitment during this year, I had a flexible and fairly free schedule with concern to interviewing and could be available at almost any time that a participant wanted to be interviewed. These design features may have helped maximise recruitment, which was particularly important in this study as the population was very small.

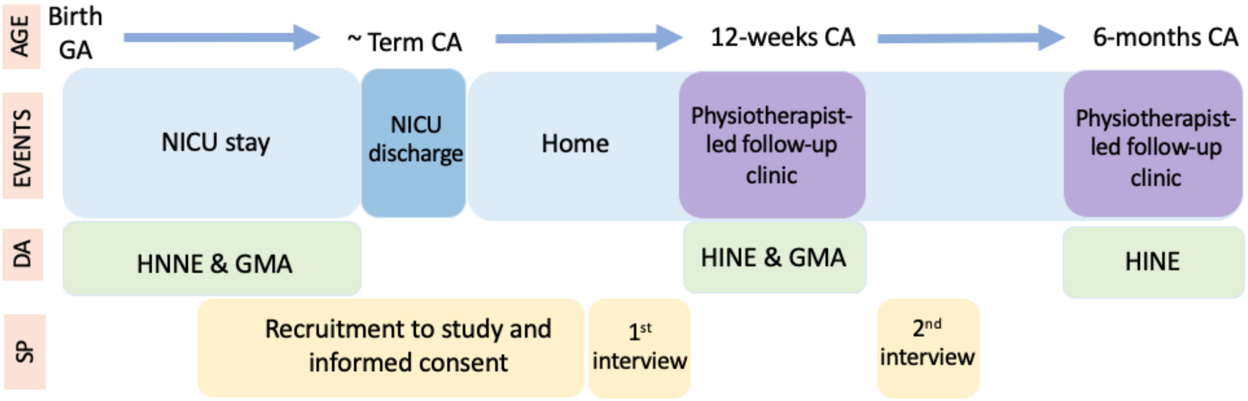
However, conducting remote interviews reduced my control over interruptions during interview, such as by the participant's household members, pets, or their doorbell ringing, if the participant was at home during the interview. On the other hand, the familiarity of this location may have helped participants to feel relaxed and speak more openly (217). To reduce the likelihood of interruptions and minimise background noise which could disrupt the audio recording, I suggested that participants selected a time when they were unlikely to be interrupted, if possible, when arranging interviews.

If there came a point where restrictions on face-to-face interviewing was lifted, parents and carers would have the option to participate in interviews face-to-face. These would be in a quiet, private room at either the LWH, AHCH, or a community clinic, depending on the participants' preference. However, the option of virtual interview would still always be provided, as some participants may be shielding, isolating or vulnerable due to COVID-19 or may simply prefer this.

3.6.3. Timing of interviews and longitudinal design

I chose to conduct longitudinal interviews as they presented several advantages. They allowed me to obtain maximum insight as I could re-visit topics which were not covered, or not fully explored in the first interview and gain additional data (215). This was particularly helpful as I was exploring potentially sensitive topics (13) and as I was a novice interviewer, so my inexperience may have limited my ability to gain sufficient detail and depth from a participant in only a single interview. Longitudinal interviewing also allowed extra opportunity for rapport and trust to develop between parents and I, aiding the collection of data (205, 215, 217). They also allowed me to draw maximum benefit from the iterative approach to data collection and analysis, as initial coding of the first interview transcript often highlighted topics which needed further clarification or explanation and this could be done in the second interview.

I planned that the first interview would take place with each participant within the couple of weeks leading up to their physiotherapist-led 12-week follow-up clinic, as I was interested in gaining insight into parents' level of understanding of neurodevelopmental follow-up and their infants' neurodevelopmental risk, and expectations for the 12-week follow up at this point. Here, I would also explore their experiences on the NICU with brain scans and developmental assessments for their infants which are the earliest stages of the process of early identification of cerebral palsy. I planned that the second interview would be arranged to take place within a couple of weeks of each participant attending the 12-week follow-up clinic, to explore their experiences of this clinic and the assessments performed here. I would also ask parents to reflect on their earlier experiences in the NICU in the second interview, to explore whether, and how, these had changed. **Figure 12** shows how recruitment to the study and interviews were planned in relation to infants' NICU stay and physiotherapist-led follow-up clinics.



GMA = general movements assessment, HINE = Hammersmith infant neurological examination,
GA = gestational age, CA = corrected age, DA = developmental assessments, SP = study procedures

Figure 12: Diagram showing how recruitment and interviews were planned to take place around the infants' NICU stay and physiotherapist-led follow up clinics

3.6.4. Interview structure and topic guides

For this study, I designed one topic guide for the first interview and another for the second interview. Next, I carefully constructed these, considering the research objective and methods being used (218, 224).

I carefully selected questions which I considered likely to generate responses relevant to the research topic, to help to fulfil the study objectives (217). To be appropriate and achieve high-quality data, I designed questions that were open-ended, sensitive and neutral (221). I avoided leading questions to encourage participants to give responses that reflected their own views (12, 205). In addition, I considered the level of knowledge of participants and designed questions based on this, so that participants would be able to understand them (221). To aid this, I asked a colleague who was unfamiliar with the topic area to read my proposed questions and provide feedback on the language used (224).

I began interviews by using orienting statements to remind participants of the research aim and the topics to focus on (239). I also reminded participants of the procedures for anonymity and confidentiality, to encourage them to feel comfortable giving honest and open responses (217). Consent was also regained here, verbally, and participants were given the opportunity to ask any questions they had. Next, I moved on to the first interview question. I chose to begin with questions that were easy to answer, to ease participants into the discussion (12, 221). For the first interview, I asked some demographic questions to fill in the structured questionnaire. Next, I moved the conversation to the topic of early neurodevelopmental follow-up by asking an initial open question. Following this, questions on the topic guide were covered in a flexible order depending on the interviewee's responses, so that the conversation flowed naturally (219, 221). Initial responses to questions were explored in detail, through follow-up questions and probes. The same was also done for issues the participants brought up that I did not anticipate, reflecting the inductive approach taken to this research (221).

I also carefully considered the way that I would end the interviews (12). After I felt all questions and issues had been covered in sufficient depth, I asked the participant if there was anything else they would like to add. This was to allow the participant to bring up issues important to them, but which were not covered in the topic guide (217). Again, reflecting the inductive approach taken. After the interview, I thanked participants for their time and for sharing their perspectives and provided a 'debrief sheet' which reiterated my thanks and contained contact details for the research team and support services which they could access if they wished (217).

As topic guides can vary in their length and amount of structure and detail, I carefully designed mine to be appropriate for the in-depth style of interviews I was using (221). As I am a novice qualitative researcher, I felt that the semi-structured style topic guides often used in medical research (218), containing around ten open-ended questions and prompts, would be most appropriate, to assist me in gaining greater depth and detail from participants (215). Having lots of probes and follow-up questions to choose from on the topic guide was particularly useful to me as a novice interviewer, whereas a more skilled interviewer may have been able to come up with these themselves. This level of detail on the topics guides was also helpful in preparing me for interviewing participants who were particularly reticent. So that the topics and questions asked about in interviews are clear to readers, the topic guides can be found in Appendix E.

3.6.5. Interview training and preparation

Interview training

As I am a novice interviewer, it was crucial that I undertook sufficient training to develop the skills necessary to conduct successful interviews and obtain high quality data (239). I attended a two-day in-depth interviewing course, read a variety of literature containing advice on in-depth qualitative interviewing and conducted two pilot interviews to prepare me for interviews.

Whilst working on this project, I experienced the steep learning curve which many researchers undergo when they initially encounter qualitative interviews (218). Skills I learnt about and tried to adopt included sensitivity to the participants' body language and tone, active listening and asking follow-up questions (204, 217, 219). I learnt that a conversational, open dialogue would help participants to feel comfortable and speak freely (218, 224). I also learnt the importance of encouraging participants to provide detailed responses through use of tones, words and silence, as well as reassuring interviewees about the content and quality of their responses, and maintaining an accepting, non-judgemental tone (205, 217, 218, 239). In addition, I learnt the important of remaining aware of the flow of discussion and how the participant was reacting to questions to tailor further questions appropriately (221, 224). I also learnt to avoid interrupting participants but instead allow silence to be a 'catalyst' for encouraging further responses from participants (218). These skills all demonstrate responsiveness to the interviewee's responses and concerns and are essential to encourage a positive interviewer-interviewee relationship and collection of rich, detailed data (204, 218, 239).

Pilot interviews and revision of topic guides

I conducted two pilot interviews with parents. These were highly useful and essential for preparing me for conducting the 'proper' interviews (12). They helped me to become familiar with my topic guides, so that when later interviews were conducted, my questions appeared more natural and fluent (217). I was able to trial the different ways that questions on the topic guide could be asked, and the responses these could give (218). Reflecting on this afterwards, I assessed the comprehensiveness and appropriateness of the topics and questions included in the topic guide, highlighted any poorly phrased questions, and then refined these (12, 205, 217, 218). Pilot interviews also allowed me to practise my interview skills and I reflected critically on these afterwards to help me develop and improve these (218, 219). I noted initial pitfalls in my interviewing technique and considered how these could be fixed or improved. Piloting also gave an idea of how much discussion can be had within the 45 minutes to one hour of designated interview time. All of this contributed towards assisting the production of rich, in-depth data in later interviews that was relevant for fulfilling the research objective (205, 239). Reflections during this piloting stage were documented as 'fieldnotes' to keep a transparent record of this process (246).

One challenge which novice interviewers are presented with is the lack of guidelines available for conducting qualitative interviews (218). However, I feel that the pilot interviews and interviewing course I attended provided me with substantial guidance and experience about the ways in which I could interview, what data this might lead to, and therefore how I might adjust my interviewing technique and improve my interviewing skills to improve the quality of my data.

3.6.6. Recording and transcribing interviews

All interviews were audio recorded and transcribed verbatim (11, 217, 224). This was useful as it allowed the exact language used by participants to be studied. As in other parts of the research process, my influence on the transcribing process was unavoidable as whilst transcribing, I made decisions about what I considered ‘data’ and interpreted the audio-recorded sounds into words (247). The relatively naturalised approach I selected for transcribing also influenced the transcripts produced as I included all significant pauses, giggles and other cues as these can assist the data analysis (11, 218, 247). My approach was not a purely naturalised one as I did include punctuation where necessary, to make the transcripts readable, however, this was done with care, to ensure the meaning of responses was not altered by the way it was written.

Transcription took place as soon as possible after each interview, so that analysis could begin promptly (218). Lines on the transcripts were numbered to aid discussion of transcripts with the research team (11). A Dictaphone was used to audio record the interviews. This was tested before any interview to ensure it was working correctly, and the recording was checked immediately after each interview, to ensure adequate data capture (12, 224).

3.6.7. Structured demographics questions

I asked some key demographic questions at the start of interviews with each participant to give me a better idea of the participants’ personal context and background, allowing me to better understand their perspectives and probe effectively. The demographic questions were determined in advance, when setting up the study. A copy of these can be found in Appendix C. I kept these questions to a minimum as this type of question can be interpreted as boring and potentially insulting by participants (224).

3.6.8. Fieldnotes

As planned, I documented my comments on aspects of the interviews which could not be captured by the audio recording, such as my observations of the interviewee’s tone of voice, mood and the interview atmosphere as fieldnotes (11). These were helped in providing additional context to the interview transcripts during analysis (11, 217). I also noted my initial comments about areas which I did not manage to probe into sufficiently in the first interview with each participant and referred back to these when preparing for the second interview with each participant, to guide me in areas in which I should seek further clarification or elaboration. I made these notes immediately after each interview, whilst the interview encounter was still fresh in my mind. I did not make these fieldnotes during interviews as this could have been distracting for both myself and the participant and disrupt the flow of conversation (12, 224).

3.7. Ethical considerations

Throughout this study I considered the ethical implications of each decision I made and action I took. Next, I will discuss these.

3.7.1. Ethical considerations during recruitment and sampling

I took the decision to exclude non-English speaking parents from the study. Whilst I wanted to include the views of as many different parents as possible, I felt that using a translator would complicate matters substantially as this requires an intricate process to ensure every word as well as the contextual use of words, such as humour and the level of emotion implied, are translated (205). Using a translator also requires additional skill of the interviewer, so I felt this may not be appropriate considering my lack of interviewing experience (205). In addition, I did not have the time available to wait for the interview to be translated into English, checked by a translator, then translated back into the original language to check that the original meaning had survived translation, before beginning to analyse it (205).

Another ethical consideration during design of the recruitment procedures was that participants may feel pressured to take part in the study. To mitigate this risk, I assigned a few individuals to act as ‘recruiters’, being the first to introduce potential participants to the study and invite them to take part. Only after this had been done, and a parent or carer had expressed an interest in taking part, did I then contact them myself.

When making decisions about how I would define my sample size, one reason I chose saturation to define the point at which I would stop conducting interviews was because it would not be ethical to take up a participant’s time if there was no additional insight being provided in the interview (218).

3.7.2. Consenting procedures

So that the consent obtained from all participants in this study was adequately informed, all eligible parents and carers invited to take part were provided with the participant information sheet

(Appendix A) and given sufficient time to read and comprehend this, before deciding whether to take part (12, 248). The participant information sheet contains information about the study's purpose, what parents' and carers' participation would involve if they chose to take part, and information about data storage and usage, confidentiality, anonymity, participants' ability to decline participation or leave the study early, potential risks, advantages and disadvantages to taking part, details of the research team and contact details for support services (12, 238, 249). I gave parents and carers the opportunity to ask any questions they had about the study, over the phone, and answered these as clearly as possible (244). By making sure these principles of informed consent were followed, I ensured that the risks to participants in this study remained low (250).

I provided all parents who were willing to participate, after reading the participant information sheet, with a consent form (Appendix B). I asked parents to read and understand this before deciding whether to sign this and return it to me. I planned that consent forms could be provided via email or post, depending on the participant's preference, so that the study could be more accessible to a range of parents.

Because of the ongoing nature of consent, even after signing the informed consent form, consent was reassessed, verbally, before each interview (12).

No parent or caregiver who lacked competency or capacity to consent for themselves was recruited. To be eligible for the study, parents and carers had to be at least 16 years of age, so they could consent to participate as adults. Plans were made for the circumstance that an individual might lose capacity to consent during the study; if this had occurred, the individual, and any identifiable data, would be removed from the study, keeping only the data that was identifiable to the research team.

3.7.3. Ethical considerations during design of fieldwork methods

Interviewee distress

One ethical consideration I made during this study was the risk vs harm to participants. Whilst the nature of qualitative research usually minimises any negative consequences for individuals participating, conversations about distressing or sensitive matters can create psychological harm.

Appreciating that having a baby in a NICU is an overwhelming and emotional time for parents, I expected it could be difficult for participants to share their experiences as these may be difficult to re-live, or still fresh in their mind, and in both cases, very personal to them (11). Additionally, I considered that the interview may cause participants to share experiences they have never previously discussed or reflected on, and that discussing sensitive topics might create anxiety for participants (238, 251). Because of this, during interviews, I carefully phrased questions to avoid upsetting participants and remained sensitive to the interviewee's reactions (217, 224). Before interviews, I took measures to ensure I was prepared to handle participants' emotions and provide psychological support where needed (218, 238).

These measures included options for support for participants throughout the entire study. I first offered support in the participant information sheet, by providing information and contact details for local organisations who could be contacted by participants who wished to seek support. At the start of all interviews, I reminded participants that their participation was voluntary, and they could choose to stop the interview or move onto another question at any point, without needing to give a reason. I also informed participants if they felt upset at any point during the interview, they had the option to speak to one of the professionals linked to this study who had agreed to act as 'support on standby' in case this was needed. After all interviews, I also provided participants with a debrief sheet (Appendix D) via email, which, again, contained the information and contact details for local support organisations participants could contact if they wished to seek support.

I also considered the potential for participants to require counselling support if they became emotionally distressed when sharing their experiences and wanted additional support (14). In the event of this, I would refer a participant to the Child Psychology Team at AHCH for an urgent review appointment, where they could sign-post parents to appropriate support services if needed. I planned that after any interview where a participant had shown signs of distress or upset, I would contact the Chief Investigator (Dr Melissa Gladstone) to define a plan and would liaise with any support services which the participant had chosen to accept, to assure the wellbeing of this participant.

I also considered what should be done should an interviewee give an indication of harm during an interview (12). This brought up issues relating to disclosure of information and confidentiality. In this circumstance, I planned to follow the appropriate response, by encouraging the participant to report this themselves, or seek help in some other way, after the interview (12).

Reimbursements

To acknowledge the time and effort expended by participants taking part in research (238), I arranged for all participants to be provided with a £20 shopping voucher as a recognition of their time in the study. This was given at the end of their participation in interviews, and participants were not informed of this in advance so that it was not seen as an inducement to take part in the study.

3.7.4. Ethical considerations during data collection and management

Confidentiality

For each remote interview, I ensured that I was in a private location where the phone or Zoom conversation would not be overheard by others, to ensure that confidentiality of the participants' responses was maintained (240). Additionally, all data collected that contained potentially identifiable information was stored securely and only accessible to the research team, not shared outside of this.

Anonymisation (pseudonyms)

To ensure participants remained anonymous in any findings shared from this study, I took measures to ensure that these contained no identifiable information (238). On recruitment to the study, participants were allocated a unique identifier which I used in place of their names, on all transcripts, fieldnotes and questionnaires containing answers to the structured demographics questions asked at the start of each interview. I also removed the names of any other individuals mentioned in interviews from the transcripts, to ensure they remained anonymous (11). I made this level of anonymisation clear to participants in the participant information sheets and reminded participants of this at the beginning of each interview, to encourage them to feel comfortable sharing their views and experiences (12).

3.8. Qualitative analysis

Next, I will describe the decision-making processes that went into designing my approach to analysis of the data I collected in this study.

3.8.1. An iterative approach

I planned for analysis to be an iterative process, alongside data collection, and so began to analyse interview transcripts as soon as possible after each interview was conducted, so that the issues found could be further explored in subsequent interviews (218). This decision also appeared sensible, as I wanted to avoid accumulating a large quantity of un-transcribed, un-analysed audio-recorded data, which would then be an overwhelming and likely impossible task to transcribe and analyse all these within a short space of time (218).

3.8.2. An inductive approach

I planned for analysis to take an inductive approach, to produce findings that accurately reflected the issues parents expressed to be important to them in interviews, rather than reflecting my own ideas, or any pre-given framework (212). However, I was aware it would be impossible to completely avoid my influence on the findings, as interpretation by the researcher is an essential and inherent part of qualitative analysis to explain the meaning behind particular aspects of phenomena in the study findings (16, 234). Before undertaking the interviews, I considered how my own background and beliefs might affect the interpretation of data. To make the reader aware of these influences, I have provided details later in this chapter (section 3.10).

3.8.3. Selecting thematic analysis

Due to the time constraints of the MPhil, being only one year long, it was not possible to read and learn about all the different types of qualitative analysis in depth. Instead, my decision about the type of analysis which I felt was most appropriate to undertake was informed by the qualitative teaching I attended, the qualitative literature I read, and supervisor guidance.

According to Braun & Clarke (252), the most appropriate type of qualitative analysis to use when conducting qualitative research for the first time is thematic analysis. I learnt that this approach involves the systematic and rigorous searching of the data to identify important themes (15, 224). As this was my first-time conducting qualitative research, and I was aiming to highlight the issues that appeared important to parents in the data, I felt thematic analysis would be the most appropriate method to undertake. This method also fitted well with my aim to take an inductive approach, as themes could be generated from the data itself (12).

Thematic analysis also appeared to be feasible within the time I had available, whereas I felt that other approaches which require more time, such as grounded theory (253), would not be appropriate. Another reason why I felt grounded theory, in particular, was not suitable to use, was because this involves theoretical sampling whereby data from one participant is analysed to inform recruitment of the next (253). Because I was already aware of the group of parents who would be able to shed light on my phenomenon, theoretical sampling would not provide any additional use in achieving a suitable sample of parents. Additionally, due to the limited time available and my aim to achieve a study sample large enough to achieve saturation in the data, I needed to be able to recruit multiple parents at once, rather than waiting until I had analysed one parent’s account before recruiting another.

3.8.4. Selecting the framework method

When exploring different ways of performing thematic analysis, I encountered the framework method. This was originally developed for policy research and is now popular in health research (12, 254). Therefore, it fits with the healthcare policy-related aim in this study to identify ways in which the process of early neurodevelopmental follow-up can be improved for parents. Framework also appeared an appropriate method as it is flexible, able to be used within many approaches to thematic analysis (254); and so aligned with my pragmatic methodological approach to this study. The use of matrices in the framework method, which sets this method apart from other approaches, appeared appropriate and useful for this study as these allow effective management and systematic, flexible analysis of the data, helping to obtain a holistic, descriptive overview of the entire data set (254). I felt that this would be useful in giving my analysis structure, guiding me as a first-time qualitative researcher, to ensure all areas of the data were interrogated sufficiently, whilst also allowing me to maintain my flexible, pragmatic approach. Framework matrices also aided me to make comparisons within and between participants' accounts whilst maintaining the context within which these were situated (12). Additionally, Gale (254) reports the framework method to be appropriate where not all members of the research team have previous experience of conducting qualitative research, and so this was particularly appropriate in this study, as this was my first-time conducting qualitative research. It was critical that I did not select an analytical method so advanced that I was unable to use it effectively and it hindered, rather than helped, the research.

Ritchie (12) provides a detailed description of the 'steps' to take within a thematic analysis using the framework method. I used these 'steps' as guidance but prioritised retaining the richness and depth of my data at all stages and performing as 'good' an analysis as possible within the time available (255). Next, I will provide the details of how I planned and performed my analysis.

3.8.5. Data management and coding

Once interviews were transcribed and checked against the audio-recordings for accuracy, I began my coding (11).

First, I read through a transcript and attached labels to pieces of data containing an accurate summary or representation of what that piece of data was about (224). I used codes to highlight topics, issues, similarities, and differences that I found within participants' narratives (11). During this, I studied the language used by participants (15), as specific nuances are relevant in denoting specific meanings, which must be carefully considered to ensure that the codes produced stay close to the data (12, 15).

I also considered the contexts that responses were given in, including the way parents' narratives were structured, so that the codes reflected the context of the data (15). As well as studying what had been said by parents, I also considered what was being omitted and topics that participants appeared to struggle to recall or share (11, 224).

I took the codes I produced and began to build an 'analytical framework'. Initially, this consisted simply of a list of codes from the first two interviews coded. Over time, this grew as I added new codes from later interviews, and I organised this so that similar codes were grouped together, causing 'categories' to arise with 'sub-categories' within these, where some codes appeared to fit into others (12). This helped the data become more manageable, which aided my later analysis.

As the dataset produced in this study was relatively small, compared to in some other qualitative studies, and interviews were conducted over three months, this allowed me to become very familiar with the dataset whilst analysing it. This helped me to make connections between issues and highlighting areas of discordance amongst parents' accounts. However, I resisted the temptation to store these in my head, instead making sure I noted down every idea I had within 'analytical memos'. The use of analytical memos is described in more detail in section 3.8.7 of this chapter.

3.8.6. Further analysis

During further analysis, I developed themes, through descriptive and explanatory analysis (12, 224). I abstracted the codes, 'categories' and 'sub-categories' in the 'analytical framework', which were initially highly descriptive and close to the data, to become more abstract concepts. However, I was careful to also remain 'close' to the data during this process so that the parents' 'voices' were still heard in the eventual presentation of the findings. I also made sure to retain the complexity of depth of the data. Categories which I considered to appear as potentially 'higher order' concepts were recognised and noted during this stage and referred to during later analysis (12).

One consideration I made whilst deciding how I would conduct these later stages of the analysis was what I would consider a 'theme' and how I would go about producing these 'themes' from the data, as the literature presents different ideas about this (11, 12, 224, 233). After reading some of the literature about this, I decided that I would consider a 'category' or 'theme' to be any concept which appeared to be an overarching idea within interviews that did not fit completely into another. When finalising the themes, I would also consider how the raw data was being reflected by the findings, to ensure the final themes and sub-themes represented the issues that parents described as being important to them in interviews, and the way they described these.

Once all transcripts had been coded and were embedded within the analytical framework, this was applied back to the raw data – a process which Ritchie (12) calls ‘indexing’. During this, I gained some new insights into the way the data should be categorised, which led me to adjust my ‘analytical framework’. These adjustments were also applied to the ‘indexing’ of transcripts, so that after finishing this process, my full dataset was indexed based on my final analytical framework (12).

After indexing, to help my later stages of analysis, I produced ‘matrices’ – one for each ‘theme’ I had produced at that point. These had a column for each ‘sub-themes’ or ‘sub-categories’ within each theme, and a row for each interview (12). The data was then sorted and entered into the correct box, in the correct matrix, for the specific ‘sub-theme’ or ‘sub-category’ it was indexed into, and the specific interview it was produced in – Ritchie (12) refers to this process as ‘charting’. Following this, I summarised the raw data in each box, in each matrix (12). This was useful for comparing different issues, views and experiences that participants had, as well as comparing different perspectives within an individual participant’s accounts, such as any changes in their perspectives between their first and second interviews.

At this stage, my interpretive thoughts included considering the key ideas which the data appeared to highlight, and the ‘meaning’ being attributed to the participants’ accounts (12). Further abstraction at this stage involved applying ‘conceptual labels’ to the data which often became the titles of the final themes or sub-themes. Through contemplating the matrices in this way, I produced descriptive accounts of the data, working on one matrix column at a time, to ensure the descriptions encompassed all components of participants’ accounts and described these accurately. These descriptive accounts, as well as the many analytical memos I had created in earlier stages of the analysis, allowed me to explain parts of the data, such as why participants appeared to have certain experiences or views. These stages constituted my ‘descriptive’ and ‘explanatory’ analysis, which Ritchie (12) describes as the ‘upper tiers’ within the ‘hierarchy’ of qualitative analysis and which I had aimed to achieve in the analysis, so that my aim to understand the experiences and views of parents could be fulfilled.

During all parts of the analysis, I maintained my iterative approach by constantly moved back and forward between the raw data set and the developing ‘themes’, to clarify any assumptions and look for further clues which could aid decisions about my final ‘themes’ and ‘sub-themes’ (12, 252).

3.8.7. Use of analytical memos

To make it clear, to any reader, how I interpreted and conceptualised the data and developed each theme and sub-theme in the findings, I made analytical memos throughout the analysis process (252, 254). This written record demonstrates how each theme was produced from the raw data itself, rather than generated from my own ideas (13). It also ensures transparency, by enlightening the reader about exactly how analysis was performed, so that they can make a well-informed judgement about the research, and so has implications for the trustworthiness of the analysis. These implications are discussed in section 3.9 of this chapter.

I also found the analytical memos helpful during my analysis as I could refer back to analytical memos made earlier in the analysis process, to help inform further data collection, as well as later stages of analysis, supporting my iterative approach.

3.8.8. Use of computer-assisted qualitative data analysis software (CAQDAS)

At the point in analysis where my analytical framework contained all codes from all transcripts and was ready to be re-applied (or ‘indexed’) to the raw transcripts, I decided that using CAQDAS would be helpful, to speed up this process as well as later stages analysis. I chose to use NVivo for this as I could access this for free through my university, whereas many other forms of CAQDAS would have been very expensive to purchase. I sought some training online and practised using NVivo to become familiar with the software, before entering my data into it (224).

I decided not to use CAQDAS before this point as I had a relatively small number of transcripts compared to other qualitative studies and found this quantity of data manageable for all analysis up to this point, using Microsoft Word. I coded all transcripts using the ‘review and comment’ function on Word, and then manually extracted my codes onto a separate word document to build my analytical framework. As CAQDAS does not help you become familiar with or immersed in the data, but simply aids data management (224), and I was much more familiar with using Microsoft Word, I felt this was more appropriate to use during the early stages of analysis. This helped me focus completely on becoming familiar with the data and interrogating it fully, whereas using unfamiliar software at this stage may have distracted from this. I had originally planned to begin using NVivo whilst initially coding transcripts, however, I changed my mind during the analysis because of the reasons above, and additionally as I was finding Microsoft Word valuable for practising my coding 'free hand' as this was my first experience coding data. This helped me stay close to the data, as it encouraged an inductive approach of creating new codes, based on the data, rather than using NVivo where the 'drag and drop' function into 'nodes' may have caused me to try and 'force' the data to fit into these.

After importing my transcripts into NVivo, I used the 'node' tool to re-apply my 'analytical framework' to all transcripts. I then used NVivo to automatically create my matrices and enter the data into these (the 'charting' process). Using NVivo for these parts of the analysis saved me time during these. NVivo also helped me refer back to parts of the raw data more easily whilst developing and finalising my themes and sub-themes as it automatically organised my data by 'index'.

3.8.9. Involvement of other qualitative researchers

Gale (254) recommends that an inexperienced qualitative researcher performing qualitative data using the framework method should be led by an experienced qualitative researcher. I met with two of my supervisors regularly who used their experience in qualitative research to guide me, ensuring I was being reflexive and rigorous in my work, including my use of the framework method (254).

Rosenthal (224) recommends that multiple members of a research team should independently read, re-read and code each of the transcripts, then meet to discuss codes and reach a consensus on the final set of themes. However, as this study was an individual student project, and my supervisors did not have the time available to read, re-read and code every transcript, a compromise was met whereby I met with my supervisors regularly and shared sections of coded transcript with them. This facilitated discussion of what the data appeared to be 'saying' and which codes would be appropriate, and I adjusted some codes based on this. This was particularly useful for me as this was my first time conducting qualitative researcher and so through these discussions I was able to develop my coding skills, by becoming more reflexive and critical of the codes I was applying and interrogating the data in greater detail. I also presented my developing 'themes' and 'sub-themes' to my supervisors as well as other individuals in the wider research team at different points, to facilitate discussion of these and gain additional perspectives on the way that the data could be categorised. Whilst having additional perspectives does not always create a 'better' analysis, I felt this did help my analysis, as individuals I shared with were experienced qualitative researchers and had expertise in the area being studied, so the discussions were insightful in providing me with alternate ways to consider parts of the data.

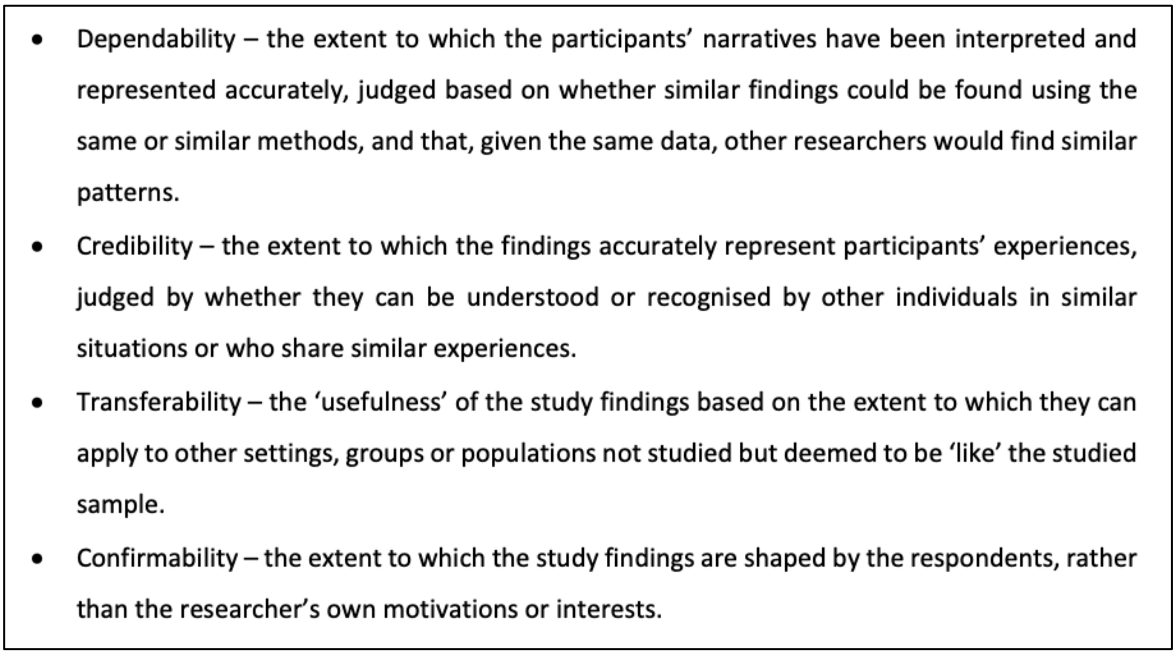
3.9. Quality assurance

3.9.1. How quality was assessed in this study

There is much debate about how quality in qualitative research should be judged (13, 256-258). I aligned my approach to this research within the interpretivist tradition, my views about what I consider to be 'good evidence' in this study differ to those that a researcher whose views aligns more with a positivist approach would have. Whilst they and I would likely consider quality, integrity and robustness to be equally important, we would judge a study's ability to possess these qualities using different criteria (11, 13, 204). Due to my interpretative approach, I do not consider 'bias' in this study in the same way that a positivist would and am not aiming for findings to be 'objective'. Subjectivity is an inherent part of this research, as the aim is to explore the subjective understanding individuals have of the phenomenon being studied and the data is co-produced in the unique interview encounter (12, 206). Because of this, I would not aim to replicate these exact findings in another study as a way to demonstrate their validity, as a positivist researcher would (208).

Lincoln and Guba (257) suggest 'trustworthiness' as the parallel term for quantitative 'rigour' and defined the elements of this to be 'credibility', 'transferability', 'dependability', and 'confirmability', which they suggest as the parallel terms for quantitative 'internal validity', 'external validity', 'reliability' and 'objectivity', respectively. However, Pope (15) and Morse (256) argue that the terms used in quantitative research should also be used to judge the quality of qualitative work. Morse (256) highlights that whilst elements of 'trustworthiness' are appropriate for *evaluating* rigour and relevance at the end of a study, following the concepts of validity and reliability can *ensure* rigour during the design and development of research. In this study, I tried to strike a balance of these opposing views. I made quality considerations during the design and conduct of the research to *ensuring* my methods would aid the collection of high-quality data, as I recognised that Morse's (256) argument about *ensuring* quality was important. However, I felt the terms used by Lincoln and Guba (257) were most appropriate to use to *evaluate* the quality of this work, so used these after conducting this research, to *evaluate* the extent to which this research meets the criteria for 'trustworthiness'. Additionally, I feel that the term 'rigour' is appropriate to use synonymously with 'trustworthiness' in qualitative work, as much of the literature describing qualitative research uses this, and so I have used the term 'rigour' in this way throughout this chapter.

Figure 13 below contains a description of the criteria within 'trustworthiness' that I used to judge quality in this study:



- Dependability – the extent to which the participants' narratives have been interpreted and represented accurately, judged based on whether similar findings could be found using the same or similar methods, and that, given the same data, other researchers would find similar patterns.
- Credibility – the extent to which the findings accurately represent participants' experiences, judged by whether they can be understood or recognised by other individuals in similar situations or who share similar experiences.
- Transferability – the 'usefulness' of the study findings based on the extent to which they can apply to other settings, groups or populations not studied but deemed to be 'like' the studied sample.
- Confirmability – the extent to which the study findings are shaped by the respondents, rather than the researcher's own motivations or interests.

Figure 13: Descriptions of the criteria within 'trustworthiness' that I used to judge quality in this study, based on definitions for these terms given by Sutton (11), Ritchie (12), Hammarberg (13), Rolfe (14), Pope (15) and Sandelowski (16).

3.9.2. Ensuring quality in this research

I will now explain the considerations I made to ensure this study fulfilled these quality criteria as fully as possible.

3.9.2.1. Dependability

By deciding to invite all eligible parents and carers in the study population to take part, and carefully designing the study to be to be as accessible as possible to a broad range of participants, I ensured I maximised the opportunity to achieve diversity in the study sample, which would, in turn, increase the dependability of the findings, by making them more relevant to a range of parents (13, 14).

During analysis, I actively sought and explored 'negative cases' (views and experiences that differed from those I had collected so far) to increase dependability of my findings (13). Involving other researchers in the analytical process also increased dependability (11). Details of this are provided in section 3.8.9.

3.9.2.2. Credibility

My prior engagement with the research field through background reading and shadowing at the LWH NICU and in follow-up clinics (as described in section 3.10.2) increases the credibility of this research (246). Additionally, being reflexive throughout the design and conducting of this study ensured its credibility (13). Reflexive comments are provided throughout this chapter as well as in chapter five, and a detailed description of my positionality is given in section 3.10 of this chapter.

Another technique I have utilised to ensure credibility in this study is transparency in this thesis (13). The first three chapters provide a detailed, transparent description of the study's background, justification of the need for this research and a clear, thorough description of the study's methodological approach, study design and methods in enough detail so that another researcher could exactly replicate this research process (12, 13). In this chapter, I have also provided my reasons for each decision I made during the design of this study, so that a reader can understand my logic behind them (13).

My analytical memos, as described in section 3.8.7, help to ensure credibility of my findings, in addition to the detailed description provided in this chapter of how analysis took place (13). During analysis, I also ensured credibility by re-applying my 'analytical framework' to my transcripts and during this, made any necessary adjustments to the 'analytical framework', so that the final version of this was comprehensive. This ensured that my analysed findings are coherent with the raw data (259).

Triangulation, whereby the research question is answered in several ways, by using several methods (13), was not formally used in this study. Whilst this can improve credibility of the study findings (13) there was insufficient time available to collect and analyse data using an additional method. However, I did make use of opportunities to gain some additional insight into parents' views and experiences by making fieldnotes after each interview (described in section 3.6.8) and shadowing at the LWH in the NICU and in follow-up clinics where the study was being set up (details given in section 3.10.2). As explained in section 3.4.1.2 of this chapter, focus groups appeared to be a useful method to explore the shared understandings parents and carers have of the process of early neurodevelopmental follow-up, and so could have been used for triangulation, but these were not appropriate to do in this study setting when parents were undergoing the earliest stages of early neurodevelopmental follow-up.

Respondent validation is another technique of increasing credibility (14, 218, 225) which was not used in this study. However, I would feel this would have potentially been an insightful technique to use, had there been sufficient time available. Details of the respondent validation I would have liked to conduct are provided in section 5.6 of this thesis.

3.9.2.3. Transferability

One way I ensured the reader can judge transferability of this study's findings was through 'dense description', whereby I presented parents' demographic information alongside the study findings, helping the reader clearly see who the findings refer to (14, 246). Collecting demographic information for all parents in the study population and highlighting differences between those who I interviewed and those who I didn't interview (given in section 5.5.2) also helps a reader to judge transferability as it is clear who the findings in this study refer to and who they do not (14). Section 5.3 also discusses the extent to which the study findings concur or relate to similar groups of parents, as well as other populations.

3.9.2.4. Confirmability

My inductive approach to this research plays a major part in ensuring its confirmability. Whilst I am aware that, due to the way the interviewer is involved in 'co-constructing' the data in an interview, my own views and beliefs will have unavoidably influenced the data generated (215), I strived to take an open-minded approach throughout this research. Various design features of the analysis process, such as the inductive coding and continual referral back to the raw data, were selected due to their ability to promote an inductive approach. To demonstrate confirmability to the reader, I have also included raw quotes within the presentation of findings (found in chapter four of this thesis), to make it clear that the themes and sub-themes presented have emerged from the interviews with parents, rather than my own ideas and interests (11).

3.10. Reflexivity and positionality of the researcher

3.10.1. Reflexive practice and why it was undertaken

Being reflexive is important in all qualitative studies, to ensure credibility (13), but was particularly important in this study, as I used interviews as the main method. Interviews have been increasingly questioned over recent decades, particularly by those who follow the constructivist viewpoint, as this argues that the interviewee's view of reality can be shaped during the interview encounter itself by asking interviewees questions they may never have been asked, and so causing them to consider phenomena in new ways (206, 215). Additionally, the responses gained are influenced by the questions asked and topics brought up by the researcher, as well as the relationship between the interviewer with the interviewee, and the context of the interview (215). Much of the literature argues this constructivist viewpoint, that whilst the researcher's role in qualitative research is to attempt to access the thoughts and feelings of study participants, their standpoints can impact their vision and it is impossible for the researcher to separate themselves from their own presumptions and biases completely. (11, 212, 218, 260) Therefore, as the interviewer, I was involved in 'co-creating' the data alongside the interviewee, and so it was essential I was conscious of my presumptions and biases, explicitly identified these and considered how they may impact the research by undertaking ongoing reflexive practice throughout this study (11, 13, 218, 260).

As part of this reflexivity, I considered the ways in which my personal background may have influenced the data collected, at each stage of the research process and clearly stating my positionality – my world view, background, perspectives and biases - which I have given below (11, 13, 14). This allows a reader to understand the lens through which this research was approached and make judgements about the extent to which my background, perspectives and views may have influenced this inquiry (14, 259). Another way I used reflexivity in this study was by being explicit how I made decisions during the design and conduct of this study (14); details of this are provided throughout this chapter.

3.10.2. Positionality of the researcher

This study was my first attempt at being an interviewer and my first time conducting qualitative research, or any primary research, for that matter. My position as a student who chose to undertake this year-long research degree, researching a topic which interests me greatly, meant that I was motivated to learn about qualitative research to conduct this research successfully. However, my skills in qualitative researching in interviewing are still limited compared to other more experienced qualitative researchers. This likely impacted the study design, participants recruited, and data collected and may have created limitations in the usefulness and quality of the findings. Further discussion of the ways that being a novice researcher may have impacted this study is provided in section 5.5.

My background as a medical student proved both useful and challenging at different times. It proved useful whilst interviewing parents, as my prior experiences interacting with patients has taken a similar form – like interviewing, the skill of 'history taking' as a medical student also requires active listening, sensitive phrasing of questions and probing for further details. This gave me some limited preparation for conducting interviews, however there are key differences between the two skills, and so I required specific training in in-depth interviewing before starting data collection, to maximise my opportunities to obtain rich, in-depth data. In addition, the principles of consent and confidentiality were familiar to me from medical ethics teaching within my medical degree and so, in this way, my background as a medical student was helpful whilst making ethical considerations during this study.

An initial challenge of entering this project from my medical degree was the stark contrast in the types of knowledge that are required. For the previous three years, during my medical training, I had learnt about a wide range of topics in some, but not extensive detail. In contrast, this project involved studying a single topic area in great detail. I experienced some of the challenges reported in the literature discussing the transition from the health care profession into qualitative medical research, such as engaging with new types of theoretical knowledge and encountering the lack of guidelines for qualitative interviews (218). During analysis, I also became aware that my background as a medical student, where we learn to compartmentalise information (for example by body system or drug category) caused me to initially battle with the data, trying to fit into discrete 'boxes'. After realising, and accepting, that qualitative findings may often overlap, fitting into more than one theme, I adjusted my approach. I carefully considered which theme I felt each piece of data fitted into *best*, to reflect what I perceived the participant was trying to get across to me in the interview.

Having never been a parent myself but having interacted with parents of babies during clinical placements, I had some understanding of the range of experiences and views that parents with a baby could have, but no direct experience of this. Studying the topic of early identification of cerebral palsy and the GMA and HINE assessments used for this prior to embarking upon data collection gave me an understanding of what the process of early neurodevelopmental follow-up, and the experience of infants undergoing developmental assessments, could be like for parents, but again, no direct experience of this. My main experience of the research field prior to beginning the interviews was gained through shadowing at the LWH NICU and follow-up clinics for high-risk babies. This took place during the first five months of this project before recruitment of parents began. Through this, I gained experience and knowledge by observing parent-professional interactions and interacting with a few parents and various professionals at the LWH. From this, I learnt about how neonatal care and follow-up is structured in Liverpool, and some of the different issues that might exist for parents regarding the process of early neurodevelopmental follow-up for their infants. From my placements during medicine, I also had knowledge of the ways that patients and professionals communicate and the structuring of healthcare services, including in follow-up clinics. I feel my engagement was useful, but also limited enough so that I did not develop any strong views or opinions about the research topic and so could remain open-minded about what parents might share in interviews.

When designing this study, I considered the potential power dynamic that might be created between myself, as the interviewer, and the parents I would be interviewing, as this can influence the data produced (12, 14, 218). As a student in my twenties, and my interviewees being parents with a young baby in their twenties and thirties, I predicted a relatively neutral power dynamic created by our relatively equal 'power' status in society and our similarities in age. If this were the case, this would be advantageous to the production of data in the study as it would help parents feel comfortable in interviews and share their experiences openly and in detail (12). I also considered the cultural dimensions of interviewer-interviewee relationships (205). As all parents and I lived in a similar area of Liverpool, I predicted there to be cultural similarities, reducing the likelihood of obstacles occurring in the interviews, that could occur if an interviewee and I had strong cultural differences (218). A discussion of the interviewer-interviewee relationships that developed in this study and how these helped or hindered the production of high-quality data is provided in section 5.5.

3.11. Conclusion

This chapter discusses the methodologies and methods that were available to use in this research, and those that I selected, with reasons for these given. The design of the methods used is also discussed in this chapter, with justification given for each decision that I made in the design process. In summary, I selected a pragmatic methodological approach, which for this study I located within the interpretivist tradition. I decided that qualitative methods were most suitable to use to explore this research phenomenon, and from the qualitative methods available, I selected in-depth interviews. I also chose to collect some demographic data by asking some structured demographics questions and make fieldnotes after each interview. To be most appropriate for the study setting and aim of the research I opted for a convenience sampling method and used semi-structured topic guides during interviews, containing open questions and probes. A longitudinal interviewing design was chosen, to interview parents once before, and once after, they attended the physiotherapist-led 12-week follow-up clinic with their infant. Data was analysed using a thematic approach, and during this, the framework method was used. Ethical and quality considerations were made at all stages of the design and conduct of the study. Reflexive practice was also ongoing throughout the research process and a detailed description of my positionality and how this may have influenced the research is provided in this chapter.

Chapter four

Findings

4.1. Introduction

This chapter presents details of the sample who participated in this study and the findings which emerged from the data analysis.

4.2. Recruitment of participants

Eight parents (six mothers and two fathers) of six infants receiving early neurodevelopmental follow-up were recruited over a four-month period. Initially, all parents of a high-risk infant eligible for a 12-week physiotherapist-led clinic taking place between 1st February and 1st May 2021 at the LWH were approached either during or after their neonatal stay, informed about the study and offered the opportunity to participate. This led to recruitment of five parents (four mothers and one father) of four infants, out of a possible nine eligible parents (56% recruitment rate), who each participated in two interviews. Following this, recruitment was broadened to those attending clinic after 1st May 2021, with whom just the "pre-clinic" interview would be conducted, to increase the number of participants. This led to recruitment of a further three parents (two mothers and one father) of two infants, out of a possible seven eligible parents (43% recruitment rate), who each took part in one interview. Because these parents were attending a clinic at a later date, they were interviewed earlier than planned. One of the three parents was interviewed shortly after their baby came home from the neonatal unit, several weeks before they were scheduled to attend the 12-week follow-up clinic. The other two parents were interviewed whilst their baby was still in the neonatal unit.

The most common reason given for not participating in the study was due to being busy with work, with four fathers declining due to this. Three parents declined with no reason given. The decision to exclude parents who required a translator led to the exclusion of three parents.

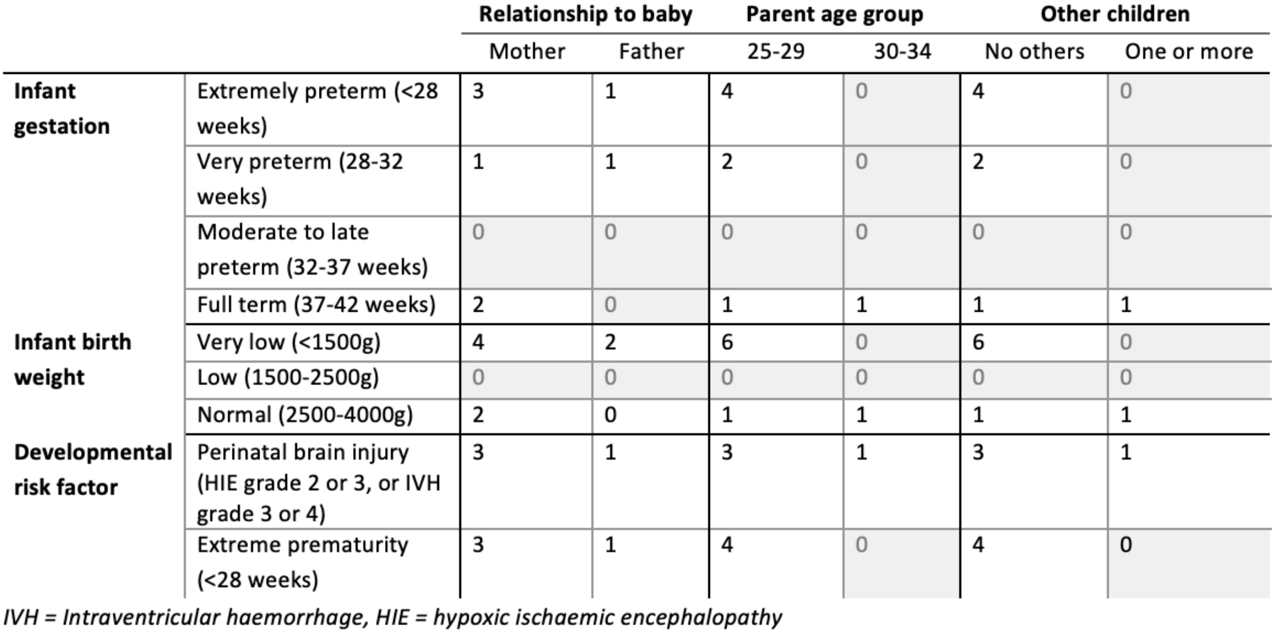
4.3. Data collection

Interviews

In total, I conducted 13 in-depth interviews with eight parents (six mothers and two fathers). Within this study sample, there were two sets of parent couples. All parents were interviewed separately. The first and second interviews with each participant averaged 43 minutes and 32 minutes in length, respectively. Interviews were conducted remotely; all participants opted for phone interviews rather than using an online communication platform. All data was collected via audio recordings. Apart from mothers who often had their baby present in the room, and one mother who appeared to be interrupted by someone else at one point, no other non-participating individuals appeared to be present during interviews.

Demographics of the parents interviewed

Parents interviewed were from six different postcodes in Liverpool. They ranged from 25 to 33 years of age. All parents were either married or living with a partner, and almost all were first-time parents, employed and of white British ethnicity. Their educational levels ranged from secondary school to degree level. All infants of parents interviewed were singletons, and under the care of their birth parents. These infants displayed a variety of risk factors for neurodevelopmental disorders; half were high-risk due to extreme prematurity, and half due to a type of perinatal brain injury. Gestational age and birth weight varied greatly, from 26 to 41 weeks and 660 to 3850 grams respectively. Full details of parent and infant demographic characteristics are shown in **table 1**.



		Relationship to baby		Parent age group		Other children	
		Mother	Father	25-29	30-34	No others	One or more
Infant gestation	Extremely preterm (<28 weeks)	3	1	4	0	4	0
	Very preterm (28-32 weeks)	1	1	2	0	2	0
	Moderate to late preterm (32-37 weeks)	0	0	0	0	0	0
	Full term (37-42 weeks)	2	0	1	1	1	1
Infant birth weight	Very low (<1500g)	4	2	6	0	6	0
	Low (1500-2500g)	0	0	0	0	0	0
	Normal (2500-4000g)	2	0	1	1	1	1
Developmental risk factor	Perinatal brain injury (HIE grade 2 or 3, or IVH grade 3 or 4)	3	1	3	1	3	1
	Extreme prematurity (<28 weeks)	3	1	4	0	4	0

IVH = Intraventricular haemorrhage, HIE = hypoxic ischaemic encephalopathy

Table 1: Demographic characteristics of parents who took part in in-depth interviews and their infants

4.4. Findings presented as themes and sub-themes

Seven themes were generated through thematic analysis of the 13 interview transcripts, with sub-themes within these (shown in **Table 2**). The defining feature of these parents' accounts was their attempt to manage their uncertainty. Parents' uncertainty related to their baby being on track, making progress and their future. The different ways they described attempting to manage this uncertainty can be grouped into three categories: 'seeking information', 'changing perspective' and 'planning ahead'. Other themes found in interviews were 'taking priority', 'trusting professionals', ‘independence in the parent role’, ‘feeling understood’, ‘patterns of care’ and ‘individuality’. The ‘taking priority’ theme has sub-themes that are areas that were clearly priorities for parents, these are: ‘the baby’, ‘the family unit’, ‘the mother’ and ‘the parents’ own wellbeing’. Sub-themes are also present within the ‘trusting professionals’ theme, these are the components parents described to be part of this theme, which are: ‘confidence in high quality care’, ‘compliance’ and ‘opting for paternalism’.

Main themes	**Sub-themes**			
(1) Attempting to manage uncertainty				
(2) Taking priority	The baby	The mother	The family unit	The parents’ own wellbeing
(3) Trusting professionals	Confidence in high quality care	Compliance	Opting for paternalism	
(4) Independence in the parent role				
(5) Feeling understood				
(6) Patterns of care				
(7) Individuality				

Table 2: Themes and sub-themes found from thematic analysis of in-depth interviews with parents describing their experiences during the current system for early neurodevelopmental follow-up for their high-risk infant in Liverpool

I will now describe and explain the content of each of these themes and sub-themes and provide quotations from interview transcripts to illustrate these. **Table 3** provides a key to the descriptive identifiers used for each quote, in place of parents’ names, to maintain anonymity.

Part 1	**Part 2**	**Part 3**	**Part 4**	**Example**
Relationship to baby e.g., ‘mother’	Baby’s gestation, given one of the following abbreviations: • <28weeks = extremely preterm (<28 weeks) • 28-32weeks = very preterm (28-32 weeks) • FT = full term (37-42 weeks)	Whether the baby had suffered perinatal brain injury. If they had, the abbreviation “PBI” is given here.	The timepoint of the interview that the quote is taken from: • Before-home = before the 12-week physiotherapist led clinic, with the baby at home • Before-NICU = before the 12-week physiotherapist led clinic with the baby still in the neonatal intensive care unit (NICU) • After = after the 12-week physiotherapist led clinic	**‘Mother/<28weeks/PBI/ Before-home’** = a quote from a mother with a baby born before 28 weeks gestation and who has suffered perinatal brain injury of some form, from an interview which took place before the 12-week physiotherapist led clinic whilst the baby was at home

Table 3: Key to descriptive identifiers used for quotes in place of parents’ names

4.4.1. Theme one: Attempting to manage uncertainty

The overwhelming feature at the heart of interviews with parents was their uncertainty about various aspects relating to their baby and their attempt to manage this uncertainty. This constituted the largest amount of data and the findings produced from these. Interviews highlighted that parents experience a heightened level of uncertainty created by their baby being in the NICU. In interviews, parents described this uncertainty as impacting their perceptions of the baby's current situation, conceptualised in terms of whether their baby is on track, and making progress. Uncertainty also impacted parents' perceptions of the future.

First, I will describe how parents conceptualised their uncertainty. This will include the areas of uncertainty parents described and the ways they described this uncertainty to be created and removed through a dynamic process of interaction between the parents, professionals and other individuals. I will then describe the different ways that these parents attempted to manage their uncertainty, the factors affecting their ability to manage uncertainty and, finally, the impact of uncertainty on their wellbeing.

4.4.1.1. Areas of uncertainty

Being 'on track'

The concept of a baby being 'on track' was used by parents when comparing expected developmental milestones with their baby's actual stage of development (**Figure 14**). Being 'on track' included growth, weight gain and feeding. Parents remarked how they were unclear about the relationship between the developmental trajectory for a premature baby versus a full-term baby. Some parents shared their expectations that their premature baby would experience some developmental delay but stated that they lacked any detailed knowledge of exactly what this would be and how long this would last.

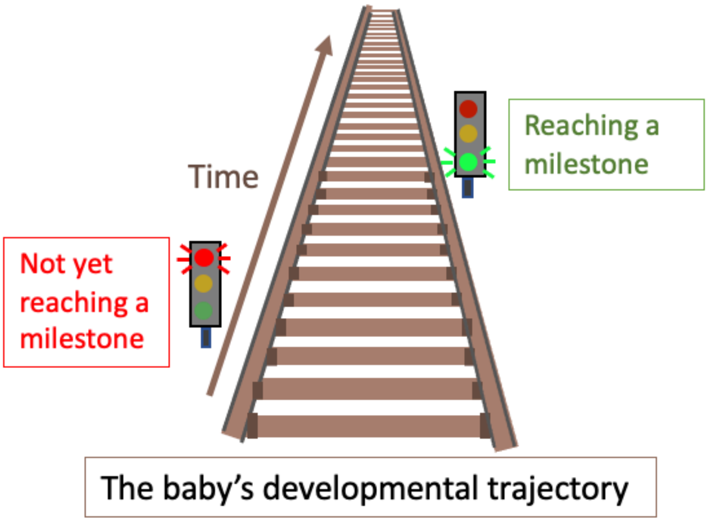


Figure 14: Diagram representing the concept of the baby being 'on track' with their developmental trajectory, described by parents in in-depth interviews about their experiences during early neurodevelopmental follow-up for their baby

Parents expressed their concerns about whether their baby was on track, their hope that the baby was on track and their need to know whether this was the case. One mother described feeling that she lacked this in the information she'd received from professionals at follow-up clinics so far:

> *"I'd just like to have seen maybe a plan in place of what, what should I be seeing… you know, what's the right developmental stage should my baby be at?"* – Mother/<28weeks/Before-home

Here she described a need for her expectations to be shaped by the professional, to manage her uncertainty. Another way parents reported attempting to manage their uncertainty about whether their baby was 'on track' was by monitoring their baby for signs of this. To assist this, some parents described looking for information online about expected developmental milestones and then applying this to their baby. Clearly monitoring is a way that some parents managed their uncertainty through seeking information. This will be discussed later in this chapter.

Running in tandem with parents' desire for their baby's life to be 'on track' was a need expressed by parents to keep their own lives 'on track'. Having a baby born either prematurely or with problems at birth and requiring a stay in the NICU disrupted parents' expectations of a normal birth. One father described how before the premature birth of his baby, he and his partner fixated on expectations for a "normal" pregnancy and birth:

> *"I think, you get wrapped up in the whole countdown to the due date… we did definitely you know we were looking at it like 'ahh two or three more months now' and you start counting things down…"* – Father/28-32weeks/PBI/After

Interviews highlighted how the arrival of a baby requiring a neonatal stay unexpectedly threw parents' lives off track and how this impacted on their emotions and wellbeing. One mother described this once at home with her baby when she considered her journey so far:

> "*it comes with post-natal depression, you get baby blues, or you just dwell on what's happened because it's not like the journey you've expected...*" – Mother/28-32weeks/PBI/After

Steps such as bringing the baby home from the NICU were described as moving parents closer to being on track with their expectations for life with a baby. One mother described feeling positive emotions towards her baby's discharge as it symbolised to her gaining a "normal" baby.

In a similar way, another mother described a substantial impact to her life when all the results from investigations for her baby were found to be "normal":

> *"you'd always have something in the back of your mind, erm, but obviously now with everything, and he's been discharged it's like, last week I think I started living, I think I started living properly…"* – Mother/FT/PBI/After

Making progress

Parents also described their baby making progress in various areas, with no set time within which the baby was expected to do certain things. They described this progress as non-linear as it was interrupted by the appearance of problems which regressed the baby's progress. This was reported by one mother who said:

> *"you take ten steps forward, and eight steps back, it's literally, it's how they work…"* – Mother/<28weeks/Before-home

The conceptualisation of problems as a "step back" was also described by another mother when she was given news that her baby had a diagnosis of hydrocephalus after a period of progress. To manage their uncertainty around whether their baby was making progress, parents expressed a need to be informed about this, as well as a need to be updated quickly when a problem arose. Whilst some parents described expecting problems to occur, they viewed these negatively, stating how this created worry, whereas they viewed progress positively, and described this creating relief and positive emotions. This desire for progress explains the actions parents described taking with the purpose of helping their baby to progress. Whilst at home, some parents described having a daily routine of exercises and providing their baby with toys that they hoped would encourage their baby's development.

The future

In interviews, parents described the impact of receiving news about their infant's development which could impact their future. This made some parents question what various aspects of their baby's future would be like and they described how this was very uncertain at this stage. One father described this when he was provided with the news that his baby had suffered a brain injury:

> *"it's really hard to you know, sit there and think about anything else apart from 'what's the next step?' you know, 'what's the next stage?' and then the long term, you know you're thinking 'will she lead a 'normal' life?'… Will she walk? Will she crawl? You know, will she be able to go to a mainstream school?"* – Father/28-32weeks/PBI/After

4.4.1.2. Parent need for information and access to professionals

It was clear from the verbatim that parents' knowledge and awareness about their baby influenced their perceptions of uncertainty. Uncertainty appeared to be created when parents lacked knowledge about their baby's developmental outcome, or other health conditions, or had an awareness of the uncertainty relating to their baby. This uncertainty in turn created parents' need for information and access to professionals for support, communication and follow-up. This included a need for involvement of the physiotherapist who performed developmental assessments on their baby. Parents who described physiotherapy to be important appeared to be those who had a greater awareness of their baby's development and the role physiotherapy could have in this. One mother who had an understanding of her child's developmental risk reported how this understanding sensitised her to possibilities, which invoked further questions relating to developmental assessments for her baby:

> "*just to ask the extra questions, why she's doing this? What, what could this be? You know, just different things to elaborate on, why she's doing, what she's checking for on [baby]…"* – Mother/<28weeks/After

In contrast, parents who appeared to be less aware of the uncertainty relating to their baby's developmental outcome seemed less curious about these topics.

Parents who showed an awareness of early identification and early interventions also expressed a need to spot any problems which might arise with their baby and act on these as early as possible. For example, one mother who had a level of awareness about early interventions, expressed an immediate need to become an 'expert' in any new condition her baby developed.

Being a first-time parent was described as creating need for general information and support, as some parents described having other children as a source of comparison and knowledge about what is "normal" for a baby. Some parents described how having no other children created a need to receive more information from professionals about their baby's development:

> *"we don't have any other living children to compare against, so this is where we need to sort of be a little bit more educated, erm, from the developmental side of things"* – Mother/<28weeks/Before-home

Receiving clarity or certainty about their baby, or information which answered their questions, clearly emerged as something that supported parents in managing their own uncertainty and reducing their need for information. For example, being informed by a professional that their baby was 'on track' with their developmental trajectory or 'making progress' reduced parents' need for ongoing information, support and follow-up. This was often described by parents as occurring at the follow-up appointments between the first and second interviews. It was clear that parents often felt more reassured and were less vocal in expressing need in the second interview, than in the first.

Several specific needs were found to be common amongst parents, many of these relating to information, some of which are illustrated in **figure 15**. Other areas of specific need related to parents' access to professionals, and the settings in which interaction with professionals occurred. I will now describe the details of some of these specific needs.

Figure 15: Image illustrating some areas of parents' uncertainty and information need expressed by parents in in-depth interviews about their experiences during early neurodevelopmental follow-up for their high-risk infant

Information to help the baby

Parents linked their need for information to wanting to help their baby. For example, one mother explained her need for developmental information for this purpose:

> *"I feel like it would be good for him to come home, and I feel fully prepared you know, to give him the best start possible… I don't want to erm delay him in any way if things can be started earlier… so I think information about all that would be really, really helpful…"* - Mother/<28weeks/Before-NICU

Another mother described her need for information about signs she should look out for which could indicate her baby had a developmental delay, as she was keen to recognise these early to initiate early intervention in the best interest of her baby, if it was needed.

Face-to-face follow-up and accurate assessments of the baby

One specific need, commonly described by parents, was for follow-up to occur face-to-face, rather than virtually, so their baby could be physically 'seen', and so the parents could receive information based on this. Parents also described how they preferred developmental information to be provided alongside an in-person assessment by a professional. For developmental assessments to be perceived as accurate, some parents described a need to feel that the professional assessing the baby had seen the baby's 'full potential'. One parent described this saying:

> "*we didn't think it was accurate… we could see that when [professional] was doing the examination on him, he was still half asleep and he wasn't doing, what we see wasn't what [professional] was seeing… we just felt like, either wait till he's woke up and then do the examination on him, because you're not getting a true reading of what he's capable of right now…*" – Mother/FT/PBI/Before-home

To help the physiotherapist see what parents perceived to be the baby's 'full potential', parents even report video recording their baby at home to show the physiotherapist.

Updates about ongoing investigations and timely results

Another specific need clearly described by parents was to be informed about investigations that were happening for their baby during the NICU stay, such as brain scans. Some parents made it clear how important this was to allow them to prepare for the results from these. Parents also described a preference to hear results as soon as possible, as the uncertain period whilst they wait for results causes stress and anxiety.

Medical expertise about 'invisible' health problems

From interviews, it is clear that parents are reliant on access to medical professionals for their expertise regarding medical problems the baby has, or may not have, particularly those which are not visible to the parent. One mother explained this as her reason for desiring follow-up by professionals for her baby's respiratory problem:

> *"we've had a few setbacks with his lungs so, I would, I'd want that checking quite often just for reassurance really cos obviously it isn't something that you can physically see…"* – Mother/<28weeks/Before-NICU

4.4.1.3. A dynamic interaction process

Interviews showed how much of a dynamic interaction process had developed between the parent, baby, and professionals. Information exchange was central to this; it was provided, sought, and received between both parents and professionals in a dynamic way with interactions occurring at many points in time during parents' journeys. This was complex as it often involved many different professionals and through many different mechanisms of interaction: in-person (in the NICU, follow-up clinics or during home visits); virtually (over the phone, via letter or through an online communication platform); in a public or private location; with or without the baby present; and with or without the parent's partner present. From my interviews, it was clear that these interactions can create uncertainty for some parents but is also important to support parents in managing their uncertainty.

In general, these dynamic interactions involved parents seeking information from professionals, professionals providing information to parents, and both parents and professionals monitoring the baby; illustrated in **figure 16.** For some parents, dynamic interactions also occurred with other parents, either on the NICU or outside of this. One mother described how interacting with other parents via an online support group for parents of preterm babies made her more aware of the uncertainty around certain topics, such as her baby's expected developmental trajectory. As previously discussed, this awareness created a need for information:

> *"until someone asks a question you don't realise that's a question you should be asking as well, so you know people are asking 'my baby was born at 25 weeks and now they're 8 weeks corrected, how soon does your baby smile at you' you know and that sort of gives that, I'm sort of intrigued as to, okay, so there are these milestones that we need to be looking at…"* – Mother/<28weeks/Before-home

This mother also described comparing her own baby's developmental stage to that of the babies of parents in the online support group:

> *"I've been sort of just getting my own research online to see how well their baby's doing, and you know comparing, and I know we should, we get told never to compare but I need some kind of milestone guidance, and I've not had that so far…"* – Mother/<28weeks/Before-home

Here, other parents and their babies acted as an information source when this mother was lacking information from professionals. Other parents described overhearing conversations between professionals and other parents on the NICU, or having conversations themselves with other parents, and how this contributed to their awareness and understanding of certain topics. Parents also reported their partners and other family members being involved within the dynamic interaction process. Some parents described either providing information to or seeking information from their partner during this time. This was usually when information from a professional had only been given to one parent in the couple, rather than both.

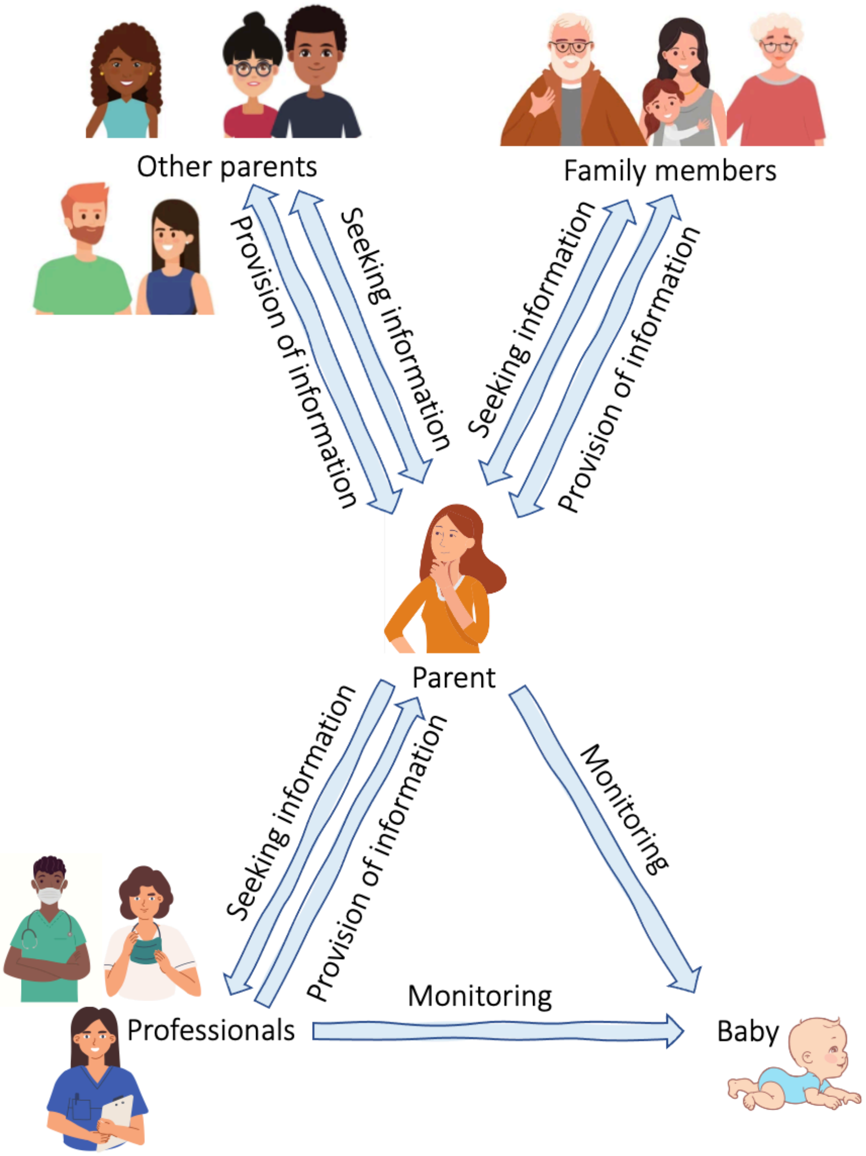


Figure 16: Diagram illustrating the dynamic interaction process that was found, in in-depth interviews with parents, to occur between parents, professionals, other parents, family members and the baby during early neurodevelopmental follow-up for their baby

Parents gained knowledge and awareness of their baby's developmental risk and the purpose of physiotherapy from their interactions with different professionals. Some parents described receiving information about developmental risk at the time of birth. In contrast, others reported not receiving information about development until later in their journey. This dynamic interaction between parents and professionals did not always keep parents and professionals 'on track' with each other, in terms of the knowledge they had about the baby's development. At times, it appeared the professionals had knowledge about the baby's development or developmental risk which the parents were not aware of until a later time point. Other times, parents reported 'knowing' their baby better than some professionals as they spent more time with them.

When information was received from professionals, the way in which it was given appeared to influence parents' subsequent understanding. Whilst all parents viewed the written information provided by the physiotherapist in the NICU to be helpful, those who had not interacted with the physiotherapist face-to-face during the NICU stay appeared poorly informed about the role of physiotherapy in their baby's development. In contrast, some parents who had spoken to the physiotherapist face-to-face appeared to understand this better. However, overall understanding amongst parents of the role of physiotherapy in development appeared to be limited. One mother, when interviewed after the physiotherapist-led 12-week clinic, reflected on her experience during the NICU, saying:

> *'I think she'd (the physiotherapist) missed us so we'd just popped out for something… I was just glancing through them, but if it was sort of in a different, separate room she'd have been able to give us the leaflets at that time… just so you've got it in your mind… I feel it's such an important thing… I wish I felt the importance of it whilst I was in neonatal…'* - Mother/<28weeks/After

Here, this mother suggests that had this information-giving been within a face-to-face setting, her understanding of physiotherapy and the developmental exercises contained in the leaflets she referred to would have been improved.

As well as providing information, this dynamic interaction between parents and staff also involved seeking and providing emotional support. Parents described receiving emotional support from professionals, their partner, family members and other parents with similar experiences to them. Emotional support from professionals was described as professionals dedicating time to sit and talk to parents, providing reassurance, encouragement and being welcoming, friendly and approachable.

4.4.1.4. Processing information

There is considerable literature on the way in which patients receive and understand information (261-263). In this study it was clear from parents that the content of information as well as the way in which information was given affected their ability to take it in. Other factors inherent to the parents were also described to impact this.

Preparation for news

When parents were unprepared for information it was received with shock before it could then be processed and understood. When a large quantity of information was given at once this was often described being as too much to take in. Parents described a need to receive information in smaller chunks over multiple conversations to help them take it in, otherwise they "zoned out" (Father/28-32weeks/PBI/Before-home) and could not do this. One mother reported this when given news that her baby had a 'brain bleed.'

Interview responses also demonstrated that the level of preparation for information affected parents' responses to it. For example, one couple described their shock at hearing the unexpected news that their baby had suffered a brain injury. They struggled to process the information and it subsequently had a negative impact on their wellbeing. The father reported that:

> "*when we got told that news that was obviously erm, that was one of the lowest parts of the time that we spent in the unit*" – Father/28-32weeks/PBI/Before-home

In contrast, one mother who reported being told by professionals to expect problems with her baby, reported that when problems occurred, they were not seen as so shocking or upsetting:

> "*they explained that obviously this is all good but to expect some setbacks like he might go backwards, he probably will, but it's not the end of the world, and he did have like a little blip but he's come back from it now…"* – Mother/<28weeks/Before-NICU

This "little blip" involved her baby moving from a low dependency oxygen support to the highest due to a worsening heart problem. From the way the mother described it, this news appeared to be relatively insignificant in her journey with her baby, possibly due to her preparation for it, or perhaps because of her personality.

Familiarity of medical terms

The words used by professionals also influenced how parents processed information. Use of medical terms which were unfamiliar to parents made information harder to understand and take in and also caused parents to feel worried and upset. One father described feeling alarmed when a doctor used medical terms, such as cerebral palsy, which he had not heard before: Initially hearing these terms was "like a bombshell" (Father/28-32weeks/PBI/Before-home); however this father described how when the same words were used in the letter he was given at discharge from the NICU, they were not so alarming as by this stage he had become familiar with them:

> "*I was totally aware that the correct scientific words, err, would be addressed on that document, I wasn't worried about that because I knew what those words meant at that point…"* – Father/28-32weeks/PBI

Emotional state

It was clear from the interviews that when parents felt overwhelmed and emotional their ability to understand information was reduced. One mother reported this being the case for her, and explained that in contrast, her partner was able to take in information better as he did not get as emotional or upset as her.

'Invisible' diagnoses

In terms of the information itself, it appeared in this study that parents found a diagnosis more difficult to process and accept when it was not visible to the parents. One father reported this when he and his partner, the baby's mother, received news of their baby's brain injury:

> "[my partner] *was really gob-smacked and shocked because looking at [baby]… her actions and her movements were not of somebody who you'd associate has got like you know, fluid or bleed on the brain… her movements were fine, there were fine, you know, she was moving around, she wasn't in any pain or distress…"* – Father/28-32weeks/PBI/Before-home

The challenge in accepting the diagnosis appeared to be created by the disbelief and shock experienced when the diagnosis was not visible to the parents.

Previous experiences

Parents' previous experiences also appeared to impact ability to process information. One father described how his background in working with children with developmental disorders helped him to understand the information he and his partner received about their baby's developmental risk. In contrast, he described how his partner, the baby's mother, struggled to process this information, as she did not have the same previous experience with disability.

4.4.1.5. Ways of managing uncertainty

In interviews, parents described managing their uncertainty in various ways, and these can be grouped into three main categories: (1) seeking information, (2) changing their perspective and (3) planning ahead.

Seeking information

All parents described actively managing their uncertainty by seeking information. They reported doing this from various sources, including professionals, other parents, their partner, and online sources. Additionally, parents described seeking information about their baby's development by monitoring their baby, looking out for signs. Often they looked out for signs that they considered important as they had been instructed by professionals to ‘keep an eye on’ them or had read about these online. However, parents remarked that the information they could gain from monitoring their baby was limited as, unlike professionals, they lacked the medical expertise to interpret the ‘signs’ they noticed. One mother described this saying:

> “*we still don’t know what we’re looking out for, it’s only professionals who, who can spot things…”* – Mother/<28weeks/After

Because of this, monitoring of the baby by professionals was described as being important. From both parental and professional monitoring, parents developed some certainty of whether their baby was ‘on track’ with their expected developmental milestones and whether they were ‘making progress’.

Professional monitoring was often reported by parents as the focus of follow-up clinics, including the focus of the physiotherapist-led 12-week clinic, as described by one mother:

> *“this appointment was basically checking that he’s hitting his milestones, and obviously his range of movement so whether it’s the same on both sides or, stuff like that… so once she done like obviously the mobility things, and the test and everything, erm, they then used the chart to kinda work out where he was…”* – Mother/FT/PBI/After

Here, the GMA performed in clinic was described as part of this monitoring:

> “*…they put him on a mat and filmed him, just doing what he wanted to do, for about 4 minutes, erm, so basically no interaction with us whatsoever, just kinda kick about and see what he did when he was left alone…”* - Mother/FT/PBI/After

However, these parents did not appear to recognise the purpose of the GMA and its ability to provide relevant information to them about their baby’s development. Instead, they described its purpose as being to provide professionals with information as part of their own training, rather than being for the parent’s or baby’s benefit.

For some parents, seeking information to manage uncertainty appeared to become an all-consuming task which they put considerable focus into. One mother, when asked if she ever sought information online about her baby’s development, responded saying:

> *“yeah I have, like obviously, it’s something that you become a little bit obsessed with really…”* - Mother/<28weeks/Before-home

Another mother, whose baby was having repeated head measurements due to a brain problem, described a similar attitude to information seeking, saying:

> *“as soon as I’d walk in I’d say ‘what was it on her plot?’… I was just asking about the plot, that’s all I was living for…”* - Mother/28-32weeks/PBI/Before-home

Some parents described how their ability to seek information was impaired when they were unable to take in or process information during a conversation with professionals, as they could not evaluate their understanding of the information at the time and could not formulate questions to ask.

Changing perspective

A change in perspective was used by some parents as a way to manage their uncertainty. Some parents described how they reduced or removed their expectations to receive information from professionals, by recognising that some questions could not be answered by professionals at that current stage. One mother reported:

> *"I realise, like, now that no one can answer them questions, no one can answer them questions now, cos no one knows what's gonna happen"* – Mother/<28weeks/Before-NICU

This approach appeared to manage some parents' uncertainty by removing their expectation to receive answers to their questions. Parents also described reducing their expectations of their baby as a way of managing their uncertainty. Some parents acknowledged that their baby's prematurity would not place them 'on track' with other babies. One father reported 'reminding' himself and his partner that they shouldn't expect too much from their baby:

> "*she's only really [age] at present now, from when you know, when she should've been born, her actual due date… that's something sometimes we have to refer to, erm, not to get ahead of ourselves… she still is only quite little compared to other babies…*" – Father/28-32weeks/PBI/After

Developmental milestones were understood by parents to provide a general framework within which their child might develop quickly or slowly in line with their own individual development. However, some parents appeared to downplay signs that their baby was not 'on track' or 'making progress', in favour of emphasising the positive aspects of their baby's development. One father described this, after being informed by the physiotherapist that his baby was slightly delayed in their ability to reach out and grab objects:

> *"I think the main focus was obviously about the reaching out, but, to be fair… she's played up for mum in there, cos in the house she does reach out quite a lot… and I've noticed now as well, over the past week she's started, she's really grabbing mum's hair…"* – Father/28-32weeks/PBI/After

Here, this father focused on the positive signs he could see, limiting his concerns about potential developmental delay the physiotherapist had informed him about.

Downplaying the significance of potentially concerning signs in babies was also demonstrated through the choice of words parents used to describe these signs. One mother referred to her baby developing a hand preference, as getting “lazy” (Mother/FT/PBI/Before-home), and another described her baby becoming unwell, reducing their feeding, and developing breathlessness as being “stubborn” and “not following the baby guide the way she should” (Father/28-32weeks/PBI/After). Describing these signs of potential developmental disability as characteristics or personality traits of the baby, reflected the different ways in which parents interpreted a baby’s development.

Some parents also expressed fear of revealing developmental issues, for example by sharing information about their baby’s development with family members. This meant sharing information with their family was not always viewed positively. One father expressed this:

> “*it’s awful when you’ve got to think about people asking how she is, and I didn’t wanna tell people… cos people go away and read up on it… the last thing I wanted was for family and people to go ‘oh yea, you know, that leads to erm, autism or something’…”* – Father/28-32weeks/PBI/Before-home

Fear of revealing developmental issues also resulted in some parents not ‘pushing’ their baby ‘too far’ in case it exposed a limit to their abilities and in this, a sign of potential delay or disability. One mother said:

> “*I don’t wanna push her too far, cos she might not be able to…”* – Mother/28-32weeks/PBI/Before-home

Another way that parents described being able to manage their uncertainty was by having their expectations shaped by information they received from professionals. One mother reported seeking this from a doctor during a virtual follow-up appointment, asking:

> “*what are we expecting, I know he’s 12 weeks premature but how much of an impact is this gonna make in life? From growing up to a young toddler or whatever or even in school years you know, what is it I’m walking away with at this stage?”* – Mother/<28weeks/Before-home

For one father, having his expectations shaped by professionals was described as providing reassurance. He said:

> “*the doctors coming round and saying to us ‘look, if you put one of them heart monitors on every baby, theirs would fluctuate up and down’ so, that was quite reassuring…”* – Father/28-32weeks/PBI/Before-home

In contrast to this, one mother described having the opposite response. The information professionals gave her to shape her expectations about her baby’s brain bleed did not manage her uncertainty:

> “[I was] *really unhappy at first because they were just saying it was a normal thing, but I was saying I was really worried because even if just a little percent have an effect, it could happen, so I still feel worry…”* – Mother/<28weeks/Before-home

Furthermore, distracting from uncertainty was described to be a useful strategy, often facilitated by nurses on the NICU taking time to sit with parents and talk to them about things other than their baby. One mother described the impact this had on her experience, saying:

> *"they made the time there easier for us, erm, and even, even down to like little things like, coming over and sitting and having a chat about something completely different, not the current situation, but just something like just the day-to-day chat that you'd have with a friend, erm which just, it does help cos they then take your mind off it for just a little bit"* – Mother/FT/PBI/Before-home

Turning down offers of support was another strategy used to manage the uncertainty situation, described by one father, who did not seek support from the NICU counsellor after being given news of his baby having a brain bleed, despite feeling this could have been beneficial to him and his partner:

> *"some days I feel like we could've used him, erm, but we just, we plodded along to be honest…*" – Father/28-32weeks/PBI/Before-home

He made sense of this by explaining the existence of personal barriers to seeking support:

> *"possibly that was just me being stubborn, maybe [partner] might've said, she might have been a little bit stubborn… I don't know if it goes back to stigma as well, erm you know it's, looking back in hindsight, yeah I would have used him, when we got told that information, but in that moment, it was more like we were just taking things day to day…"* – Father/28-32weeks/PBI/Before-home

'Taking things one day at a time' was a strategy also reported by other parents. Here, this, and 'plodding on' were recognised as ways of reducing anxiety and focusing on the present. Internal questioning was also common; parents appeared to have questions in their mind at various points in their journeys that they did not seek answers for. This may have been due to personal preferences, similar to the personal barriers described in the quote above, or a desire to avoid the answers. It also may have been due to parents lacking access to a professional to ask, however this is unlikely as parents generally reported always having access to a professional to whom they could ask questions whilst in the NICU.

Planning ahead

'Planning ahead' by ensuring that measures were in place to provide the baby with the appropriate care if any developmental problems arose in the future was described by some parents as a way of managing their uncertainty. Parents seemed to do this when they were aware of the potential for future developmental problems to occur. One mother described this, saying:

> *"[professional's name] did actually wanna discharge him but I said no, only for the simple reason because I'm still worried the head even though I know everything's alright, I'd rather [professional] be there than not be there, where, touch wood, if anything did go wrong, I haven't got her…"* – Mother/28-32weeks/PBI/Before-home

One father also described this being the reason for his preference to have a plan in place for the baby. He described how he shared this need with a professional, saying:

> "*'she'll need a care plan straight away', that's something I've, I asked that, I said look I said 'I'm not willing to leave [baby] until she's four or five and you know… she's doing things that a four or five year old 'normal', as they class them, child doesn't do' so you know that's something that I've kept an eye on, you know something that I've pushed for…*" – Father/28-32weeks/PBI/After

In interviews, some parents also described having a contingency plan in place to use if their baby began to show a sign or behaviour they were concerned about, stating that in this circumstance they would contact a health professional. Usually, parents reported how they would do this immediately, without hesitation.

4.4.1.6. Access to professionals for managing uncertainty

Having a clear point of contact from whom parents could access support, information, and advice was described as being crucial for managing their uncertainty. The group of parents interviewed can be split into two groups, one containing parents who received follow-up from the Community Neonatal Liaison Specialist (CNLS) at the LWH, another containing parents who did not receive this follow-up. Parents who received follow-up from the CNLS described how this was their preferred, main, or even sole point of contact for support and information. They reported the CNLS provided regular home visits, which some parents described as being on a 'parent request' basis, via a text or phone call. Upon contacting the CNLS, parents reported consistently receiving a swift response which resolved or managed their query. All parents followed up by the CNLS described this professional in a very positive light and expressed their reliance on them for information and support. One mother when asked who she would go to for information and support in absence of the CNLS, said:

> "*if [CNLS] wasn't there I'd, I don't know to be honest with you*" – Mother/28-32weeks/PBI/Before-home

In contrast, parents who did not report receiving follow-up from the CNLS, described feeling they lacked a clear point of contact from whom they could access support and manage their uncertainty, and expressed a need for this. Some parents in this sub-group described how they were 'in between' healthcare services, with professionals from multiple services turning them away when they attempted to seek information, directing them to another service, where other professionals did the same. One mother described this, saying:

> *"When I went to Alder Hey they just keep saying for me 'you should ask the woman hospital' and the woman hospital told me 'you should ask the Alder Hey'... so you know, you are in the middle… I am in the middle with nothing…"* – Mother/<28weeks/Before-home

Making it clear to parents where they could access information, both during and after the NICU stay, as well as what types of information they could access appeared important to parents by the way they described their thought processes behind their decisions to seek information. Parents interviewed expressed that they would seek information if they thought they would receive answers, and not be turned away.

The willingness of professionals to provide information also influenced parents' ability to manage their uncertainty through this method. During their baby's NICU stay, all parents, apart from one, described professionals as willing to provide information. For example, one mother said:

> "*she'd (the doctor) always say, or he (the doctor) would say 'if there's something that you don't understand, erm, I'm always available all day, and if you just need to give us a yell, just get someone to contact me' and then they would've come back round to speak to us, so they were really helpful and willing to give information…*" – Mother/FT/PBI/Before-home

In contrast, one mother described professionals to be unwilling and reluctant to provide information to her in the NICU and that this made it challenging to fulfil her information needs:

> "*you tried to ask them about information about what is going on and they just said 'ohhh don't worry we will send you the leaflet to read it' 'okay, but I should not read it, you should answer my question! I should not have to read the letter, but even the letter you did not send it for me"* – Mother/<28weeks/Before-home

Another mother reported struggling to access information from professionals at the LWH after discharge from the NICU. She described being turned away despite believing that the professional she was speaking to did have the answers she needed:

> *"I felt like couldn't get any advice from them… they just apologised that they couldn't help… they probably do know the answers to some of the things that I was asking"* – Mother/FT/PBI/Before-home

Follow-up clinics were also described as an opportunity for parents to manage their uncertainty through seeking information. However, for one mother, inadequate communication about upcoming clinics prevented her from being able to attend:

> *"[the physio] called to remind me, erm, of an appointment that afternoon… I'd had no letter or correspondence at all… I still had enough time to get [baby] ready to go to the hospital, but I wasn't able to go to the appointment, so my husband went on my behalf… it's just a shame really cos I would've really wanted to be at that appointment…*" – Mother/<28weeks/After

The lack of communication about the clinic before this phone-call caused this mother to miss a valuable opportunity to manage her uncertainty of her child's current and future development. This did not occur for any other parents; all others were aware of the 12-week physiotherapist-led clinic in advance before attending.

The form of communication parents described preferring for being informed of clinics varied: some were satisfied with the letter they received in advance, whilst others felt a need for a digital reminder (phone call or SMS) closer to the time of the clinic. This may explain the differences in parents' awareness of upcoming clinics, although inconsistencies in communication from hospitals to parents about clinics may also have occurred.

4.4.1.7. Impact of uncertainty on parent wellbeing

It was clear from interviews that uncertainty impacted parents' wellbeing. They described feeling 'relaxed' and 'at ease' when uncertainty was well managed. When it was poorly managed, they expressed intense anxiety and worry, and some parents even described physical symptoms such as feeling sick, being unable to sleep and even lacking motivation to care for their wellbeing such as lacking motivation to eat or drink. Times of great unmanaged uncertainty caused parents to feel unable to cope:

> *"I went home and I was just like 'ohh, I can't do this…" "to be honest I felt sick, and I felt like some days it was just like 'ohh I can't do it, I can't go into that hospital', I'd think 'what else is gonna happen?"* - Mother/28-32weeks/PBI/Before-home

When parents felt more reassured, however, they were able to cope and described the uncertainty as manageable.

4.4.2. Theme two: Taking priority

From interviews, it was clear that priorities parents had during their journeys were: the baby, the mother, the family unit and their own wellbeing.

4.4.2.1. The baby

It was clear that for the majority of parents interviewed, their baby was their priority. Parents described prioritising their baby's needs and their responsibility as the baby's parent or carer. Parents also described wanting to be with their baby as much as possible and viewing periods of separation from their baby whilst they were in the NICU to be negative:

> *"you miss the baby because you just want to be with him all the time you want him to come home…"* – Father/<28weeks/Before-NICU

Some parents describe prioritising spending time with their baby over their own wellbeing. Parents reported being in the NICU “all day every day” until staff tell them to “just go home” and rest (Mother/FT/PBI/Before-home). One mother described how she sacrificed seeking support for her own wellbeing from the NICU counsellor, as the priority of her visits to the NICU were the baby.

Priorities for the baby’s care and development shifted over time:

> *“at 30 weeks its more about like… can they survive, trying to get them off the airflow and trying to get them to not have the bradys and how they are in themselves and are they feeding? Are they tolerating the milk? That’s all it is mainly on the intensive care part, it’s when they go to the nursery, that’s when it’s more development…”* – Mother/28-32weeks/PBI/Before-home

It was clear from interviews that when an acute problem arose, this became the priority, superceding other aspects of the baby’s care. Acute problems were sometimes described to displace developmental concerns and parents’ perceptions of development as a priority. One mother described how her ability to focus on and take in information about development from professionals was restricted for a period of time, as she was distracted by an acute problem her baby had, and that this reduced her awareness and understanding of development during this period. During the NICU stay, parents report receiving verbal and written information from the physiotherapist about exercises that can help their baby’s development. One mother described how the extent to which she carried out these exercises, when her baby was initially discharged home, was limited by her need to bond with her baby. She said:

> *“when we finally brought him home it was, we had a lot to learn about each other, he was learning about me and I was learning about him, so, you sorta keep everything like physiotherapy to one side, it’s not, it’s not a priority at that time…”* – Mother/<28weeks/After

Because of these other priorities present at the time the baby first arrives home, one parent suggested that receiving a reminder about the developmental exercises, via a phone call from a member of staff, could be beneficial in encouraging parents to comply with these exercises.

Parents appeared to view their need for follow-up through the lens of their priorities for their baby. One father, interviewed at a particularly early stage, whilst his baby was still in the high dependency unit of the NICU, reported his need for follow-up once the baby was finally discharged from the NICU to be to ensure the development of the baby’s “organs” and making sure the baby is “healthy”, and not the baby’s motor milestones as these would “come in time” (Father/<28weeks/Before-NICU). This father, at this early stage, did not appear aware of the potential for his baby to have developmental disorders, whereas parents interviewed at later stages did appear to be aware of this. For example, another father interviewed shortly after attending the 12-week physiotherapist-led follow-up clinic, focused in this interview on his need to encourage his baby to reach their motor milestones, and talked at great length about his baby's risk of not achieving these. Overall, this demonstrates how parents' perception of development as a priority changes over time.

When development is a priority, parents often focus on one particular area of development, often, the area that parents are aware may be impaired. One parent described focusing on their baby's use of both sides of their body after being informed that the brain injury they suffered could cause unilateral impairment.

Parents described sometimes having to balance competing priorities in their life to spend time with their baby. One father described the mental burden he felt when having to take time off work to prioritise visiting his baby in the unit:

> *"I felt pressured and stressed, they were really good with me to be fair, even making that phone call I felt anxious, I felt as if like, err, I was letting them down kind thing cos I was taking time off…"* – Father/28-32weeks/PBI/Before-home

After going back to work when his baby was discharged from the NICU, he described rearranging work commitments so he could be present at home visits for the baby, but still, was at work most of the time whilst the mother cared for the baby. He described how this caused feelings of guilt. Interestingly, the other father interviewed did not describe guilt, despite continuing to work during his baby's neonatal stay. This may be because he reported still being able to visit the unit every day after work, and being heavily involved in his baby's care.

4.4.2.2. The mother

During parents' time in the NICU and in the first few months after discharge, parents and professionals also appeared to prioritise the mother. The interviews elicited a narrative which focused on the mother's perspective. This was often because experiences discussed in interviews were experienced by the mother only, without the father present, and so fathers could only describe their interpretations of the mother's perspective of these. Similarly, mothers reported their interpretation of the fathers' experiences during events where the father was present, but the mother was not, but this occurred less frequently during parents' journeys; if a single parent was present this was usually the mother. One father described directing his attention to the mother's reactions, responses and perspectives during experiences when he was present and reported how he often tried to reassure the mother. He explained his reason for doing this as being because the mother's wellbeing was his main priority. He also reported that staff on the unit focused more heavily on the mother, than him:

> *"on the wards a lot of the staff, they were really nice to the both of us but obviously, they were more erm, focussed on mum…"* - Father/28-32weeks/PBI/Before-home

He described this being because the mother expressed her emotions to the staff, whereas he kept his hidden, and so the staff mainly focused on providing emotional support to the mother:

4.4.2.3. The family unit

During interview narratives, the idea of 'we' as the family unit, consisting of a parent couple and their baby, was frequently used. Parents described wanting to both be present during the journey with their baby – at the birth, in the NICU and at follow-up clinics - and felt dissatisfied if they couldn't. One father reported feelings of frustration due to not being able to attend follow-up clinics with his partner and baby:

> *"I was really frustrated and fed up… I thought 'I can't even go in and you know, be there you know these milestones, you know if [baby], or to enjoy them"* – Father/28-32weeks/PBI/After

One father framed his visits to see the baby in the NICU with his partner as "family time" (Father/<28weeks/Before-NICU) and viewed this time positively. Another parent described feeling fortunate as they were able to go through the neonatal experience with their partner, together as a couple, and compared to the experiences of other parents on the unit who went through the experience without a partner present.

4.4.2.4. The parents' own wellbeing

While parents described their wellbeing as a priority; it was not always clear that it was prioritised. One father expressed feeling a responsibility for him and his partner to look after their own wellbeing as a 'duty of care', to allow them to be fit to care for their baby. He reported:

> *"…without being selfish, we were making sure that we looked after ourselves, I didn't want to go in there and the parent was to, not look well or, you know, not properly eating, not drinking, because I thought at the end of the day, you know, it's our responsibility anyway, to have a duty of care…"* – Father/28-32weeks/PBI/Before-home

This father also described his partner's wellbeing as his main priority and how he tried to ensure that she was looking after her wellbeing sufficiently; he said:

> "*there was time where I got a little bit erm, infuriated with [mother] because I was insisting 'go and drink, go and eat' and I know where there was moments she didn't want to because of how she was feeling…"* – Father/28-32weeks/PBI/Before-home

The mother, who was also interviewed, described her lack of motivation to eat or drink, and shared that this was because she was prioritising her baby over taking time to care for her own wellbeing.

Parents also talked about keeping their emotions ‘bottled up’ to avoid upsetting or worrying their partner. Interestingly, this was only described in interviews with fathers.

Clinicians were often described to recognise the importance of parents’ wellbeing, and express concern for this, such as encouraging them to go home from the NICU and rest if they had been there all day. Parents described a positive response to professionals being concerned for parents’ wellbeing, as well as the baby’s:

> “*the nurse asked [mum] how she’s getting on and things which is nice you know, that they’re caring about the parents as well as the baby…”* – Father/<28weeks/Before-NICU

4.4.3. Theme three: Trusting professionals

4.4.3.1. Confidence in high quality care

In interviews, parents reported high levels of confidence in the quality of care being provided to their baby:

> “*that made me feel a bit at ease that like [baby] was in the, in the right place and he’s got the right people looking after him… when I got home I didn’t think I was gonna sleep but I slept quite a bit…”* – Father/<28weeks/Before-NICU

One father, whilst recognising the quality of care being provided to his baby, felt this did not counteract the concerns and uncertainty he had about his baby’s development:

> *“I know the job they were doing was fantastic and I knew she was in the best place with the best care, that never crossed my mind, it was every day I was thinking ‘ohhh has she done this?’ or ‘is she developing right?’ or ‘are they gonna say this to us?”* – Father/28-32weeks/PBI/Before-home

Despite this variation in parents’ perspectives, they shared the same belief that professionals had good intentions for their baby. However, parents’ perceptions of the ‘priority’ a professional had for their baby was found to vary and be influenced by whether the professional caring for the baby was familiar to the family. For some parents, this appeared to influence their feelings of reassurance:

> *‘it’s the familiarity of just feeling a bit safe, seeing the same face that you recognise…it was just a reassuring feeling…’* - Mother/<28weeks/After

One father who reported feeling less reassured when an unfamiliar nurse was caring for the baby, described how he stayed at the NICU for longer than usual, as he was concerned that the nurse’s knowledge about the baby was insufficient to interpret and respond to the baby’s reactions.

Parents described professionals who cared for their baby as knowledgeable and experienced. Most parents reported trusting the information they received from professionals, with one mother stating that professionals knew “exactly what they’re talking about” (Mother/<28weeks/After). However, one mother expressed how she felt the information she had been given about her baby was incorrect and overly negative and that the baby was not showing any of the signs that professionals had told her would occur:

> “*she is just like a normal baby but they didn’t tell us that they were just, it was all the negatives like ‘she mightn’t be able to walk, she mightn’t be able to talk, she will have learning difficulties’ but obviously there’s no signs of that at the moment.*’ – Mother/28-32weeks/PBI/After

This demonstrates the difficulties staff seemed to have in tailoring information to parents’ needs.

4.4.3.2. Compliance

Parents demonstrated their trust in professionals by how they followed professional advice and guidance they were given. One father described how he followed advice from a nurse after receiving the news of his baby’s brain injury:

> “*she (the nurse) said to me ‘look I’ve been in this job for well over 15 years, I’ve seen children with this kinda bleed before’ she said ‘and there’s no reason why it won’t reduce itself because of her behaviour and [baby]’s actions and, you know, her character, they’re all positive signs’ so you know we took that in our stride…”* – Father/28-32weeks/PBI/Before-home

Allowing this advice to shape his perspective helped him to deal this news. The few parents who reported not completely following the advice they had been given either took it and adapted it slightly or had the intentions of following it but still needed to “get round to [it]” (Mother/FT/PBI/After); it appeared that these were for reasons other than a lack of trust in professionals, such as having a limited understanding of the importance of the guidance professionals provided.

Parents were keen to act in their baby’s best interests and this often involved following clinician’s recommendations even when parents were dissatisfied with a situation. One mother described a few experiences where she felt information was given inappropriately or did not satisfy her needs, but still “had nothing against” the care being provided and “didn’t mind doing” what had been asked of her by the professional.

4.4.3.3. Opting for paternalism

Some parents appeared, in interviews, to opt for a completely paternalistic approach, aligning their needs and actions with those of the professionals:

> *“if he’s happy with how he’s progressing, and they don’t need to see him anymore, fine, that’s absolutely fine as well, but if they did still want to… just over like the next few years we’ll do a follow-up in 12-months’ time say… that would be fine with me as well, just, if that was something that they needed… whatever they think would be best…”* – Mother/FT/PBI/Before-home

This mother felt she was happy to comply with whatever the professional's "need" was for the baby's follow-up and did not have any independent need aside from this. In contrast, other parents, whilst happy to comply with all follow-up and other services provided by professionals, described their own independent needs for follow-up and professional involvement. This was usually described alongside a justification of why they felt this was needed, demonstrating an understanding of their baby's needs for these services. One mother, interviewed whilst her baby was still in the NICU, already felt a need for follow-up to take place once her baby is discharged:

> *"I'd say maybe three times a year, erm, cos, just cos of how early he was born, maybe even more if he still has issues like erm, at the minute obviously he's still on respiratory help and stuff, we've had a few setbacks with his lungs so, I would, I'd want that checking quite often…"* – Mother/<28weeks/Before-NICU

In addition, one mother described her need for information about her baby's development to exceed the NICU professionals' need for developmental information:

> *"I think obviously neonatal have everything they need to know for his development, but I don't think we have enough information for his development…*" – Mother/<28weeks/Before-home

Another way in which some parents demonstrated a need for a paternalistic approach was in their preferences for seeking information from professionals only. Some parents described their preference to avoid online sources as they trusted that professionals would provide them with all information they needed:

> *"I'd never go on google and take, you know, try someone online who's advising you, I'd rather go through the people that are trained in that area, obviously, you know, let them give us the right advice and guidance…"* – Father/28-32weeks/PBI/After

In contrast, some parents reported seeking information online as an additional source of information to the information received from professionals. Those who did so, reported that their information needs exceeded that which they received from professionals, for example, feeling a need for an alternative perspective or additional details they were lacking. For example, one mother described looking up her daughter's diagnosis online as she felt she was lacking sufficient information about the range of potential outcomes, and that doctors had provided only the negative aspects of the diagnosis, not the positives:

> *"I did look at the [diagnosis], erm, only to see what other people's outcomes was because you don't really get, you just get told the situation but you don't ever get told of any other outcomes, like you'll always get told the negatives not the positives so I did read some other people's stories…"* – Mother/28-32weeks/PBI/Before-home

One mother described an alternative reason for seeking information online: she reported feeling conscious of asking professionals too many questions, because of the impression this might give:

> "*sometimes I feel like I come across as like, not over-protective, but, well yeah over-protective, like I don't want anyone to think that I'm questioning their abilities or their judgement because obviously they want the same as we do, you know, we want [baby] happy and healthy…"* – Mother/<28weeks/Before-NICU

Whilst she described her trust in professionals' intentions for her baby, she preferred to seek answers to her questions online rather than asking professionals, to avoid appearing over-protective of her baby or doubtful of professionals' abilities.

4.4.4. Theme four: Independence in the parent role

Wanting to fulfil the parental role

From interviews, it was clear that when a baby has a neonatal stay, the parents' involvement in and control over their care differs from that which would occur in the 'normal' situation where the baby is taken home immediately after birth. In interviews, parents were found to initially lack control over their baby's care and had limited involvement in this. Instead, the professionals undertook most of this. Over time, parents described how professionals facilitated their involvement by teaching parents how to care for their baby and giving them opportunities to do so. Effort made by professionals to involve parents in the baby's care was viewed positively by parents:

> "*they include us in everything for [baby]… just today, erm [baby] gets weighted today and they're waiting for us to come up to weight him, which is a nice thing, it's a nice touch that, you know, cos that's a big thing for us…*" – Father/<28weeks/Before-NICU

Parents' desire to be involved in their baby's care was linked, in interviews, to their identification as the 'parent' and the responsibility within this role to care for the baby:

> "*we're his parents, we should be doing that anyway…*" – Father/<28weeks/Before-NICU

To fulfil the 'parent role' to be informed and involved in the baby's care, parents described a need to be present at follow-up clinics. One mother described her need for her partner, the baby's father, to be present at clinics for this purpose:

> "*He is a part of her life as well so he does need to be involved in it, it can't just be me all the time, because it has to be him as well, so, he does need to come to the appointments to know what's going on…*" – Mother/28-32weeks/PBI/After

One father described his anger and frustration at being unable to attend a clinic, due to restrictions in place as a result of the COVID-19 pandemic:

> '*I've felt angry inside, frustrated at the fact that I'm working… I thought I'm going to work everyday… I can't even go in and you know, be there… I felt isolated…'* - Father/28-32weeks/PBI/After

Some parents did not agree with the COVID-19 restriction that only one parent could attend a clinic in-person. However, during these restrictions, being able to videocall their partner in a clinic was viewed positively.

One mother highlighted the difference between knowing and feeling motherhood. While seeing her baby as her son, her identity as a mother was disrupted by the medical equipment surrounding her baby on the NICU:

> "*I knew that was my son, and he was my baby and he was my responsibility, but as feeling like a mum, it's definitely something that you need to work on*…" – Mother/<28weeks/After

Barriers to independence and being involved

The mother, quoted above, who described her ability to feel like a mother being disrupted on the NICU, explained this as being due various barriers that existed here. These included a lack of privacy whilst breastfeeding, not feeling completely comfortable, and distractions created by the noises of other people present, medical equipment and monitors. The potential for her baby to become unwell meant this mother was watching the monitors constantly to check how her baby was:

> *"you're not in your own comfort zone… it's constant anxiety of why the beeping noise is going on all the time… my mind was never on me and [baby], I was constantly watching the monitor…that takes away a lot of the emotional bonding that you really need to do… it was never that sort of sentimental time with your baby…"* - Mother/<28weeks/After

The constant "beeping" sounds of monitors was found to create anxiety for other parents too. In addition, the extensive medical equipment surrounding a baby was also commonly described amongst parents as a barrier to being involved in their baby's care as it made handling more challenging. One father described this, saying:

> "*we did ask for a little bit of shadowing, especially changing the nappies cos it was a little bit difficult I think the pair of us got a little but flushed at times, obviously, being, it's not something normal to put your hand into an incubator with all the wires… at sometimes it was a little bit overwhelming…"* – Father/28-32weeks/PBI/Before-home

Removal of medical equipment, such as the transition from an incubator to a cot, was described by parents as a significant event as it granted them some independence:

> "*so when [baby] got moved from an incubator to a cot, that's a massive deal to us… it meant I was able to pick him up, you know, without asking someone…"* – Mother/<28weeks/After

Parents with a premature baby described their baby's size and fragile appearance as being barriers to handling initially:

> *"cos he was so small I felt like if I touched him you know, wrongly, I was gonna hurt him, erm, so you're a bit on edge sort of thing…"* – Father/<28weeks/Before-NICU

Lacking confidence was also described as a barrier to being involved and caused parents' dependence on professionals to increase. One father described a loss of confidence after receiving news of his baby's brain injury as he questioned whether he had contributed to this:

> "*it did make me worry when I was lifting her, I was thinking 'am I being a little bit heavy handed?... it did knock my confidence, it did, and I had to say to one of the nurses 'can I have a bit of support?"* – Father/28-32weeks/PBI/Before-home

Whilst parents described wanting to be involved in their baby's care, these barriers affected their ability to do so. One father described himself and his partner making the decision early on to be involved in the baby's care, as he felt this necessary to prepare him and his partner for taking the baby home in the future. However, this couple sometimes felt overwhelmed due to the experience of caring for their first child in an NICU being very new to them, and at these points, "took a step back" (Father/28-32weeks/PBI/Before-home), becoming less involved.

Overcoming barriers

Parents described how over time, with support and encouragement from staff, and as the baby grew, their confidence in handling their baby increased, and they became more involved in their care:

> "*you just get used to it, erm and you know, you do it, like, you do it like the nurses do it now cos you've been doing it for so long…*" – Father/<28weeks/Before-NICU

Through this, parents were able to gain independence in their role, as they gradually progressed from being heavily reliant on professionals, to being much more independent. One mother described this transition as having to:

> "*gradually go through getting that independence as a mum*" – Mother/<28weeks/After

Gaining responsibility

Parents described how professionals gradually gave them more responsibility over time, so that they were prepared when the time came to take their baby home. Despite this preparation, parents described how they did not feel fully prepared to care for their baby independently once discharged from the NICU. One mother described her worry at this stage, which she explained as being because:

> "*you will be alone, you will feel a little bit unsafe at home not in the hospital…"* – Mother/<28weeks/Before-home

Once home with the baby, it was clear from interviews that parents' lack of confidence and dependence on professionals persisted. Parents described relying on professionals for information and medical expertise in their transition to home and this was particularly true where this was their first baby.

Power and choice

Parents expressed a desire to have choice in their involvement over their baby's care. One father described how he appreciated the way in which professionals allowed him and his partner to adjust their involvement in their baby's care:

> *"I think they got the balance right as well because I think they could see that it was all new to us and, obviously we were really keen to obviously do erm, get involved, but they also took a step back, and I think that was a good thing…"* – Father/28-32weeks/PBI/Before-home

One mother described how she wanted to make her own choice about how she fed her baby and felt negatively about staff trying to push her to follow a particular method:

> "*I didn't like the idea of forcing me to do something, like telling me a different idea but without forcing me to do a specific one, let me choose what I, what I feel is the right thing"* – Mother/<28weeks/Before-home

Parents also described the control they were able to exert over the ways healthcare services were provided to them and their baby. They described lacking control in many areas, such as the way staff shifts are organised and the restrictions in place as a result of the COVID pandemic. As well as lacking control, parents also appeared to lack power relative to professionals. The nuances with which parents describe their interactions with professionals give insight into a parent-professional power relationship, whereby parents perceive professionals to have greater power than them. This is illustrated in the use of phrases such as professionals "allowing" parents to do things, "letting" parents in and out of the unit and at discharge, "keeping" parents in overnight, and "telling" parents to do things. At other times, parents described how they were given power and control. One father described being given a choice regarding whether physiotherapy for his baby was started after discharge from the unit. Some parents also described being informed by professionals of their ability to self-refer to the physiotherapist if they felt their baby needed this service. Additionally, parents who were seen at home visits by the Community Neonatal Liaison Specialist (CNLS) described having some control over the time at which they were discharged from this service.

Having their voice heard

Some parents also described how much they valued having the ability to express their views to professionals and for these to be taken on board. One father, in particular, expressed this, saying:

> "*the consultant was there to speak to us about it and, took our opinion on board which is, you know, really good for us that we're actually getting listened to, because we, we're there every day, we know what [baby]'s like and we know how, what he likes and what he doesn't like…*" – Father/<28weeks/Before-NICU

This father described how he believed that his viewpoint was valuable in helping his baby receive the right care, as the significant time he had spent with his baby on the NICU gave him substantial knowledge of their needs.

4.4.5. Theme five: Feeling understood

Feeling understood by professionals

Feeling understood by professionals was found to be important to the parents interviewed for three reasons. Firstly, to help fulfil their information needs. One mother described how speaking to a familiar nurse meant that the nurse was able to understand her information need, which helped her to fulfil this:

> ***"****it was reassuring when I needed to speak to a nurse, if I'd already spoke to them, it was sort of well, we're on the same lines here if anything's wrong I need to know about it…"* – Mother/<28weeks/Before-home

Secondly, feeling understood appeared to provide emotional support to parents. This appeared to occur by the following mechanism: by understanding how parents felt, professionals could then respond appropriately, providing emotional support to parents, such as encouragement and reassurance. This was described by one mother:

> "*they were just absolutely amazing in there, they could see that you were worried and they'd be like 'cmon [mother] let's do this, let's do that' and they did get you through your days in there to be honest, they did*" – Mother/28-32weeks/PBI/Before-home

Lastly, parents described their need for professionals to understand their perspective to fulfil their role as the sole 'advocate' for their child. One mother illustrated this, saying:

> *"you're your child's advocate and you have to advocate for your child as much as possible, there's no one else to do it for them, you're the parent, you're the, erm, carer so it was upto me to voice anything that I wasn't happy about…"* – Mother/<28weeks/Before-home

It appeared, in the interview narratives, that when professionals were familiar to the family, this helped them to be "understanding" towards parents, as they knew the personal circumstances of the parents and baby.

Feeling understood by other parents and family members

One father described how he felt understood by other parents on the NICU, and was therefore being able to seek emotional support from them:

> "*I found that, I found that really reassuring that there's like a family room, and erm so I just used to go in there… it was nice to hear from them if they were like ready to go home or in the*

> *middle, so it was nice to hear how their journey's been and how they felt, you sort of feel like 'oh this is how, others feel like this now', sort of things…*" – Father/<28weeks/Before-NICU

Here, this father described how the other parents on the NICU were able to understand him as they had shared similar experiences. In contrast, this same father described how his friends and family could not provide emotional support; he assigned this to the fact that none of them had experienced having a baby on an NICU.

Interestingly, whilst neither father interviewed in this study felt able to seek emotional support from their family members, one mother described how her parents frequently provided emotional support when she visited the NICU alone:

> *"I facetime my mum and dad with the baby and stuff I find that, I find that helps especially if I'm feeling really emotional, I'll just ring my mum and get support from her…"* – Mother/<28weeks/Before-NICU

4.4.6. Theme six: Patterns of care

Addition and removal of medical care and follow-up

During the period of early neurodevelopmental follow-up, patterns of care were found to exist, whereby certain events had a certain meaning to parents. One pattern was that reduced involvement of medical staff and equipment signaled to parents that their baby was doing well and created reassurance. All parents considered discharge as being a positive thing, and a relief as it symbolised to them that the baby was doing well:

> *"it obviously shows signs that he's on the right path, erm, so it is reassuring in a way that he doesn't need to be seen by neonatal"* – Mother/<28weeks/After

Similarly, moving from higher to lower dependence care within the NICU was associated by parents with the baby being well, and because of this, parents had a lower expectation for problems to occur once their baby was receiving lower dependency care:

> "*when she left the intensive care we were like 'oh great everything must be fine she's going to the nursery', that's the next step to home…*" – Mother/28-32weeks/PBI/Before-home

In contrast, addition of medical teams was described as worrying and perceived negatively. One mother reported this when the neurological specialist team at AHCH became involved in her baby's care:

> "*they said they would have to get in touch with like the neo-, you know the, what do you call them, the head experts in Alder Hey, so then, it was more worrying then, we were like 'oh for god's sake'…"* – Mother/28-32weeks/PBI/Before-home

Patterns of information-giving

As well as patterns of care, patterns of information-giving were also found in parents' accounts. Parents described how information was typically provided by doctors at their baby's bedside, often during ward rounds. This became a mundane and routine event, and so when a professional broke this routine by asking to speak to parents in a private side room, this was reported to trigger parents' 'gut instinct' that the information the professionals had to share was particularly 'bad' or unusual. One mother describes this, saying:

> *"this one day they came in and they said to us 'oh it's a bit noisy in here at the moment we're gunna take you into a separate room' and straight away your gut then says to you, 'why, why are you not telling me in front of like where you've told me all the rest of the information?... but, we understood why, and we knew, we knew in our gut they had something to tell us"* – Mother/FT/PBI/Before-home

Whilst this 'gut instinct' feeling was not a nice one, parents report there being no easy way to receive 'bad' news, they expressed that they appreciated being taken out into a room to receive this type of news privately, rather than publicly at the bedside. It was clear in interviews that the concept of publicly versus privately given information is important to parents; one mother described some experiences in the NICU where nurses "let slip" news about their baby "in passing conversation" (mother/<28weeks/Before-home) at the bedside, without warning and how she found this distressing. The mother perceived this to be an inappropriate way to provide significant or 'bad' news and described how it also limited her ability to seek further information as the nurses who "let slip" this news could not provide any further information about it. Instead, this mother had to wait for a consultant to be available to answer her questions. This mother, and others, described their preference to receive this type of information privately, in a side room, alongside a full explanation and the opportunity to ask questions.

This patterning of information-giving was also found for not receiving information. Where parents perceived news-giving to signify bad news, receiving no news was viewed positively as it signalled to parents that things were going well with the baby:

> *"no news is good news really in neonatal, you know, you don't want all these meetings all the time because there's always something happening with your baby…"* – Mother/<28weeks/Before-home

4.4.7. Theme seven: Individuality

A recurring theme of 'individuality' has been found in the data, whereby characteristics of parents, professionals and babies are unique to the individual. This was found in analysis to run through all themes, except for themes 5 and 7 ('feeling understood' and 'patterns of care'), because whilst parents appeared to manage their uncertainty in different ways, have individual needs, preferences and priorities, they all reported wanting to feel understood, and perceived the same patterns of care.

This individuality is seen between interviews, and also reported by the parents themselves. One father expressed his view that professionals should consider the individuality of parents when providing information:

> *"I think, when you're speaking to, erm, people of different backgrounds, obviously we're from different walks of life, different job sectors, I think its best always keeping it erm, clear, concise and informative…"* – Father/28-32weeks/PBI/Before-home

Another parent described how important they felt it was that professionals provided tailored information about their baby's development, due to the individuality of this:

> *"I know babies develop at different stages, erm, so if it's like a website I wouldn't want parents to think, to worry and think their baby's not doing something and then cause unnecessary stress… maybe something a little bit more tailored… to that baby"* – Mother/<28weeks/Before-home

When an unfamiliar professional was caring for the baby, parents described feeling less reassured and expressed concern that they would not understand their baby's individuality.

Individuality within the development of babies was a source of reassurance for parents, as they understood that babies develop at slightly different rates to each other:

> *"if he's not doing such and such at this time don't worry, they all do it at different times, I mean, that's just a reassuring thing, they do, babies will do things at their own time…"* – Mother/<28weeks/Before-home

Parents valued receiving help from a consistent group of staff in the belief that this continuity produced a better understanding of the baby. One father described this:

> *"sometimes you just want consistency erm, someone that knows [baby] because you know, every baby is different, aren't they?"* - Father/<28weeks/Before-NICU

Individuality was also found in parents' needs and preferences for information and support. Often there was an asymmetry between the two parents in a couple; they had different levels of involvement in the baby's care and development, and different needs for information. Where maternal illness occurred after birth, the father was reported to be more involved in the baby's care, received more information from professionals and this led to him having greater awareness than the mother. Where the father worked and the mother was on maternity leave, the mother was described to be more involved in the baby's care. Where only one parent could attend clinics, due to COVID-19 restrictions, there was an assumption present amongst parents that the mother would be the one to attend:

> *"it's just one parent, but obviously the mum's gonna go in with them"* - Mother/28-32weeks/PBI/After

Individuality was also found within the level of certainty required for a parent to feel reassured. Some parents described feeling constant anxiety and worry until all uncertainty relating to their baby's development was resolved, for example until their baby reached all their milestones. Other parents reported feeling reassured and unconcerned despite their child having some areas of their development which are slightly delayed, providing they are mostly 'on track'.

Other areas of individuality described were parents' preferences about the extent to which they wanted to be involved in their baby's care, individual ways that different parents dealt with their emotions, and individual areas of needs which were found to be influenced by their previous experiences. For example, one father described how his needs and preferences for seeking information differed to his partner's, and how this was influenced by his previous experiences working with children with disabilities as part of his job. Additionally, one mother described having a greater information need than her partner and how this meant that she was left with an unfilled need for information if updates about the baby were transferred to her from professionals via her partner, as he did not seek sufficient information from professionals to fulfil her needs:

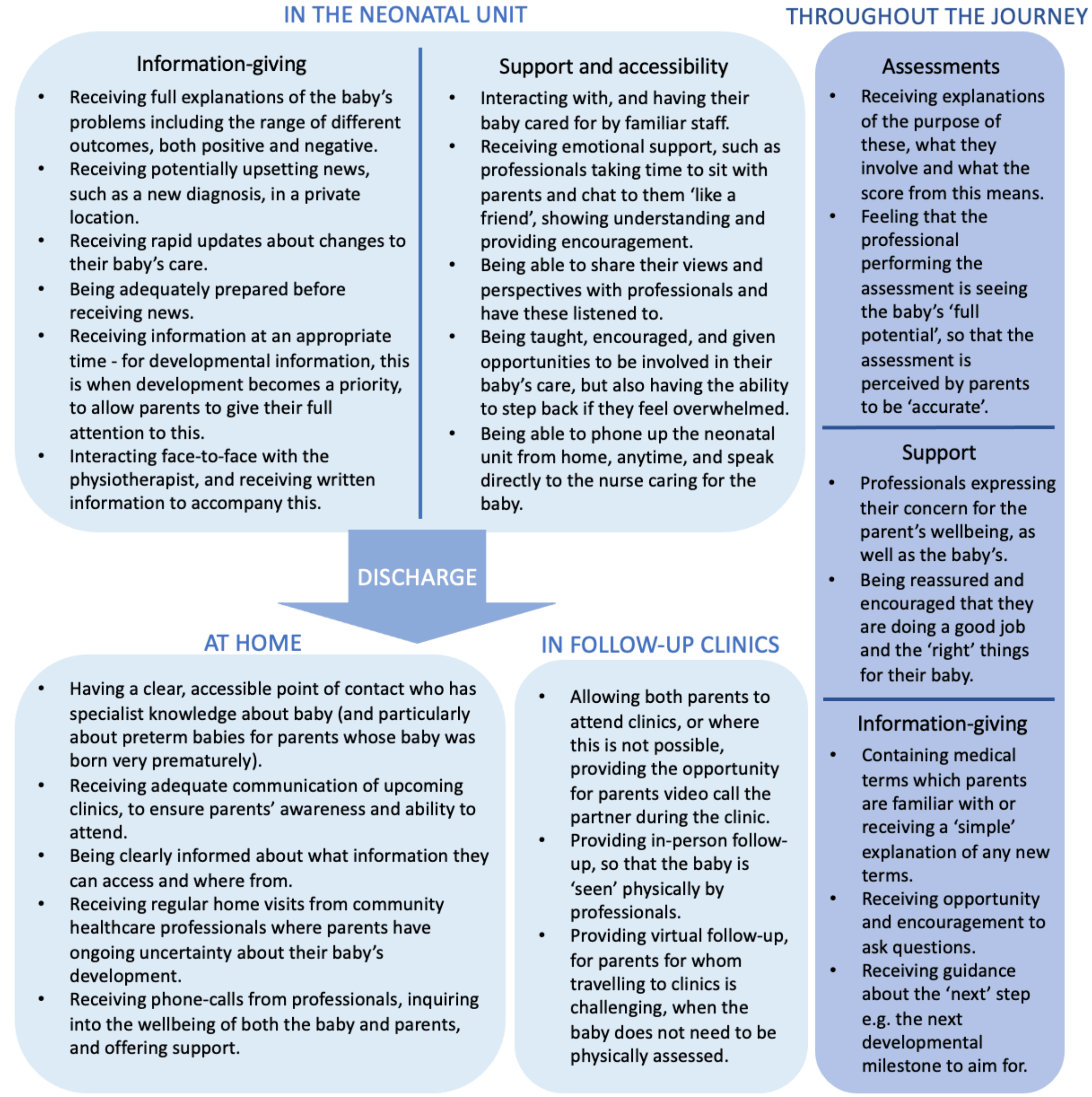
> *"I would've had those questions ready to be asked and [partner] definitely would not…"* – Mother/<28weeks/Before-home

Parents also reported professionals to have individuality; they described how professionals working for different healthcare services or hospitals had different levels of knowledge and expertise. This influenced parents' preferences in terms of who they would rather contact for information and support. General Practitioners (GPs) were perceived by parents to lack specialised knowledge about babies, particularly preterm babies; therefore, they were not parents' preferred point of contact for information. Instead, parents described their preferences to seek information from professionals at the LWH or AHCH as they were perceived to have more knowledge about this. Parents' views on the levels of expertise of professionals at these two hospitals differed; some felt the staff at LWH could not provide them with the information they needed after being discharged from the NICU here, whereas the staff at AHCH could. Others regarded staff at LWH as having greater expertise in neonatal care than those at AHCH. Parents also compared how different healthcare services are organised and described how this affected their satisfaction with these services. Additionally, parents reported individual professionals to differ from each other:

“*every nurse is different how they do their job…*” - Mother/<28weeks/Before-home

4.5. Facilitators to a ‘good journey’ through early neurodevelopmental follow-up

Parents’ responses highlight areas which were important to them in facilitating a ‘good journey’ through the early neurodevelopmental follow-up provided during the NICU and the first few months after being discharged home with their baby.



IN THE NEONATAL UNIT

Information-giving

- Receiving full explanations of the baby’s problems including the range of different outcomes, both positive and negative.
- Receiving potentially upsetting news, such as a new diagnosis, in a private location.
- Receiving rapid updates about changes to their baby’s care.
- Being adequately prepared before receiving news.
- Receiving information at an appropriate time - for developmental information, this is when development becomes a priority, to allow parents to give their full attention to this.
- Interacting face-to-face with the physiotherapist, and receiving written information to accompany this.

Support and accessibility

- Interacting with, and having their baby cared for by familiar staff.
- Receiving emotional support, such as professionals taking time to sit with parents and chat to them ‘like a friend’, showing understanding and providing encouragement.
- Being able to share their views and perspectives with professionals and have these listened to.
- Being taught, encouraged, and given opportunities to be involved in their baby’s care, but also having the ability to step back if they feel overwhelmed.
- Being able to phone up the neonatal unit from home, anytime, and speak directly to the nurse caring for the baby.

DISCHARGE

AT HOME

- Having a clear, accessible point of contact who has specialist knowledge about baby (and particularly about preterm babies for parents whose baby was born very prematurely).
- Receiving adequate communication of upcoming clinics, to ensure parents’ awareness and ability to attend.
- Being clearly informed about what information they can access and where from.
- Receiving regular home visits from community healthcare professionals where parents have ongoing uncertainty about their baby’s development.
- Receiving phone-calls from professionals, inquiring into the wellbeing of both the baby and parents, and offering support.

IN FOLLOW-UP CLINICS

- Allowing both parents to attend clinics, or where this is not possible, providing the opportunity for parents video call the partner during the clinic.
- Providing in-person follow-up, so that the baby is ‘seen’ physically by professionals.
- Providing virtual follow-up, for parents for whom travelling to clinics is challenging, when the baby does not need to be physically assessed.

THROUGHOUT THE JOURNEY

Assessments

- Receiving explanations of the purpose of these, what they involve and what the score from this means.
- Feeling that the professional performing the assessment is seeing the baby’s ‘full potential’, so that the assessment is perceived by parents to be ‘accurate’.

Support

- Professionals expressing their concern for the parent’s wellbeing, as well as the baby’s.
- Being reassured and encouraged that they are doing a good job and the ‘right’ things for their baby.

Information-giving

- Containing medical terms which parents are familiar with or receiving a ‘simple’ explanation of any new terms.
- Receiving opportunity and encouragement to ask questions.
- Receiving guidance about the ‘next’ step e.g. the next developmental milestone to aim for.

Figure 17: Facilitators to a ‘good journey’ through neurodevelopmental follow-up, described by parents in in-depth interviews

Chapter five

Discussion and conclusion

5.1. Introduction

In this chapter, I will discuss the contribution of this research to existing knowledge of this topic, including how the results from this study support and add to related literature. I will also make recommendations for clinical practice based on this study's findings including the facilitators to a 'good journey' through early neurodevelopmental follow-up outlined in chapter four and discuss this study's strengths and limitations. Finally, I will outline my recommendations for further research in this area, before concluding this thesis.

5.2. Summary of findings

My study aimed to understand parents' and caregivers' views and experiences during the process of early neurodevelopmental follow-up for their high-risk infant. During interviews, parents provided in-depth insight into their views and experiences during the early neurodevelopmental follow-up their infant received in the NICU and at a 12-week follow-up clinic by a physiotherapist. This included their experiences and views regarding their infant undergoing the HINE and GMA. The findings also shed light on these parents' perceptions of their baby's developmental risk and their interactions with healthcare professionals about this. Many parents' understanding of these developmental assessments and the purpose of physiotherapy appeared to be limited in these early stages of neurodevelopmental follow-up. It is important to note that whilst the aim of this study was to explore parents' and caregivers' views and experiences, most of the participants were mothers, and so the findings primarily report mothers' views and experiences.

I identified seven themes from my interviews with parents. Theme one describes the overwhelming feature in parents' accounts: the managing of their uncertainty. Parents described uncertainty relating to their baby making progress, being on track and their future. The many ways they described managing their uncertainty can be grouped into three main categories: seeking information to resolve their uncertainty, changing their perspective to consider the uncertainty in a different way, and planning ahead to ensure the baby had adequate care in place in case they required it in the future. It appeared that parents' needs for follow-up, support and communication with professionals were driven by this uncertainty.

Theme two describes parents' priorities during this time, which appeared to be their baby, the mother, the family unit and their own wellbeing, however it was not always clear that their own wellbeing was prioritised. In addition, different aspects of the baby's care were prioritised at different times: the many acute issues that occurred during this time often took priority over development.

Theme three describes the high levels of trust parents had in professionals, and their confidence in the quality of care being provided for their baby. This theme also describes parents' compliance with advice given to them by professionals. In addition, some parents appeared to opt for a completely paternalistic approach, aligning their needs and actions with those of the professionals, whereas other parents expressed having their own needs, independent of those of professionals.

Theme four describes how, initially, parents appeared to lack control and involvement in their baby's care in the NICU and required professionals' support and encouragement to gradually become involved over time. This theme also describes the positive views some parents had of being given choice in their baby's care and being able to express their views to professionals and have these listened to. Parents described how gaining independence in their role as parents was important to them, but that challenges to this existed, because of their baby staying in the NICU.

Theme five describes the importance of feeling understood by others to be able to seek emotional support and to help fulfil parents' information needs. For this reason, some parents described their preference to communicate with, and have their baby cared for, by familiar staff.

Theme six describes patterns parents perceived within their baby's care and information they were given about this. Their baby moving from high to low dependency in the NICU or being discharged from a follow-up service was viewed positively by these parents, who described this as symbolising that their baby was doing well.

Finally, theme seven describes the individuality that existed between different parents' views, needs and levels of understanding, as well as different babies' developmental trajectories, creating a need for tailored information.

5.3. Discussion of findings

The findings from this study contain some unique and in-depth insights into parents' views and perspectives during early neurodevelopmental follow-up for their high-risk infant. In this section, I will discuss the relevance of these findings and how they support, challenge and add to the current literature.

The use of qualitative methods in this study allowed parents to speak freely about issues they felt were important to them and an inductive approach to data analysis allowed the findings to reflect the parents' own views. The broad range of issues identified by parents both relating to early neurodevelopmental follow-up and within other areas of healthcare provided for their infants, demonstrates that during this time these parents encountered many issues and areas of need relating to their infant's care and development. These areas include parents' need to manage their uncertainty via access to, and appropriate communication with, healthcare professionals; their need to receive support for their wellbeing; the competing priorities to development which exist; the level of consistency of healthcare staff; gaining independence in their parent role and their individualised needs.

5.3.1. Managing uncertainty

5.3.1.1. The need to manage uncertainty

The overwhelming feature in parents' accounts was their uncertainty about their infant's current situation and future. When uncertainty was poorly managed, it was clear that parents' wellbeing suffered, and they struggled to cope; describing feelings of anxiety and signs of depression. There is a large body of literature which also describes parents' uncertainty in similar situations (165, 168, 170, 173-176, 264). This includes studies which report parents' experiences when receiving a diagnosis of cerebral palsy, suggesting that uncertainty may persist in a similar way throughout the journey leading to a diagnosis for a child and their family (151, 173, 183, 265, 266). However, this is the first study to report the ways parents experience uncertainty during early neurodevelopmental follow-up with the HINE and GMA.

In general, the uncertainty expressed by these parents persisted despite parents reporting high levels of trust in the care that their baby was receiving. Professionals at the LWH NICU (and follow-up clinics) were reported to be both knowledgeable and the 'experts'. However, it was clear that this was often not enough to manage parents' uncertainty and that additional measures must be taken to do this. Obviously, if uncertainty can be resolved by providing information, this should be done, but these infants' neurodevelopmental outcome is not actually known during this time, making it impossible to provide reliable and honest certainty. Managing parents' uncertainty should therefore be considered during all stages of early neurodevelopmental follow-up. Professionals' awareness of the impact of parental uncertainty about their infants' developmental prognosis is important. For parents, uncertainty sometimes stimulated them to seek information, however this was not always the case.

The way that information about the baby's uncertain situation is given, and the way that parents manage this uncertainty by accessing information from professionals, is crucial.

Next, I will discuss features of parents' access to healthcare services and communication with professionals that appeared, in interviews, to be essential for managing their uncertainty.

5.3.1.2. Access to healthcare professionals

Accessing information from professionals

Parents, in my interviews, described the importance of needing to access healthcare professionals to receive information to minimise their uncertainty. This is supported by other studies (173, 176, 265, 266). However, some parents in my study described feeling unclear about how they could access information from professionals and what information different professionals could provide. This lack of clarity appeared to discourage some parents from seeking information. Despite their baby being followed up at the LWH, parents did not feel a level of attachment to the hospital which might have enabled them to ask questions. One of the learning points from this might be that health staff need to emphasise the types of information and support available to them from the LWH (or from elsewhere) after their baby is discharged.

A clear point of contact

The parents interviewed after their baby was discharged from the NICU fell into two equal-sized groups – those receiving follow-up from a Community Neonatal Liaison Specialist (CNLS) after their infant was discharged from the NICU (three parents) and those who were not (three parents). Parents followed up by the CNLS felt this professional gave them a clear, accessible point of contact; this professional was reported to be highly supportive, understanding and responsive to their needs. This was in strong contrast to parents who were not followed up by the CNLS, who felt they lacked a clear point of contact who could answer their questions and provide support. Neonatal services in Liverpool are divided between two hospitals – the LWH and AHCH. After their infant had been discharged from the LWH NICU, parents not receiving follow-up from the CNLS reported a lack of contact with healthcare professionals because they felt they were between two hospitals. One mother described a complete lack of communication from healthcare professionals for several weeks after her baby came home from the NICU; another mother described being 'in the middle with nothing'.

A longitudinal mixed-methods study from London, UK, found that parents provided with a service, run by two healthcare professionals, which aimed to fulfil their needs around the time of diagnosis of visual impairment in their child was beneficial. The service provided emotional and informational support to parents through discussions and helped link parents to further support services (201). This service appeared to be run in a similar way to the CNLS role. My interview findings suggest that a similar service, provided to parents with a high-risk infant undergoing early neurodevelopmental follow-up in Liverpool, who are not followed up by the CNLS, could also be highly beneficial. In general, parents described their preference for a clear point of contact to someone who could be easily accessed, was already familiar with them, was aware of the care the baby had already experienced in the NICU and could answer their questions by having expertise in high-risk infants. In line with other research (190) these requirements were not best fulfilled by the parents' general practitioner (GP).

Face-to-face follow-up and assessments

A particular requirement expressed by parents was for face-to-face assessments of their baby by professionals. Whilst some parents described regularly assessing their baby for signs of abnormal development themselves, they lacked confidence in their own monitoring as they felt they lacked the knowledge to spot and interpret developmental signs. In-person developmental assessments were seen as a way of reassuring parents that their baby had been 'properly checked.' Other qualitative studies also describe this (190, 195, 267, 268). The parents I interviewed were mostly first-time parents, which further limited their confidence in monitoring their baby, as they lacked other children to whom they could compare their baby. Another qualitative study that explored the experiences of parents with multiple children more extensively found this provided parents with knowledge of what was 'normal' for their baby (190).

5.3.1.3. Communication with healthcare professionals

The parents who participated in this study provided detailed insight into the ways professionals provided information, and how this was either effective or ineffective in fulfilling their needs and managing their uncertainty.

Information needs – is my baby on track and making progress?

'Being on track' and 'making progress' were the two ways that parents conceptualised their uncertainty about their infant's current situation. This has not been previously identified in the literature which I could access. Conversations with professionals, following developmental assessments, allowed parents in my study to understand whether their baby was on track with their developmental trajectory. If the baby was not quite on track, parents could still be satisfied if their baby was at least making some progress.

Parents with a preterm baby often described needing more information about their baby's expected developmental trajectory, as they expected their baby to have developmental delays in comparison to full-term babies. Parents wanted to know how long these delays would persist and understand at least some rough guidance of the time points when they should expect their baby to reach certain milestones.

Information from the physiotherapist in the NICU

All parents described finding the verbal and written information provided by the physiotherapist on the NICU helpful and reported it met their needs, at that point in time. The written information was useful as they could refer to it later once at home with their baby. However, one mother felt that on reflection, she would have been able to give her full attention to the conversation with the physiotherapist had it been held more formally, in a private side room, rather than at her baby's bedside. A 2020 study trialling a programme for structured meetings between parents and healthcare professionals in the NICU found their small sample of parents viewed this positively, and felt it helped them to improve their knowledge of their baby's developmental care (167). Receiving information from the physiotherapist in a more structured, formal way, as in this study, could be beneficial for the parents in my study for understanding their infant's developmental risk better.

Some parents did not understand the purpose of physiotherapy or the physiotherapist-led follow-up clinic before attending it. One mother reported not complying with advice and guidance from the physiotherapist to perform exercises with their baby at home. In other studies, parental knowledge of the benefits of performing exercises for their baby has been found to be a factor affecting parents' adherence to performing the exercises (269). This mother in my study appeared to have very limited awareness of the importance of these exercises and the role of physiotherapy for her baby, which might explain her non-adherence. All families who participated in this study attended the physiotherapist-led follow-up clinic, however this clinic has had some families not attend. Competing priorities for a baby have been found to be a reason for parents not attending follow-up clinics for their baby (270). This demonstrates the need to ensure parents understand the importance of physiotherapy exercises and physiotherapist-led follow-up for their baby to ensure that parents undertake these exercises and attend the clinics. This corroborates with rigorous qualitative and quantitative research into parents' compliance in home programmes for their children with cerebral palsy (98, 269).

Processing information and preparing parents

For many parents interviewed, the way that information was provided affected their ability to process it and, therefore, their ability to understand topics such as their baby's developmental risk. Several studies exploring parents' experiences receiving a diagnosis of cerebral palsy report the need to prepare parents adequately for the diagnosis (149-151). In my interviews, as well as other studies (157, 265, 266), when parents are not prepared for information, such as a diagnosis of brain injury in their baby, this can be a massive shock, making it difficult to process and highly distressing. Professionals must give information to parents during early new developmental follow-up in a way that parents can take in and understand so that if a diagnosis of cerebral palsy is given, they are prepared for this.

It was clear that parents often struggled to take in information if it was given in large quantities all at once or if professionals used medical terms with which parents were unfamiliar, without explaining these sufficiently. This is not a new finding and is completely consistent with other studies (124, 149, 195, 271, 272). There is a need for information to be given over multiple sessions, and tailored to the individual, based on the professionals' awareness of the parents' understanding of different medical terms. Parents described struggling to accept a diagnosis when it was not visible to them such as a diagnosis of brain injury, particularly where the baby had no symptoms or signs of this. As an early diagnosis of cerebral palsy will most likely be given before any visible signs emerge in the baby, parents may not be able to see any problems with their baby's development themselves and must be prepared for the diagnosis in other ways. This could include conversations with professionals about the baby's developmental risk and using other motor assessment tools during this time, such as the Alberta Infant Motor Scale (AIMS) (273) to highlight any motor delay to parents. Being prepared for a diagnosis of cerebral palsy has been shown to help parents adjust to it once they receive it which, in turn, helps to maximise their engagement in interventions for their child (151, 157). This is crucial, as the early interventions which show the most promising results for improving infant developmental outcomes are those where parental involvement plays a key role (18, 114).

The inability to take in and process information during a conversation with a professional may result in parents not asking questions at the time of receiving the information. Providing a question prompt list to parents has been shown in one study to be helpful for parents in suggesting questions they may wish to ask during conversations with professionals about their baby's developmental risk (274). This could also be helpful for the parents followed up at the LWH.

Keeping parents informed

Timely updates about their baby that are clear and comprehensive and the prompt delivery of news were all viewed by parents as important. Some parents described a need to be informed of investigations, such as brain scans, whilst their baby was undergoing these, to help them prepare for receiving the results. This concurs with findings from other studies (176, 195, 275). In addition, parents described wanting to hear results from scans as soon as possible as they experience stress and anxiety whilst waiting for these. However, a US study which used surveys to explore 30 professionals' perspectives demonstrates that this is often not something these professionals prioritised when identifying cerebral palsy early (119).

Information during developmental assessments

When describing their experiences with the physiotherapist performing the HINE and GMA examinations, some parents described a need to feel that the professional performing the assessment saw an accurate display of their baby's abilities. This study was undertaken whilst the physiotherapist running the new follow-up clinic was still using the GMA as 'pilot' examinations to gain experience performing this assessment. As a consequence, the parents participating in this study reported that the physiotherapist did not provide them with any findings from the GMA. This is probably why described the purpose of the GMA as being for the professionals' training only, rather than being able to provide them with information about their baby.

As this clinic develops, and parents begin to receive results from the GMA, professionals will need to consider how they can do this appropriately. In addition, parents generally appeared to lack knowledge about both the GMA and HINE, and this should be improved. A US mixed-methods study collected parents' perspectives regarding their infant being assessed with the HINE and GMA and receiving an early diagnosis of cerebral palsy following this (119). Through deductive analysis they found these parents desired to be informed of the name and purpose of assessments and what they involve, given via a brief description whilst performing the assessment followed by a summary at the end (119). This may also be successful for better informing parents about the HINE and GMA in Liverpool.

A need for information-giving with both parents present

Parents in my study were all either married or living with a partner and often described having a different information need to their partner. Therefore, some parents felt dissatisfied when information was given to their partner only, as whilst it may fulfil their partner's needs, it does not necessarily fulfil theirs. Some parents also described their anxiety when professionals gave them information on their own, to pass on to their partner, in case they could not remember all the information or miscommunicated it to their partner. Therefore, giving information to both parents in a parent couple at the same time, would likely improve parents' experiences.

5.3.2. Support for parents' wellbeing

Of course, supporting parents appropriately when they first go home with their baby is important to improve their wellbeing (155, 276-278). However, for parents with a baby born preterm or with medical health problems this support is even more important because of their increased susceptibility to poor mental health (279, 280). Additionally, support for these parents is crucial, as poor parental mental health can damage parent-infant bonding, which can negatively impact the infant's development (152-154). I will now discuss ways that parents in my study described accessing support for their wellbeing during their NICU stay and early neurodevelopmental follow-up, and suggest ways this could be improved.

Sources of support

Several qualitative NICU-based studies have reported that professionals and other parents who have had similar experiences on the NICU are sources of emotional support for parents (149, 167, 272). In my study, it appeared that these individuals could provide support for parents because they were able to understand the parents' experiences. In contrast, both fathers interviewed described how they could not seek emotional support from their friends or family as these individuals did not understand the parents' situation. Interestingly, one mother described her family members being a main source of support, suggesting a hypothesis that mothers with a baby in an NICU are better able to access emotional support from family members than fathers. A quantitative study from 1999 reports that mothers and fathers have equal 'family functioning and social support' whilst in the NICU (281). Further research into this could be valuable, to explore a potential gap in support for fathers, relative to mothers, who have a baby in an NICU.

Parents in my study described how nurses sitting and chatting with them 'like a friend' about general topics, other than their baby, helped to take their mind off their baby's highly uncertain situation. One father also described being able to gain support by talking to other parents on the NICU in the 'family room' which parents can use whilst they visit their baby. These are ways that NICU staff should continue to provide parents with emotional support, to help their wellbeing during this time. Staff simply inquiring into parents' emotional state can also be viewed as supportive in itself (272) and can be a simple but effective gesture to support parents better.

Seeking support

Not surprisingly, parents placed the highest priority on the care of their baby. All parents made sacrifices, some at the expense of their own wellbeing; spending long days in the NICU and not taking time away from this to seek counselling or rest for themselves. Parents also described bottling up feelings of worry and 'plodding on' without seeking emotional support from a counsellor. Professionals should be aware of this and encourage parents to seek support and make time for their own wellbeing. Additionally, the 'family room' was only mentioned by one father in my study as a place for support. Only two parents mentioned the counsellor who works at the NICU, with neither of these parents seeking support from this counsellor. This suggests that professionals may need to make more parents aware of the existence of the family room and counsellor on the NICU and encourage them to use these.

Lack of support after discharge

Some parents in my study described a lack of support from professionals after their baby was discharged from the NICU. Some mothers suggested that, after their baby's discharge from the NICU, a phone call from a professional to 'check in', enquire about both the baby's and parents' wellbeing and coping at home, and to offer counselling support, would have been beneficial for their mental health. There is currently no counselling service available to parents during the time between their infant's NICU stay and being referred onto AHCH services – introducing this would likely be greatly beneficial for parents. Additionally, as the 'pilot' physiotherapist-led follow-up clinic for the HINE and GMA becomes better established, infants may begin to receive an early diagnosis, and parents will need the option to access counselling support at this time.

Managing parents' anxiety

When going home with the baby, issues such as a recurrence of seizures or brain bleeds and signs of neonatal encephalopathy or abnormal development were all talked about and were a source of anxiety for some parents. Some parents reported needing reassurance about these when they saw professionals at follow-up appointments and home visits.

One couple in my study described how their confidence in handling their baby was significantly lowered after receiving news of their baby's brain bleed, as they questioned whether they had made the brain bleed worse by handling their baby incorrectly. This clearly caused them a great deal of stress and concern. Being mindful of the concerns parents might have in being responsible for their child's situation (e.g. in this case – a brain bleed) is something that professionals might want to be aware of and consider tackling.

5.3.3. Competing priorities to development

In my study, parents had a lot of different priorities during the time of early neurodevelopmental follow-up, including their baby's acute medical issues. When acute issues arise, these became parents' top priority. It is possible that professionals should time conversations about development and physiotherapy carefully, providing this information when development is more of a priority for parents. Specifically, one mother described how the issue of long-term development was 'put to one side' during the first few weeks after her baby came home from the NICU. This mother recommended that once parents have completed this initial 'settling in' period, a phone-call from a professional reminding them about the importance of reading and using the information on leaflets provided by the physiotherapist about their baby's development would be helpful.

5.3.4. Continuity of care

A need for continuity of care underpinned several themes in the findings of this study. This was particularly described relating to nurses caring for the baby in the NICU. Some parents in my study described how interacting with familiar nurses helped them to receive emotional support. Nurses who knew the family could understand their situation, recognise their emotional state, and respond to this appropriately. Interacting with familiar nurses also helps parents to gain the information they need as a familiar nurse would already be aware of her information needs and could tailor their information-giving to fulfil these.

A 2021 systematic review exploring parent-professional communication in NICUs found that parent-nurse relationships impact parental stress (271). In my study, parents explained they felt more reassured by how well a nurse 'knew' their baby and considered their baby a priority when the nurse had a familiar relationship with the family. Additionally, some parents described how interacting with familiar nurses enabled them to perceive the NICU as a safe and comfortable environment, whereas many unfamiliar staff caring for the baby created the opposite effect, feeling 'chaotic'. Overall, this suggests that keeping staff consistent would help to improve parents' experiences. For professionals, speaking to the same parents regularly could also be helpful, as they could tailor their information-giving based on what they know about that parent's level of understanding, and their individual information needs. However, professionals' perspective of this would need to be explored, to be certain of this.

5.3.5. Gaining independence in the parent role

Several qualitative studies in various settings (such as in NICUs and at home during the first few years of an infant's life) have found that parents lack control in the NICU and rely heavily on professionals to care for their infant (164, 172, 175, 181, 185, 266, 271). It was clear that parents required professionals to teach them how to be involved and to provide them with opportunities and encouragement to do so, so that over time they could gradually gain control and independence as parents. Parents described barriers to me, including initial fear to hold their baby because of their small, fragile appearance and the extensive medical equipment surrounding them, which they described as making them feel overwhelmed.

In my study, parents described their need to be involved in their baby's care to fulfil their role as the baby's parent, and that becoming involved created positive feelings. There is much evidence-based literature encouraging a 'family-integrated care' approach where professionals support parents to become the primary caregivers for their baby (282-285). In one qualitative study, professionals assisting parents to hold their baby greatly encouraged parent-infant bonding (164). One mother I interviewed described her 'incomplete bonding' with her baby meant she had to put developmental issues and physiotherapy 'to one side' whilst she worked on this. Therefore, it is important that professionals continue to teach and encourage parents to be involved in their baby's care and handle their baby to encourage parent confidence and independence and facilitate parent-infant bonding.

Parents often described a lack of confidence in caring for their baby on their own once discharged from the NICU and felt nervous to go home as there would not be any professionals there if the baby suddenly became unwell. This further evidences the need for professional involvement and support after discharge. One study suggests conversations with parents around discharge are a key opportunity for planning professional involvement and follow-up post-discharge with parents (286).

5.3.6. Individualised needs

In my study, it was clear that parents' needs, views and experiences all differed. There was no single way of interacting with parents or providing care which would have satisfied the needs of all parents. For example, in my study, one parent found a nurse's positive outlook to be helpful and reassuring, whereas another felt dissatisfied by doctors providing what she viewed to be an optimistic perspective of her baby's potential outcomes, which did not fulfil her need to know the 'worst case scenario'. Professionals will need to tailor information to the parent based on an understanding of the parent's individual needs. There is a large body of evidence which supports professionals providing tailored information for parents to aid parent-professional interactions (119, 176, 287, 288). This way, personalisation of information about neurodevelopmental assessments performed in the NICU and at physiotherapist-led follow-up clinics could improve parents' currently limited understanding of these.

5.4. Implications for clinical practice

The findings from my study have highlighted some areas of importance to parents, including areas of early neurodevelopmental follow-up that appear to be working well, and areas that could be improved, to improve their experiences. I will now discuss these further and set out my recommendations for clinical practice. These recommendations fall into five categories: (1) communication, (2) follow-up clinics, (3) developmental assessments, (4) support and (5) access to professionals. I will now summarise these recommendations in each of these areas. Further details are provided in **figure 18**.

5.4.1. Communication

Based on parents' accounts, there are a number of ways communication between professionals and parents could be improved to better manage parents' uncertainty and ensure their satisfaction with the information they receive. These could be used in any interaction between professionals and parents, but there are also specific recommendations relating to a few areas. One is communicating sensitive news to parents appropriately, such as abnormal findings from a brain scan. Another is providing appropriate developmental information to parents about their baby, to fulfil their information need and ensure they are aware of their baby's developmental risk. A third is communication between the physiotherapist and parents in the NICU, so parents better recognise the role of physiotherapy in their baby's care, and the importance of physiotherapist-led follow-up.

5.4.2. Follow-up clinics

There are recommendations relating to the practical aspects of follow-up clinics. These involve ensuring parents are adequately informed about upcoming follow-up clinics at the LWH so they are able to attend these, as well as ensuring follow-up clinics are provided in a suitable setting for parents (i.e. in-person or virtually) and allowing both parents to be present where possible.

5.4.3. Developmental assessments

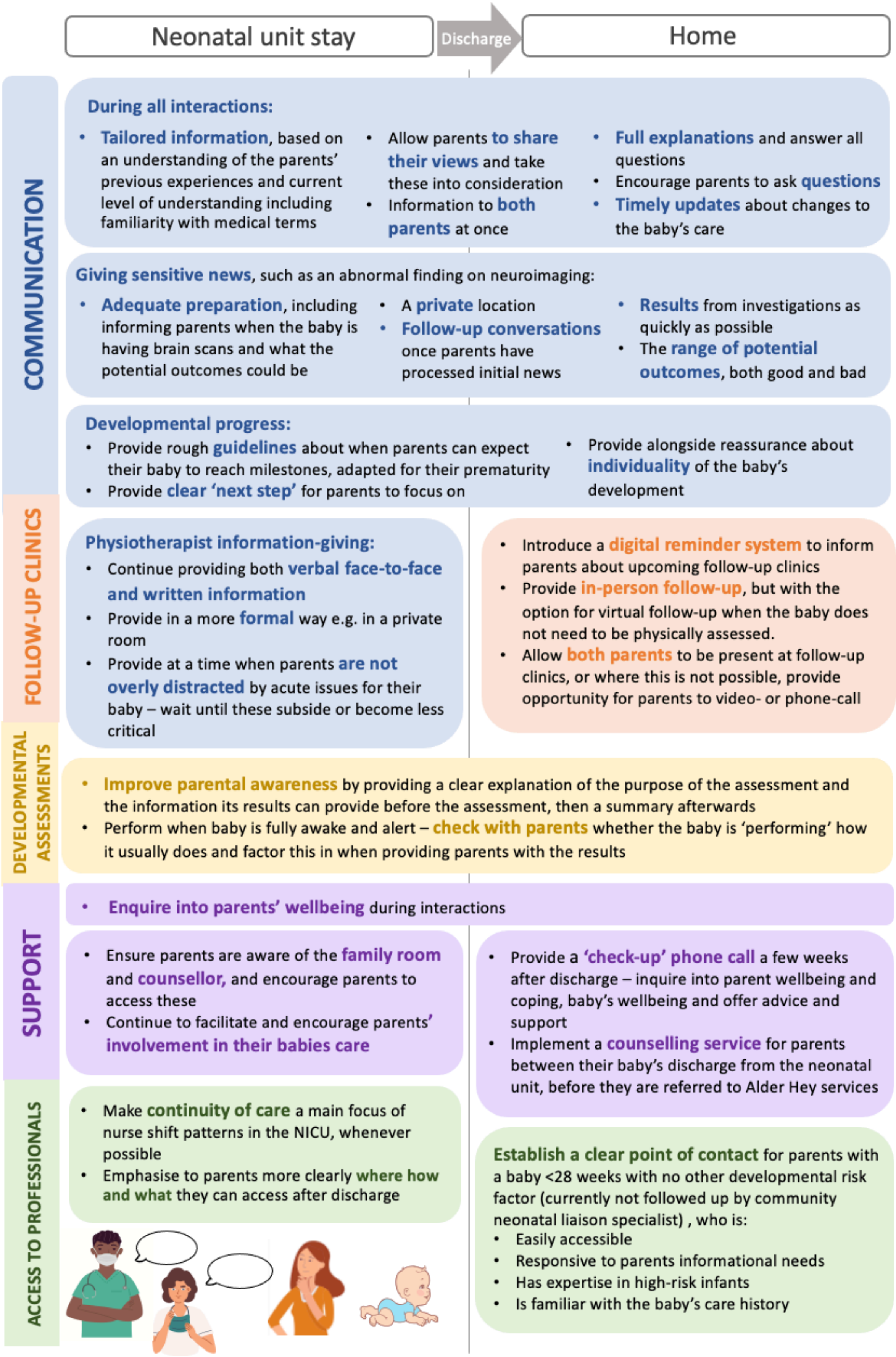
For parents to perceive developmental assessments as meaningful and accurate they need to feel that the professional performing the assessments witnesses their baby's full capabilities. To improve parents' current limited understanding of developmental assessments professionals must adequately inform parents about the purpose of an assessment and the information it can provide about their baby. There are a few recommendations relating to these issues.

5.4.4. Support

As previously discussed, providing adequate support to parents during the time their infant is undergoing early neurodevelopmental follow-up is critical. Based on parents' accounts, there are ways professionals can ensure parents are well supported in the NICU and after discharge. These involve ensuring professionals express their concern for parents' wellbeing, improving parents' awareness of current sources of support available in the NICU and introducing new sources of support after discharge which are currently lacking.

5.4.5. Access to professionals

Based on parents' accounts, there are a few changes that could be made to the way parents access professionals, to help to fulfil their needs and improve their experiences. These involve adjusting nurses' shift patterns in the NICU and ensuring parents are better informed about where they can access information after their baby is discharged. There are also recommendations for introducing an appropriate point of contact for parents whose infant is born under 28 weeks' gestation, but with no other neurodevelopmental risk factors, who are not currently followed up by the Community Neonatal Liaison Specialist (CNLS).



Neonatal unit stay → Discharge → Home

COMMUNICATION

During all interactions:

- **Tailored information**, based on an understanding of the parents' previous experiences and current level of understanding including familiarity with medical terms
- Allow parents **to share their views** and take these into consideration
- Information to **both parents** at once
- **Full explanations** and answer all questions
- Encourage parents to ask **questions**
- **Timely updates** about changes to the baby's care

Giving sensitive news, such as an abnormal finding on neuroimaging:

- **Adequate preparation**, including informing parents when the baby is having brain scans and what the potential outcomes could be
- A **private** location
- **Follow-up conversations** once parents have processed initial news
- **Results** from investigations as quickly as possible
- The **range of potential outcomes**, both good and bad

Developmental progress:

- Provide rough **guidelines** about when parents can expect their baby to reach milestones, adapted for their prematurity
- Provide **clear 'next step'** for parents to focus on
- Provide alongside reassurance about **individuality** of the baby's development

FOLLOW-UP CLINICS

Physiotherapist information-giving:

- Continue providing both **verbal face-to-face and written information**
- Provide in a more **formal** way e.g. in a private room
- Provide at a time when parents **are not overly distracted** by acute issues for their baby – wait until these subside or become less critical

- Introduce a **digital reminder system** to inform parents about upcoming follow-up clinics
- Provide **in-person follow-up**, but with the option for virtual follow-up when the baby does not need to be physically assessed.
- Allow **both parents** to be present at follow-up clinics, or where this is not possible, provide opportunity for parents to video- or phone-call

DEVELOPMENTAL ASSESSMENTS

- **Improve parental awareness** by providing a clear explanation of the purpose of the assessment and the information its results can provide before the assessment, then a summary afterwards
- Perform when baby is fully awake and alert – **check with parents** whether the baby is 'performing' how it usually does and factor this in when providing parents with the results

SUPPORT

- **Enquire into parents' wellbeing** during interactions

- Ensure parents are aware of the **family room** and **counsellor,** and encourage parents to access these
- Continue to facilitate and encourage parents' **involvement in their babies care**

- Provide a **'check-up' phone call** a few weeks after discharge – inquire into parent wellbeing and coping, baby's wellbeing and offer advice and support
- Implement a **counselling service** for parents between their baby's discharge from the neonatal unit, before they are referred to Alder Hey services

ACCESS TO PROFESSIONALS

- Make **continuity of care** a main focus of nurse shift patterns in the NICU, whenever possible
- Emphasise to parents more clearly **where how and what** they can access after discharge

Establish a clear point of contact for parents with a baby <28 weeks with no other developmental risk factor (currently not followed up by community neonatal liaison specialist) , who is:

- Easily accessible
- Responsive to parents informational needs
- Has expertise in high-risk infants
- Is familiar with the baby's care history

Figure 18: Summary of recommendations to the current process of early neurodevelopmental follow-up for parents with a high-risk infant in Liverpool, based on parents' responses in in-depth interviews

5.5. Discussion of study design

5.5.1. Strengths

This is the first study, to my knowledge, to explore parents' experiences of early neurodevelopmental follow-up for their high-risk infant, using the HINE and GMA in depth and with an inductive approach. This is also the first study to use qualitative one-to-one interviews to explore parents' experiences of this topic, and to explore this topic in the UK. The limited previous work in this area has used focus groups and quantitative surveys and been conducted in the US only (119, 125, 126). The use of qualitative methods and an inductive approach was a strength of this study as it allowed an in-depth exploration of this phenomenon and enabled parents to bring up issues that were important to them. Using in-depth interviews was a strength as it allowed rich, detailed data to be gathered, helping me, and hopefully any reader, to understand parents' experiences and views from the findings.

Performing two interviews with each parent, when possible, allowed me to explore parents' perspectives at two different time points, a few weeks apart, to gain a detailed insight into their perspectives during this time period. As a novice interviewer, I found the second interview valuable as it gave me an additional opportunity to gain detail and clarification on parents' responses in the first interview which I had not yet explored in sufficient depth. Conducting interviews over the phone also had an unanticipated benefit for me as a novice interviewer; in absence of any visual dimension to the interview, I was able to focus on just the auditory dimension. This reduced my need to 'multi-task' and helped to simplify my role as the interviewer; I could focus better on the participants' verbal accounts and considering my next question or probe. I was able to note down details in participants' responses which I wished to come back to later in the interview, and gain further detail on, without this appearing as if I were rude or disinterested (224).

The sampling and recruiting methods I used ensured only participants with direct experience of early neurodevelopmental follow-up were interviewed, so that all participants interviewed could shed light on the phenomenon being studied. This was very effective as every participant interviewed had at least some direct experience of early neurodevelopmental follow-up. At least one parent from almost every family approached during initial recruitment agreed to participate, suggesting that efforts to make the study as accessible to participants as possible were effective. Infants of parents interviewed had a wide range of demographics, a strength of the study as this allowed a wide range of parents' experiences of early neurodevelopmental follow-up to be gathered, as their baby's characteristics (e.g. gestational age and medical issues) influence events in this journey.

The timing of my interviews meant they were able to capture parents' experiences during a crucial period for the neonatal follow-up service in Liverpool. Interviews coincided with the initiation of a pilot physiotherapist-led follow-up clinic, performing the HINE and GMA assessments on high-risk infants in Liverpool for the first time. As this clinic is being implemented, issues may appear which compromise parents' experiences and satisfaction with healthcare services. This study was able to explore parents' experiences and views, and successfully uncover ways in which this process could be improved for parents.

My position as a medical student allowed me to take an open-minded approach to this research. Had a healthcare professional working in this area undertaking this research, they may have had stronger views and pre-conceptions about this topic, which may have caused them to influence the data collection and analysis more heavily. My position as a student, rather than a healthcare professional, is also likely to have helped parents feel able to talk about their experiences and view of healthcare services more openly and honestly, as I am not directly involved in their baby's care.

My position as a student and being a similar age to parents I interviewed helped a neutral interviewer-interviewee power relationship to develop, meaning I experienced no issues during the data collection relating to power dynamics, which may have occurred had a healthcare professionals conducted these interviews (12). Additionally, as I expected, participants and I had cultural similarities due to all living in Liverpool. This helped me to understand and interpret their specific language, as almost all parents spoke with a scouse accent, and used phrases and nuances common to the Liverpool dialect, with which I am familiar.

The robust methodology used, and in-depth analysis performed, and measures taken to ensure trustworthiness and quality of the findings are also strengths of this study. These are detailed in chapter three (methodology and study methods).

5.5.2. Limitations

Qualitative inquiry is a skill that is learned and improves with practice (255). I am aware that this work, being my first attempt at both qualitative research and interviewing, will therefore have limitations. I have done my best to gain teaching and training throughout this year and put my learning into practice as effectively as possible to adopt the qualities required to be a competent qualitative researcher. However, I am mindful that as with any skill, my qualitative research skills will improve with further projects as my methodological understanding increases, and that this work may likely have been done better had it been undertaken by someone with more experience (255). For example, there were, understandably, areas in many interviews where I felt, retrospectively, that I could have probed more effectively or deeply to gain further clarification, which may have helped to reach a deeper, more comprehensive understanding of the meaning behind some responses. As this work has been my first experience as an interviewer, it has been a huge learning experience, and I hope to use the knowledge and experience I have gained to improve any research I conduct in future.

This MPhil course had time constraints. I had to design the research project, receive ethical approval, conduct data collection, analyse the data, and write up the findings all within one academic year. However, qualitative research has no shortcuts (255). To ensure adequate time to learn about qualitative research, familiarise myself with and analyse the data, and lastly write up the study, I had to limit the data collection period to just a few months. As the physiotherapist-led clinic around which interviews were held takes place once per fortnight seeing only a few infants at each clinic, this meant that sample size was limited. In qualitative research, a small sample is often acceptable as the researcher aims for depth not breadth in the findings (217). Nevertheless, saturation was a target of this study, to promote the quality of the research (234). In an attempt to mitigate the limitations on sample size, I adapted recruitment partway through the study to include parents who were attending follow-up during a later month. However, as these additional parents did not have their 12-week follow-up during the data collection period, only a pre-clinic interview could be conducted with them. Considering the limitations present, I feel that achieving thirteen interviews with eight parents was a reasonable sample size, and alongside the use of in-depth interviews and conducting two interviews with most participants, over 200 pages of contextually rich and highly detailed transcribed interview data were collected, allowing the in-depth insight into parents' views and experiences in the findings.

Saturation is a complex issue; there is no exact way to judge it (231), so I will now explain my thoughts on this. Whilst reviewing my data, I found that no new main issues or concepts were brought up in the last or second-to-last interview, but that new views and perspectives – which could be thought of as 'negative cases' - on these topics were still being given. Therefore, I can consider saturation of main issues or concepts to have been reached, signifying that all topics considered important to parents were covered. However, as new negative cases were still appearing in the final interview, the range of different views parents have surrounding each issue cannot be considered saturated. Some sources state that saturated data is 'full, rich and complete allowing resultant theory to make sense, be clear and not have any gaps' (234) and I do consider the data collected in this study to be adequate to enable the views and perspectives collected to be understood. Additionally, I feel that despite its small sample size, my study is credible and my findings are highly insightful, because of the rigorous methods used, and the in-depth insight it provides (289).

Fewer fathers were interviewed than mothers as some fathers declined to participate in the study due to being too busy with work. Mothers were more likely to be on maternity leave rather than working and feel they had time available to participate. This may have led to a smaller sample size and unequal exploration of fathers' and mothers' perspectives. In addition, despite there being some single parents in this population, all parents who agreed to take part in the study were either married or living with a partner. Parents of white British ethnicity were also more likely to take part than parents of other ethnicities, meaning only one parent of non-white British ethnicity was interviewed. In addition, no parent under 25 years old participated, despite there being some parents younger than this in the study population. Therefore, this study did not collect the views of these parents, which may have differed from the views of parents who took part.

Another limitation of the study is that parents were only interviewed during the very early stages of early neurodevelopmental follow-up, as during my data collection period infants were only being seen in the clinic at 12-weeks corrected age. Research to explore parents' views and experiences at the later six-month follow-up, and beyond that, when a diagnosis of cerebral palsy may be given, would be valuable, to understand how to improve these parts of neurodevelopmental follow-up for parents. Had this research project been longer than one year, I would have conducted data collection for a longer period and interviewed parents at these later stages. I would also like to have performed some respondent validation by conducting a focus group with some of the parents who took part in interviews and present my findings back to them for discussion. I will share my findings and recommendations for clinical practice with parents via a newsletter and consider any feedback parents provide on this to ensure that these findings reflect parents' preferences as well as possible.

This study was conducted whilst the physiotherapist-led follow-up clinic was still being piloted, and the GMA was also being used for training purposes only meaning that parents were not receiving results from this assessment. This clinic may change over time as it becomes better established within the neonatal follow-up system in Liverpool and expands to include infants outside the Liverpool and Sefton areas. I hope that, rather than this invalidating the findings of this study, these findings will be useful to guide the development of this clinic, so that it becomes highly acceptable for parents and allows them to be feel supported and have some positive experiences, despite this being such a difficult time.

This study's findings may be transferrable to other NICUs and early neonatal follow-up services in the UK, where the findings may be useful for improving the way that professionals provide parents with information and support in the NICU and during early neurodevelopmental follow-up. However, as this study was based only in the UK, its transferability to international settings is limited. Transferability is also likely to be limited to UK NICUs with a similar neurodevelopmental follow-up service to Liverpool, due to a lack of a national standardised system.

5.6. Recommendations for further research

This study only specifically explored parents' views and perspectives regarding the NICU stay and the 12-week follow-up clinic. Once parents begin having their six-month follow-ups and once the clinic becomes better established and some parents begin to receive an early diagnosis of cerebral palsy in their infant, further qualitative research should be performed to understand parents' perspectives during this time. In this case, I would suggest repeated in-depth interviews, ideally with parents who participated in this study, to explore how their individual needs changed over time, but also or alternatively other parents undergoing this process.

Additionally, as this study only captures parents' perspectives, a need remains for professionals' perspectives of early neurodevelopmental follow-up to be explored and understood. This could be valuable by allowing professionals' perceived barriers and facilitators to implementing and conducting early neurodevelopmental follow-up to be uncovered and understood. This research would be particularly helpful in Liverpool, where early neurodevelopmental follow-up with the recommended assessments is currently in its early stages of implementation. This may also help implementation in other settings, as only a few neonatal follow-up systems, worldwide, are currently performing early identification and early diagnosis of cerebral palsy. For this research, I would suggest initially performing one-to-one interviews with professionals to understand their individual views and perspectives regarding early identification of cerebral palsy, as I feel these would be drawn out more easily using this method than in a group interview or focus groups. Following this, I would suggest using focus groups as a potentially fruitful method for exploring professionals' shared perceptions of barriers and facilitators and allowing clinical recommendations to be developed as a group. I feel this research would promote successful implementation of early neurodevelopmental follow-up and early diagnosis of cerebral palsy in Liverpool. It would be beneficial to present the findings from my study (and any further research with parents) during professional focus group discussions so that parents' needs and perspectives are considered, hopefully allowing changes to the early neurodevelopmental follow-up service to improve parents' experiences.

5.7. Conclusion

This is the first study, to my knowledge, to explore parent experiences of early neurodevelopmental follow-up, involving HINE and GMA in depth and with an inductive approach. It is also the first study, to my knowledge, to explore parents' experiences with HINE and GMA using qualitative interviews, and in the UK. The findings provide in-depth insight into parents' views and experiences during the process of early neurodevelopmental follow-up and highlight areas that are important to parents, including areas that are currently viewed positively by parents, and other areas which could be improved, to better fulfil parents' needs. My recommendations, set out in this chapter, are based on these findings and aim to improve parents' experiences during early neurodevelopmental follow-up. These recommendations relate to five main areas: (1) communication, (2) follow-up clinics, (3) developmental assessments, (4) support and (5) access to professionals. Implementing these should improve parents' experiences and could boost clinic attendance rates, as well as improve parents' awareness of their infants' developmental risk, so they are better prepared if their infant is later diagnosed with cerebral palsy. This study has many strengths, such as its robust methodology, use of appropriate qualitative methods and the in-depth insight its findings provide. However, it is limited by its small sample size, as the range of views different parents have about issues explored in this study was not completely saturated. It is also limited by only gaining insight into the earliest stages of early neurodevelopmental follow-up. Further research is required to explore parents' perspectives of the later parts of neurodevelopmental follow-up as well as receiving an early diagnosis of cerebral palsy once these begin to take place in Liverpool. Additionally, exploring professionals' perspectives of how this system could be better implemented in Liverpool could be beneficial. I hope that this research will be useful to guide improvements to the current process of early-neurodevelopmental follow-up in Liverpool and that this will have a positive impact to the experiences parents have during this process.

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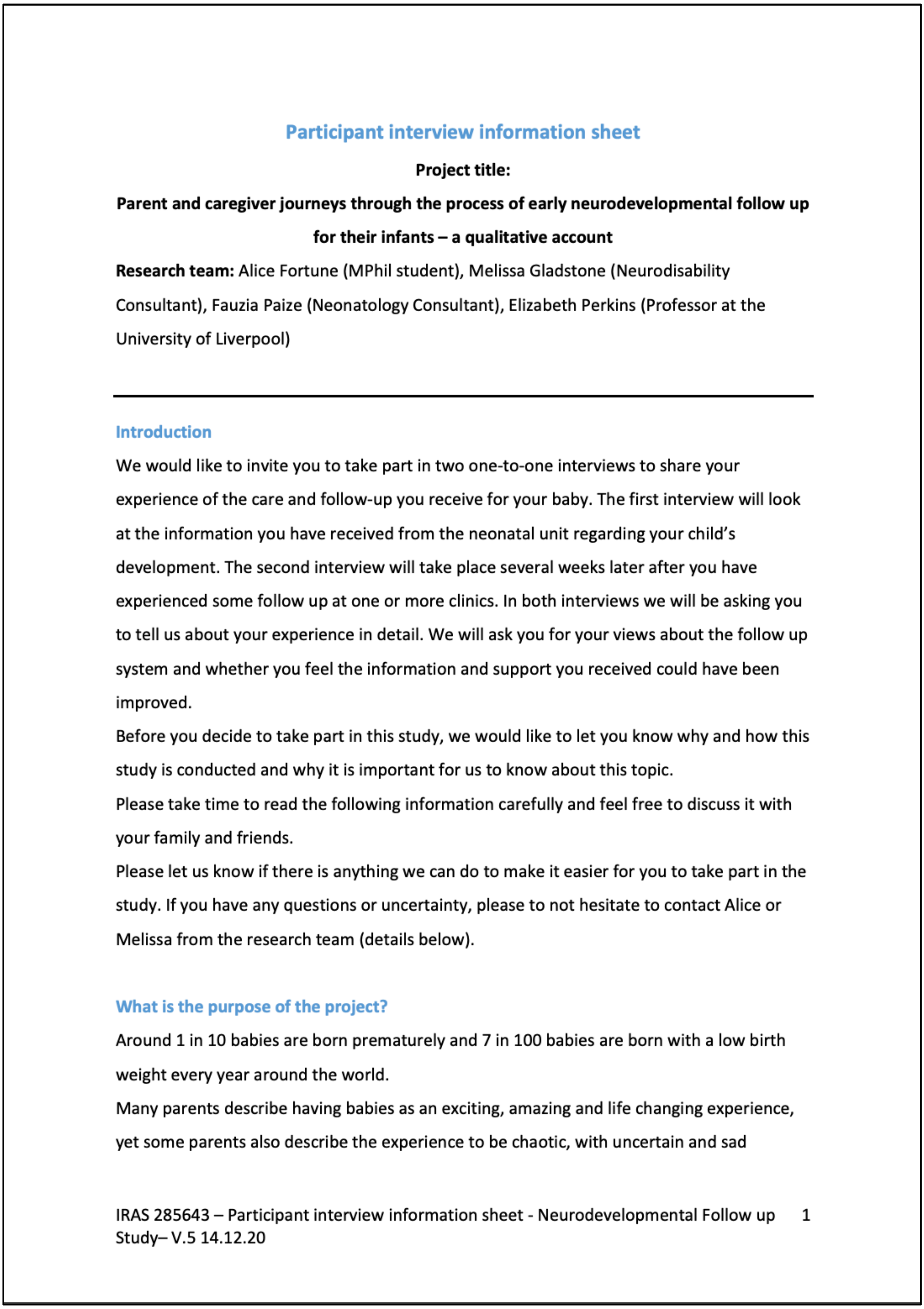
Appendix

Appendix A: Participant information sheet



Participant interview information sheet

Project title:

Parent and caregiver journeys through the process of early neurodevelopmental follow up for their infants – a qualitative account

Research team: Alice Fortune (MPhil student), Melissa Gladstone (Neurodisability Consultant), Fauzia Paize (Neonatology Consultant), Elizabeth Perkins (Professor at the University of Liverpool)

Introduction

We would like to invite you to take part in two one-to-one interviews to share your experience of the care and follow-up you receive for your baby. The first interview will look at the information you have received from the neonatal unit regarding your child's development. The second interview will take place several weeks later after you have experienced some follow up at one or more clinics. In both interviews we will be asking you to tell us about your experience in detail. We will ask you for your views about the follow up system and whether you feel the information and support you received could have been improved.

Before you decide to take part in this study, we would like to let you know why and how this study is conducted and why it is important for us to know about this topic.

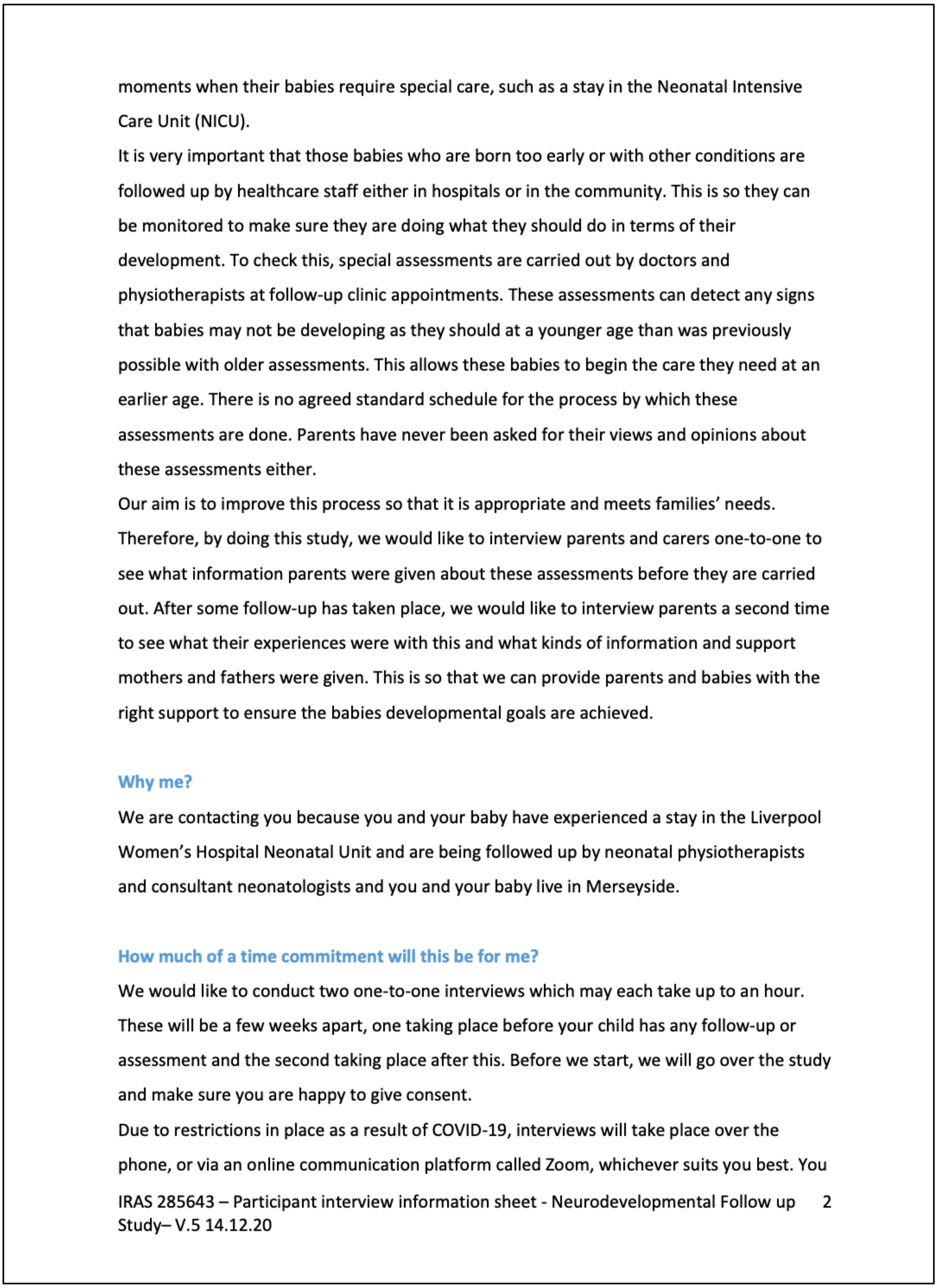
Please take time to read the following information carefully and feel free to discuss it with your family and friends.

Please let us know if there is anything we can do to make it easier for you to take part in the study. If you have any questions or uncertainty, please to not hesitate to contact Alice or Melissa from the research team (details below).

What is the purpose of the project?

Around 1 in 10 babies are born prematurely and 7 in 100 babies are born with a low birth weight every year around the world.

Many parents describe having babies as an exciting, amazing and life changing experience, yet some parents also describe the experience to be chaotic, with uncertain and sad



moments when their babies require special care, such as a stay in the Neonatal Intensive Care Unit (NICU).

It is very important that those babies who are born too early or with other conditions are followed up by healthcare staff either in hospitals or in the community. This is so they can be monitored to make sure they are doing what they should do in terms of their development. To check this, special assessments are carried out by doctors and physiotherapists at follow-up clinic appointments. These assessments can detect any signs that babies may not be developing as they should at a younger age than was previously possible with older assessments. This allows these babies to begin the care they need at an earlier age. There is no agreed standard schedule for the process by which these assessments are done. Parents have never been asked for their views and opinions about these assessments either.

Our aim is to improve this process so that it is appropriate and meets families' needs. Therefore, by doing this study, we would like to interview parents and carers one-to-one to see what information parents were given about these assessments before they are carried out. After some follow-up has taken place, we would like to interview parents a second time to see what their experiences were with this and what kinds of information and support mothers and fathers were given. This is so that we can provide parents and babies with the right support to ensure the babies developmental goals are achieved.

Why me?

We are contacting you because you and your baby have experienced a stay in the Liverpool Women's Hospital Neonatal Unit and are being followed up by neonatal physiotherapists and consultant neonatologists and you and your baby live in Merseyside.

How much of a time commitment will this be for me?

We would like to conduct two one-to-one interviews which may each take up to an hour. These will be a few weeks apart, one taking place before your child has any follow-up or assessment and the second taking place after this. Before we start, we will go over the study and make sure you are happy to give consent.

Due to restrictions in place as a result of COVID-19, interviews will take place over the phone, or via an online communication platform called Zoom, whichever suits you best. You can choose the time and date that would suit you best. If COVID-19 restrictions are lifted, there will also be the option to conduct interviews face-to-face, in a quiet, private room at either the Liverpool Women's Hospital, Alder Hey Children's Hospital or in the community. This room will be large enough to maintain social distancing and with all individuals present wearing adequate PPE. However, there will still be the option to conduct the interviews virtually if you would prefer this. We will try our best to ensure that all interviews take place at a venue, time and date which is convenient for participants.

If, after the second interview, you receive more information which you would like to add to the study, you can get in contact with the research team to let us know. If we feel that the information you have to add will be of benefit to the study, we will arrange a third interview at a venue, time and place which is convenient for you.

How will the information be recorded?

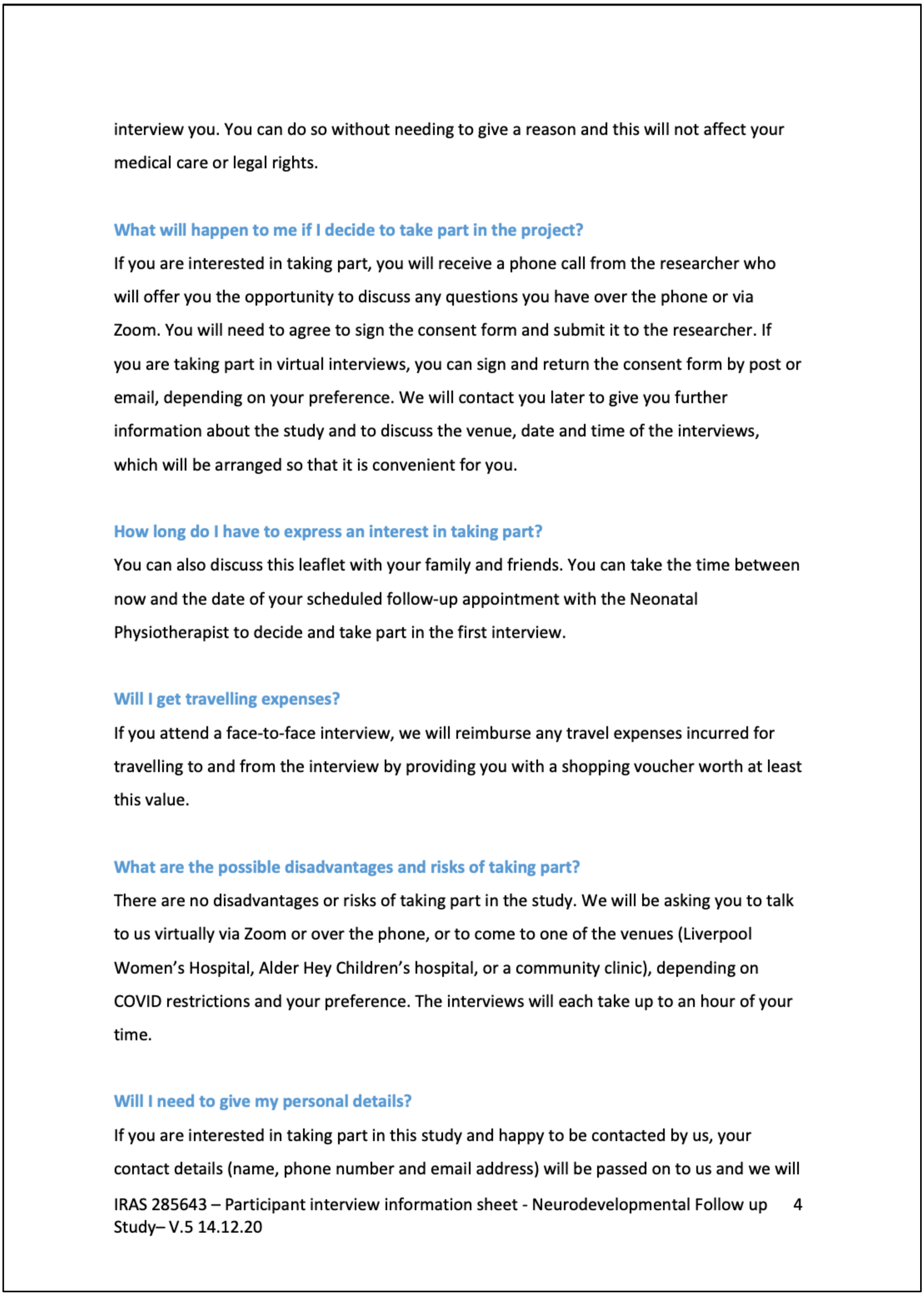
With your permission, we will be audio recording the interviews. These recordings will be stored securely by the researchers on the secure University of Liverpool computer system on password protected computers and transcribed so we can analyse them and compare your views and opinions with those of other parents. On Zoom, you will have the option to have your webcam turned on or off depending on your preference. Your video will not be recorded if you choose to have your webcam switched on, only your audio.

Is everything confidential?

Any information we discuss will be kept strictly confidential. Once interview recordings have been transcribed, they will be deleted. Transcribed interviews will be completely anonymous, with any personal identifiable information removed, such as you and your baby's names.

Do I have to take part?

No. It is entirely up to you whether or not you take part in this study. If you do not wish to take part, please ignore this information sheet. If you initially agree to take part in the study but change your mind, you are free to withdraw from the study at any point before we



interview you. You can do so without needing to give a reason and this will not affect your medical care or legal rights.

What will happen to me if I decide to take part in the project?

If you are interested in taking part, you will receive a phone call from the researcher who will offer you the opportunity to discuss any questions you have over the phone or via Zoom. You will need to agree to sign the consent form and submit it to the researcher. If you are taking part in virtual interviews, you can sign and return the consent form by post or email, depending on your preference. We will contact you later to give you further information about the study and to discuss the venue, date and time of the interviews, which will be arranged so that it is convenient for you.

How long do I have to express an interest in taking part?

You can also discuss this leaflet with your family and friends. You can take the time between now and the date of your scheduled follow-up appointment with the Neonatal Physiotherapist to decide and take part in the first interview.

Will I get travelling expenses?

If you attend a face-to-face interview, we will reimburse any travel expenses incurred for travelling to and from the interview by providing you with a shopping voucher worth at least this value.

What are the possible disadvantages and risks of taking part?

There are no disadvantages or risks of taking part in the study. We will be asking you to talk to us virtually via Zoom or over the phone, or to come to one of the venues (Liverpool Women's Hospital, Alder Hey Children's hospital, or a community clinic), depending on COVID restrictions and your preference. The interviews will each take up to an hour of your time.

Will I need to give my personal details?

If you are interested in taking part in this study and happy to be contacted by us, your contact details (name, phone number and email address) will be passed on to us and we will contact you to answer any questions you may have, organise the signing of the consent form and arrange the interviews. After the study is complete, we will also get in contact to provide you with the results. We will delete all copies we have of your contact details 12 months after the study is complete.

If you take part in this study, we will need to know some personal details from you and your baby's medical record about you and your baby. This information will include your name, age, the area you live in and details about your baby including their birth weight, how many weeks they were born at and whether they have had any diagnoses. At the start of the interview, we will also ask some questions about you, your baby and life at home. We will use this information to do the research as it will help us to understand your personal circumstances. We will keep all information about you safe and secure and it will only be accessed by the two main researchers, who's details are provided on the next page. People who do not need to know who you are will not be able to see your name or contact details; your data will have a code number instead. We will delete all our copies of your personal information 12 months after the study is complete. All data which forms the results of the study which undergoes analysis will be completely anonymous.

Where can I find out more about how my information is used?

You can find out more about how we use your information:

- At: www.hra.nhs.uk/information-about-patients/
- At: https://www.liverpool.ac.uk/legal/data_protection/ for access to the data protection officer
- By asking a member of the research team, who can be contacted via the details at the bottom of this leaflet

What if I am not happy and I want to make a complaint?

All our studies are covered through University of Liverpool. If you want to make a complaint you can get in touch with sponsor@liverpool.ac.uk.

If you wish to make a complaint or seek advice about taking part in our study, you can also contact the Patient Advice and Liaison Service (PALs) at either Liverpool Women's Hospital or Alder Hey Children's Hospital. Please see the details below.

Liverpool Women's Hospital: Call 0151 702 4353 or write to PALS, Liverpool Women's NHS Foundation Trust, Crown Street, Liverpool, L8 7SS.

Alder Hey Children's Hospital: email pals@alderhey.nhs.uk, call 0151 252 5374 or 1051 252 5161 or write to PALS, Alder Hey Children's NHS Foundation Trust, Eaton Road, Liverpool, L12 2AP.

What if I decide to leave the study early?

You can leave the study at any time, without giving a reason. However, as all data is anonymised at the point of recruitment to the study, it will not be possible to withdraw the information in your interview from the study once the interview have taken place.

What will happen to the results of the research study?

We will write our reports in a way that no-one can work out that you took part in the study. The result of the study will be shared between healthcare professionals from Alder Hey Children's Hospital, Liverpool Women's Hospital and community neurodevelopmental follow-up clinics. We will provide you with a newsletter to report our findings.

Who is the sponsor for the study?

The University of Liverpool is acting as the sponsor organisation for this study. Any reference to 'we' in this information sheet refers to the sponsor and research team, not the study site or hospital.

Who can I contact for further information?

If you want to know more about the study or have questions, please do not hesitate to contact Melissa Gladstone: 0151 252 5139 (M.J.Gladstone@liverpool.ac.uk)

Who can I contact for support?

We understand that this is an overwhelming and stressful time for you and your family. If you would like to access support, please do not hesitate to access the following services:

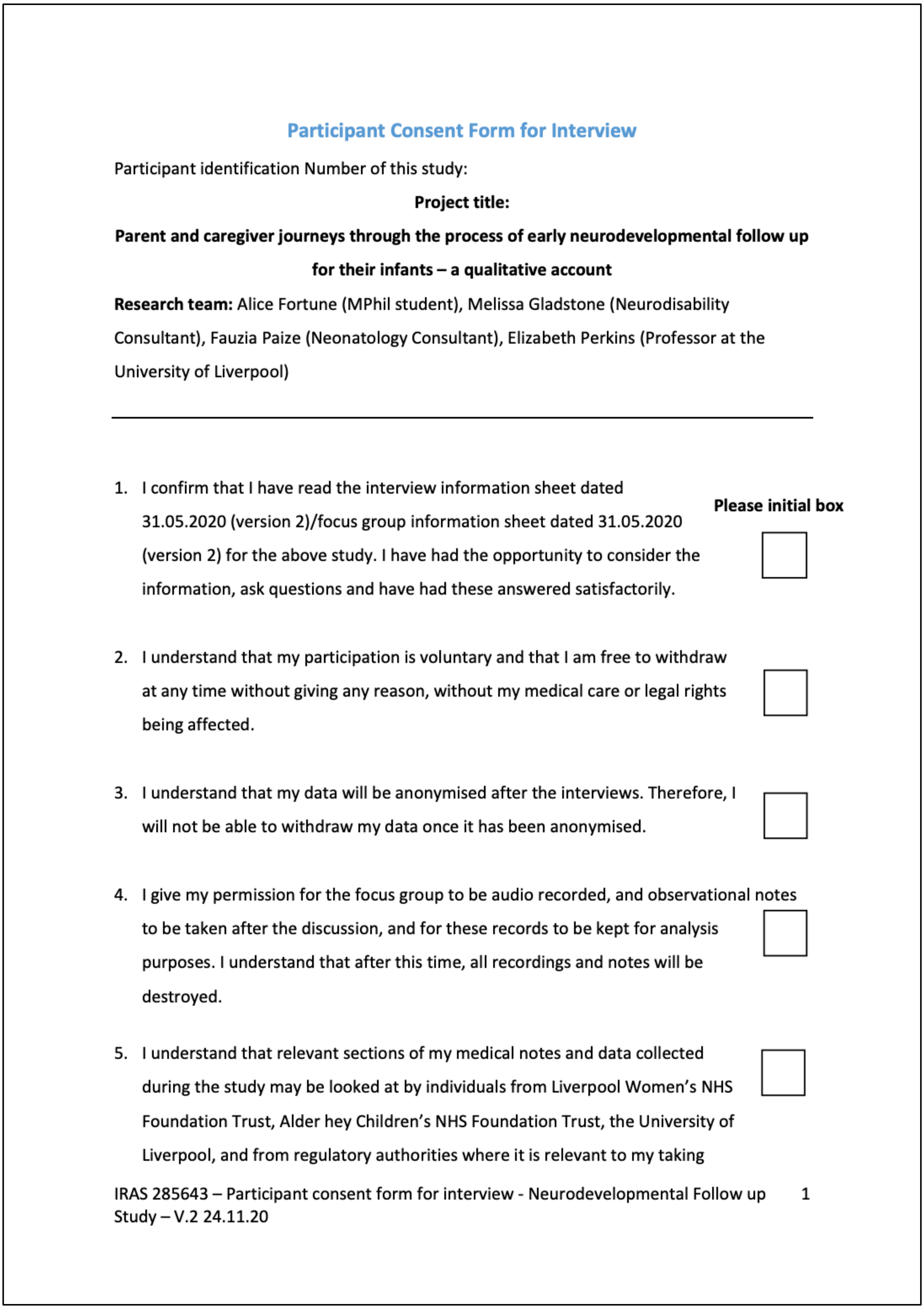
- **TalkLiverpool** – a free NHS service offering psychological therapies to adults in Liverpool who are feeling depressed or anxious. They can be accessed by phone on

0151 228 2300 (Central Office) or 0151 228 2300 (South Office) or email talkliverpool@merseycare.nhs.uk. More information is available on their website: https://www.talkliverpool.nhs.uk.

- **Positivitree** - a social enterprise led by parents and carers of children with physical health conditions, providing support for parents in similar circumstances. They currently provide (virtually at the moment) online coffee mornings, workshops and yoga sessions. They can be contacted by phone on 07877 782 826 or email Rachel@thepositivitree.com. Further information is available on their website: www.thepositivitree.com.

Before we begin any interview, we will also provide you with more information about support which is available to you, such as someone to talk to afterwards if you would like to.

Appendix B: Consent form



Participant Consent Form for Interview

Participant identification Number of this study:

Project title:

Parent and caregiver journeys through the process of early neurodevelopmental follow up for their infants – a qualitative account

Research team: Alice Fortune (MPhil student), Melissa Gladstone (Neurodisability Consultant), Fauzia Paize (Neonatology Consultant), Elizabeth Perkins (Professor at the University of Liverpool)

Please initial box

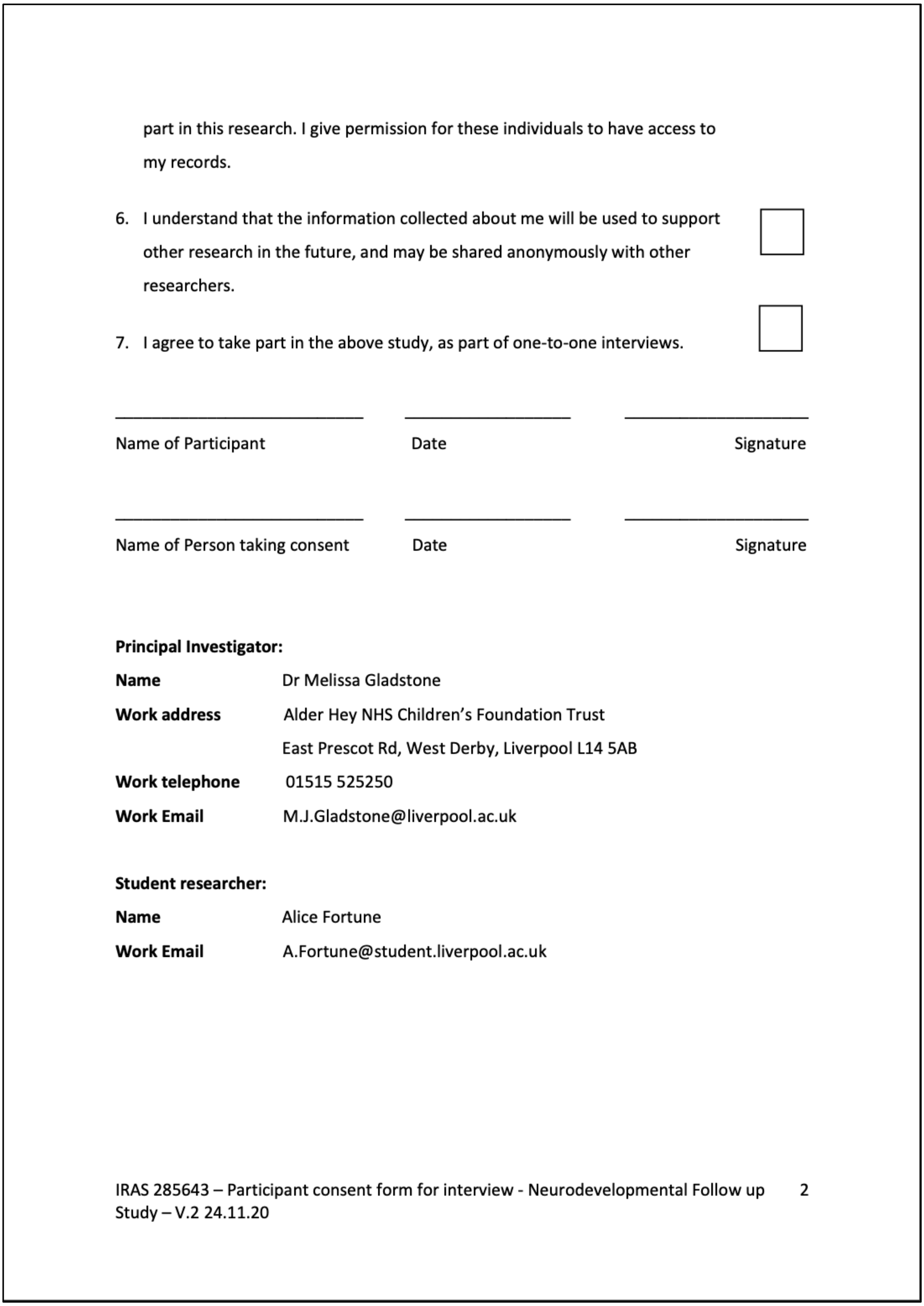
1. I confirm that I have read the interview information sheet dated 31.05.2020 (version 2)/focus group information sheet dated 31.05.2020 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that my data will be anonymised after the interviews. Therefore, I will not be able to withdraw my data once it has been anonymised. ☐

4. I give my permission for the focus group to be audio recorded, and observational notes to be taken after the discussion, and for these records to be kept for analysis purposes. I understand that after this time, all recordings and notes will be destroyed. ☐

5. I understand that relevant sections of my medical notes and data collected during the study may be looked at by individuals from Liverpool Women's NHS Foundation Trust, Alder hey Children's NHS Foundation Trust, the University of Liverpool, and from regulatory authorities where it is relevant to my taking ☐



part in this research. I give permission for these individuals to have access to my records.

6. I understand that the information collected about me will be used to support other research in the future, and may be shared anonymously with other researchers. ☐

7. I agree to take part in the above study, as part of one-to-one interviews. ☐

Name of Participant	Date	Signature
Name of Person taking consent	Date	Signature

Principal Investigator:

Name Dr Melissa Gladstone

Work address Alder Hey NHS Children's Foundation Trust
East Prescot Rd, West Derby, Liverpool L14 5AB

Work telephone 01515 525250

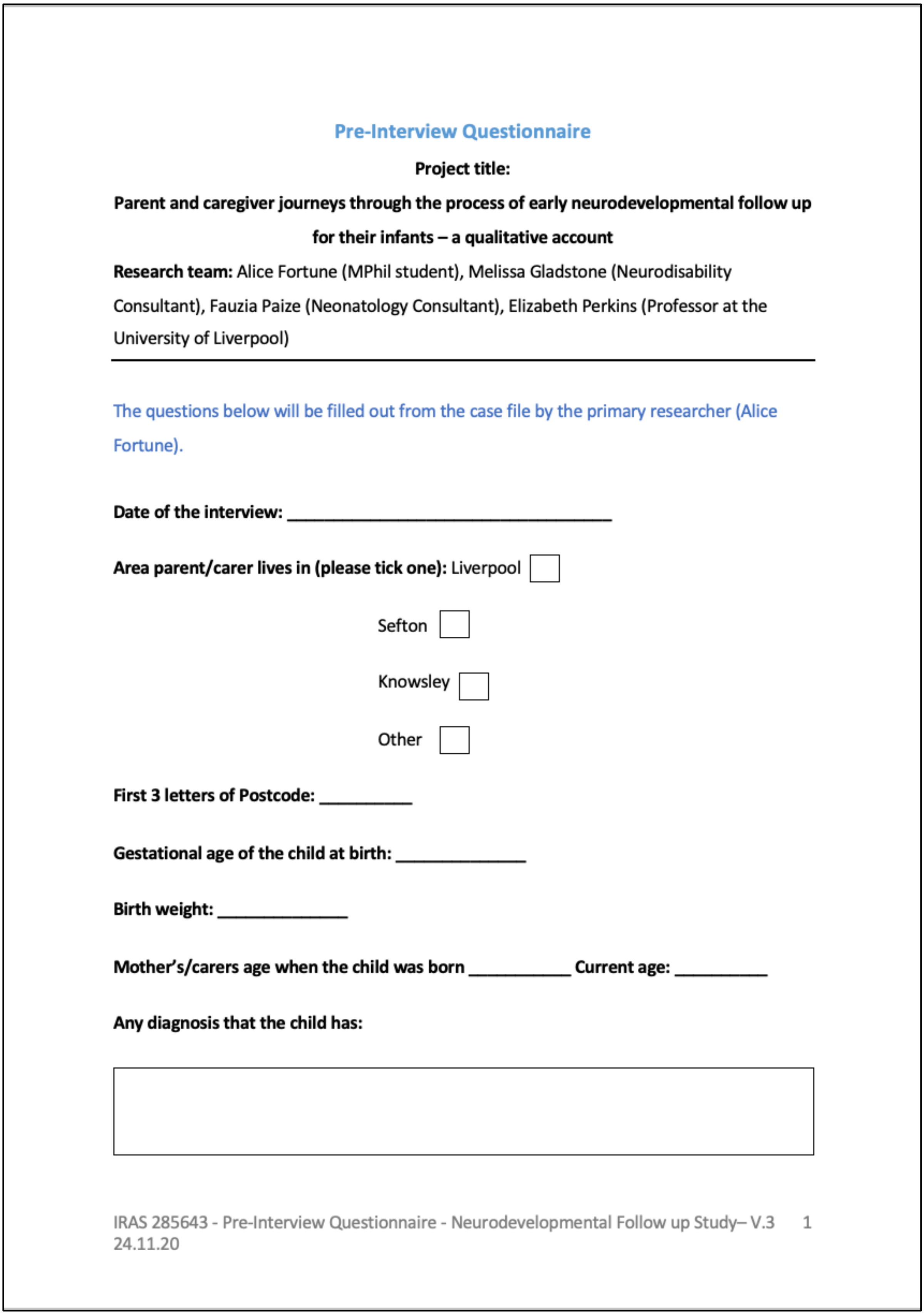
Work Email M.J.Gladstone@liverpool.ac.uk

Student researcher:

Name Alice Fortune

Work Email A.Fortune@student.liverpool.ac.uk

Appendix C: Pre-interview questionnaire



Pre-Interview Questionnaire

Project title:

Parent and caregiver journeys through the process of early neurodevelopmental follow up for their infants – a qualitative account

Research team: Alice Fortune (MPhil student), Melissa Gladstone (Neurodisability Consultant), Fauzia Paize (Neonatology Consultant), Elizabeth Perkins (Professor at the University of Liverpool)

The questions below will be filled out from the case file by the primary researcher (Alice Fortune).

Date of the interview: ______________________________________

Area parent/carer lives in (please tick one): Liverpool ☐

Sefton ☐

Knowsley ☐

Other ☐

First 3 letters of Postcode: __________

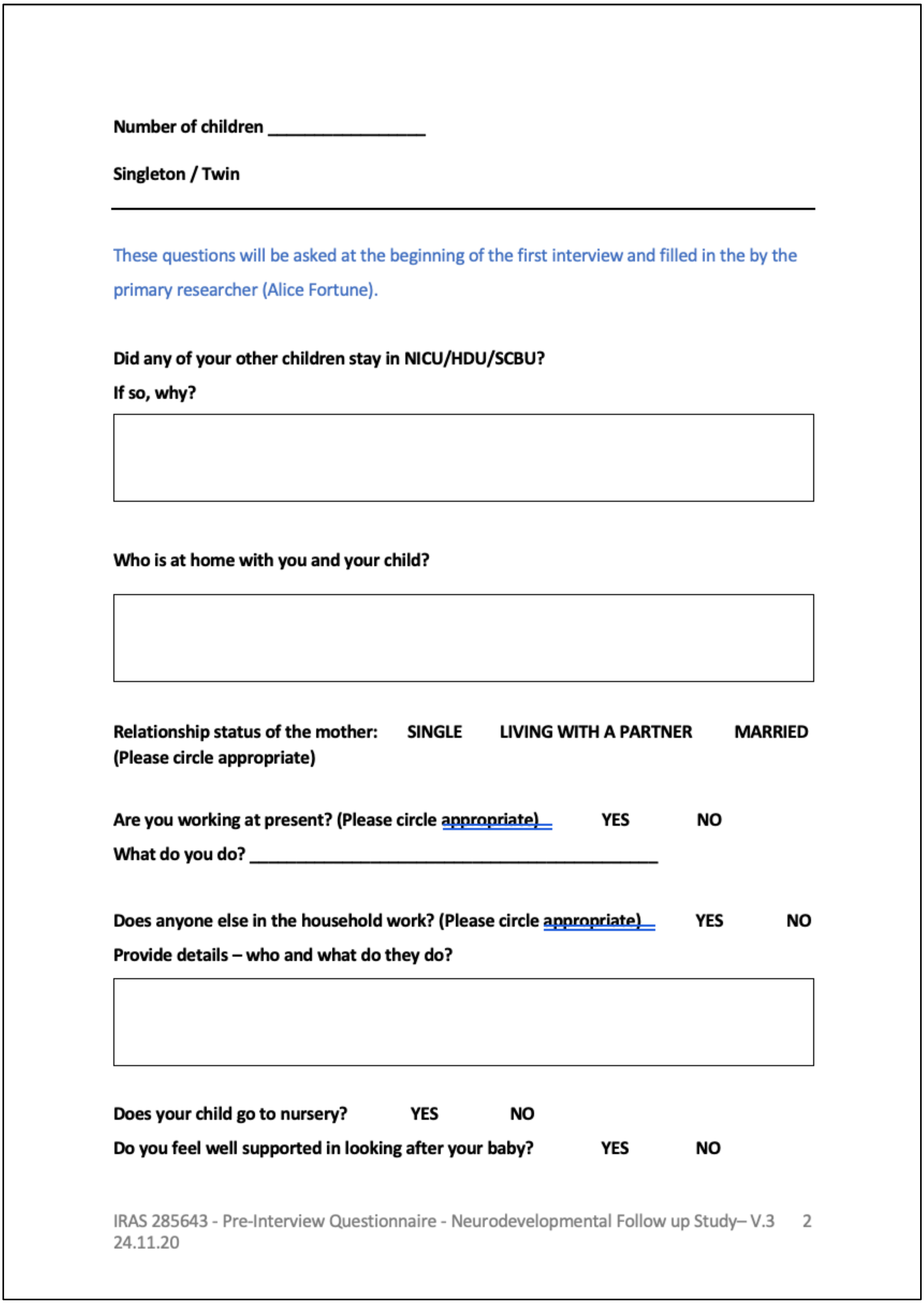
Gestational age of the child at birth: ______________

Birth weight: ______________

Mother's/carers age when the child was born ___________ **Current age:** __________

Any diagnosis that the child has:

IRAS 285643 - Pre-Interview Questionnaire - Neurodevelopmental Follow up Study– V.3 24.11.20 1



Number of children ________________

Singleton / Twin

These questions will be asked at the beginning of the first interview and filled in the by the primary researcher (Alice Fortune).

Did any of your other children stay in NICU/HDU/SCBU?

If so, why?

Who is at home with you and your child?

Relationship status of the mother: **SINGLE** **LIVING WITH A PARTNER** **MARRIED**
(Please circle appropriate)

Are you working at present? (Please circle appropriate) **YES** **NO**

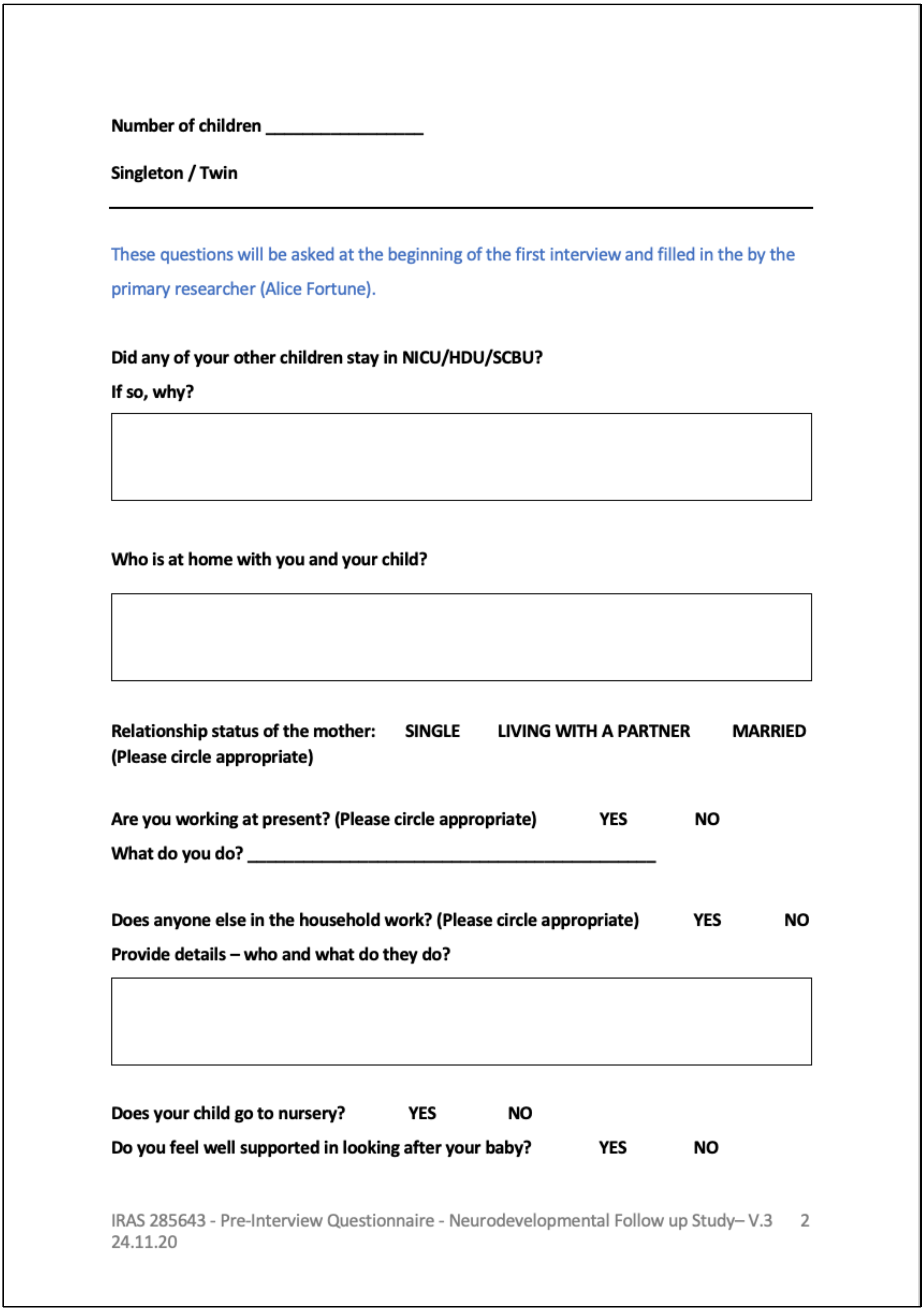
What do you do? ____

Does anyone else in the household work? (Please circle appropriate) **YES** **NO**

Provide details – who and what do they do?

Does your child go to nursery? **YES** **NO**

Do you feel well supported in looking after your baby? **YES** **NO**



Number of children ________________

Singleton / Twin

These questions will be asked at the beginning of the first interview and filled in the by the primary researcher (Alice Fortune).

Did any of your other children stay in NICU/HDU/SCBU?

If so, why?

Who is at home with you and your child?

Relationship status of the mother: **SINGLE** **LIVING WITH A PARTNER** **MARRIED**
(Please circle appropriate)

Are you working at present? (Please circle appropriate) **YES** **NO**

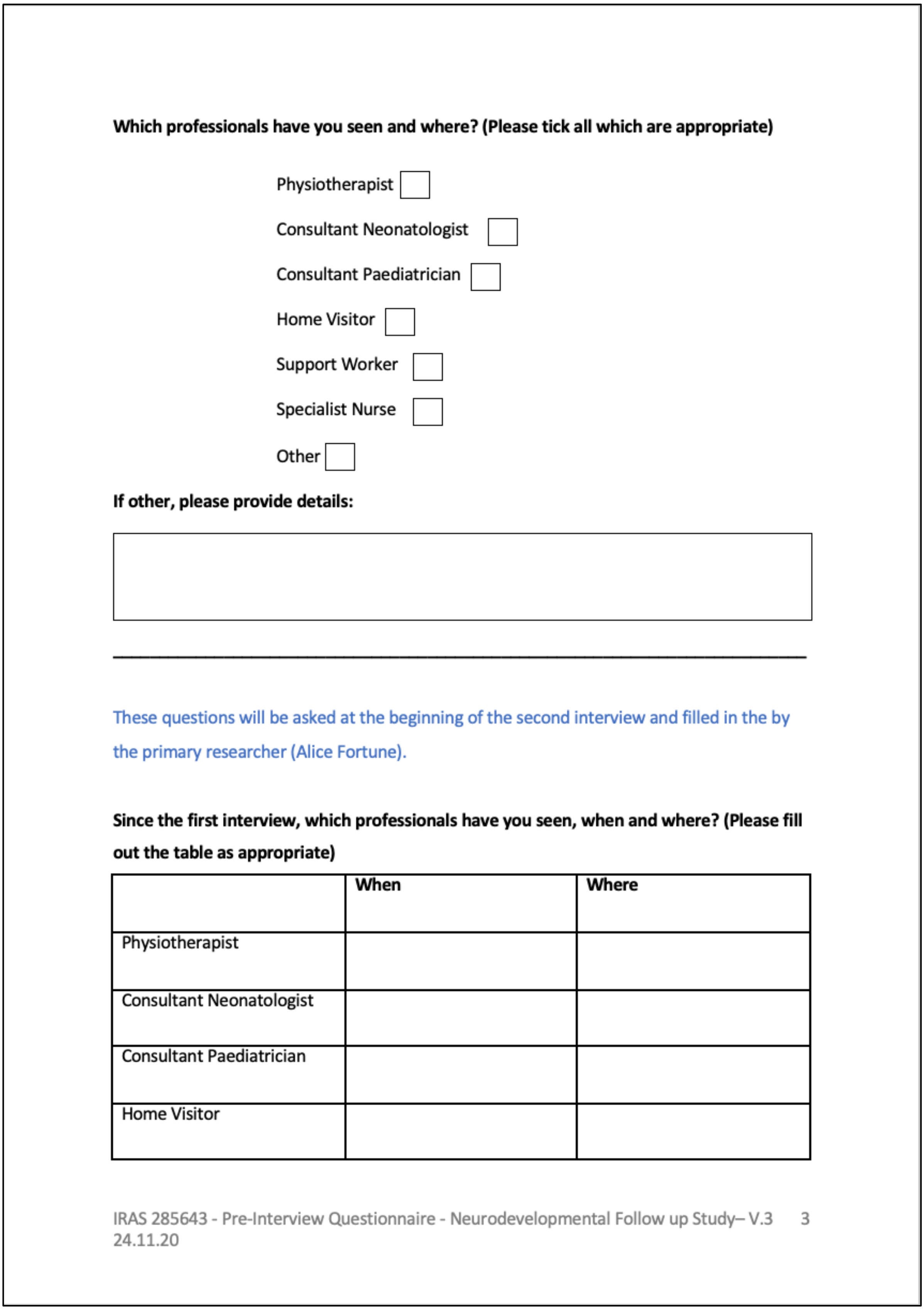
What do you do? ____

Does anyone else in the household work? (Please circle appropriate) **YES** **NO**

Provide details – who and what do they do?

Does your child go to nursery? **YES** **NO**

Do you feel well supported in looking after your baby? **YES** **NO**



Which professionals have you seen and where? (Please tick all which are appropriate)

Physiotherapist ☐

Consultant Neonatologist ☐

Consultant Paediatrician ☐

Home Visitor ☐

Support Worker ☐

Specialist Nurse ☐

Other ☐

If other, please provide details:

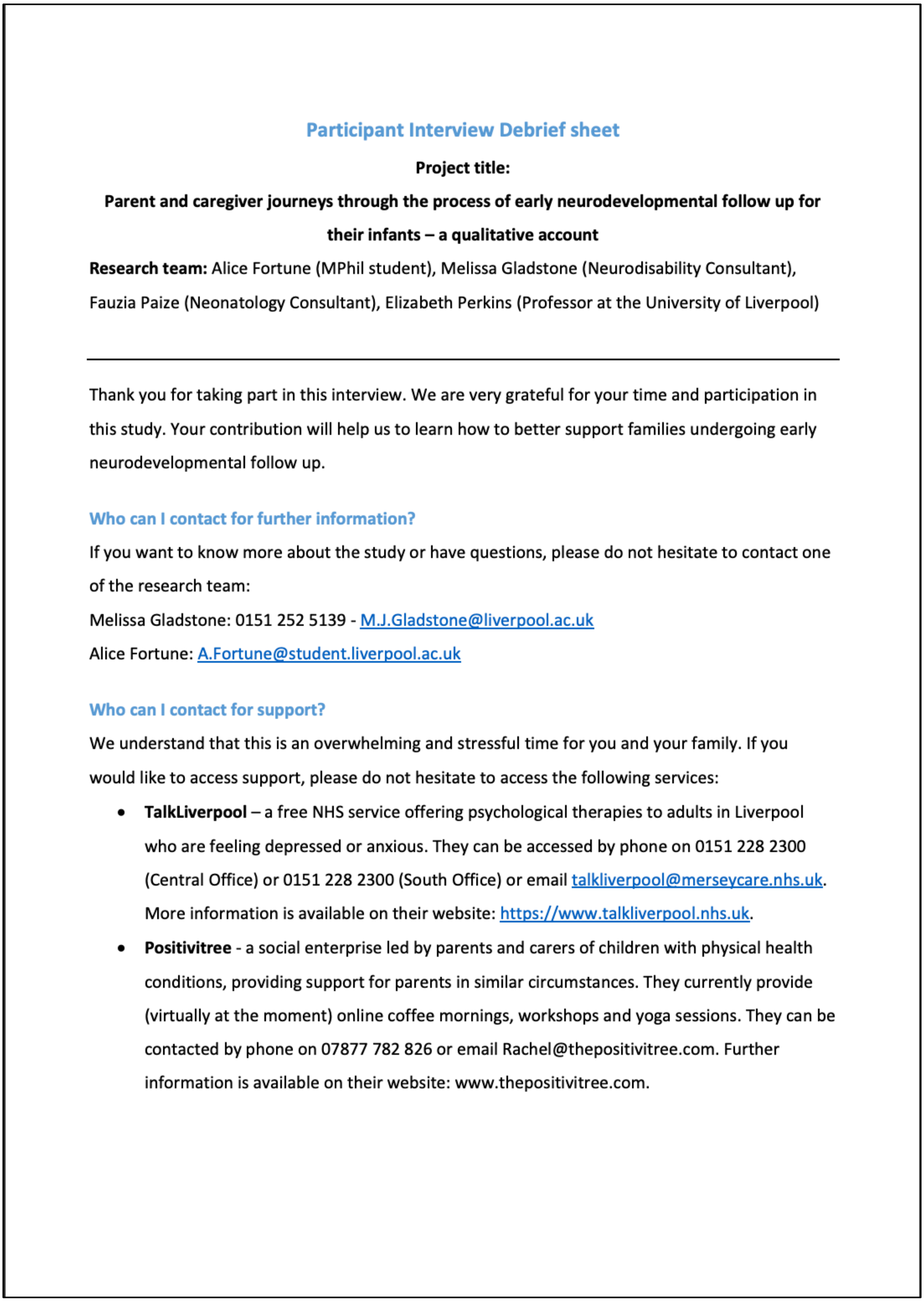
These questions will be asked at the beginning of the second interview and filled in the by the primary researcher (Alice Fortune).

Since the first interview, which professionals have you seen, when and where? (Please fill out the table as appropriate)

	When	**Where**
Physiotherapist		
Consultant Neonatologist		
Consultant Paediatrician		
Home Visitor		

Support Worker		
Specialist Nurse		
Other – please provide details:		

Appendix D: Interview debrief sheet



Participant Interview Debrief sheet

Project title:

Parent and caregiver journeys through the process of early neurodevelopmental follow up for their infants – a qualitative account

Research team: Alice Fortune (MPhil student), Melissa Gladstone (Neurodisability Consultant), Fauzia Paize (Neonatology Consultant), Elizabeth Perkins (Professor at the University of Liverpool)

Thank you for taking part in this interview. We are very grateful for your time and participation in this study. Your contribution will help us to learn how to better support families undergoing early neurodevelopmental follow up.

Who can I contact for further information?

If you want to know more about the study or have questions, please do not hesitate to contact one of the research team:

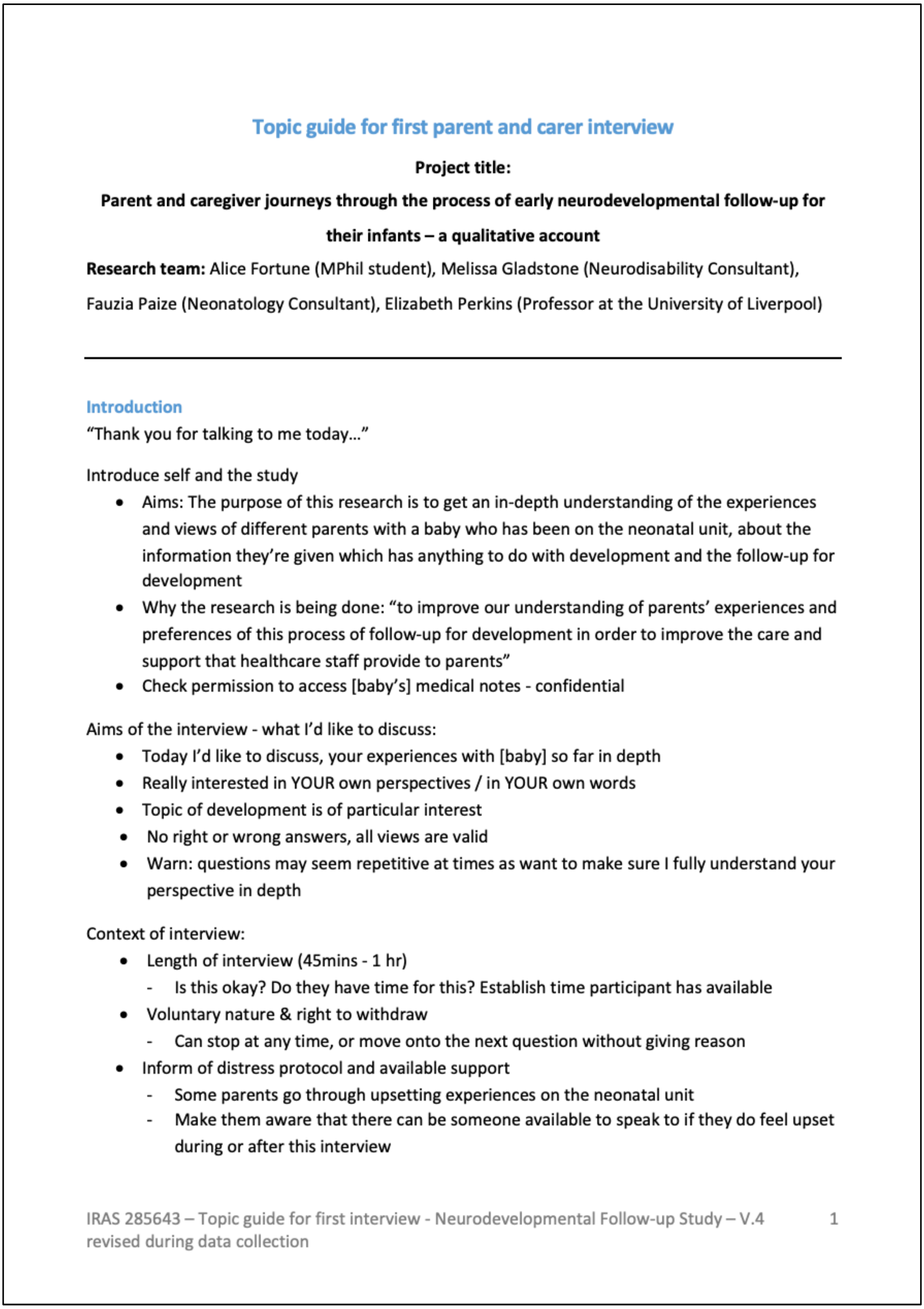
Melissa Gladstone: 0151 252 5139 - M.J.Gladstone@liverpool.ac.uk
Alice Fortune: A.Fortune@student.liverpool.ac.uk

Who can I contact for support?

We understand that this is an overwhelming and stressful time for you and your family. If you would like to access support, please do not hesitate to access the following services:

- **TalkLiverpool** – a free NHS service offering psychological therapies to adults in Liverpool who are feeling depressed or anxious. They can be accessed by phone on 0151 228 2300 (Central Office) or 0151 228 2300 (South Office) or email talkliverpool@merseycare.nhs.uk. More information is available on their website: https://www.talkliverpool.nhs.uk.
- **Positivitree** - a social enterprise led by parents and carers of children with physical health conditions, providing support for parents in similar circumstances. They currently provide (virtually at the moment) online coffee mornings, workshops and yoga sessions. They can be contacted by phone on 07877 782 826 or email Rachel@thepositivitree.com. Further information is available on their website: www.thepositivitree.com.

Appendix E: Topic guides



Topic guide for first parent and carer interview

Project title:

Parent and caregiver journeys through the process of early neurodevelopmental follow-up for their infants – a qualitative account

Research team: Alice Fortune (MPhil student), Melissa Gladstone (Neurodisability Consultant), Fauzia Paize (Neonatology Consultant), Elizabeth Perkins (Professor at the University of Liverpool)

Introduction

"Thank you for talking to me today…"

Introduce self and the study

- Aims: The purpose of this research is to get an in-depth understanding of the experiences and views of different parents with a baby who has been on the neonatal unit, about the information they're given which has anything to do with development and the follow-up for development
- Why the research is being done: "to improve our understanding of parents' experiences and preferences of this process of follow-up for development in order to improve the care and support that healthcare staff provide to parents"
- Check permission to access [baby's] medical notes - confidential

Aims of the interview - what I'd like to discuss:

- Today I'd like to discuss, your experiences with [baby] so far in depth
- Really interested in YOUR own perspectives / in YOUR own words
- Topic of development is of particular interest
- No right or wrong answers, all views are valid
- Warn: questions may seem repetitive at times as want to make sure I fully understand your perspective in depth

Context of interview:

- Length of interview (45mins - 1 hr)
  - Is this okay? Do they have time for this? Establish time participant has available
- Voluntary nature & right to withdraw
  - Can stop at any time, or move onto the next question without giving reason
- Inform of distress protocol and available support
  - Some parents go through upsetting experiences on the neonatal unit
  - Make them aware that there can be someone available to speak to if they do feel upset during or after this interview

IRAS 285643 – Topic guide for first interview - Neurodevelopmental Follow-up Study – V.4 revised during data collection 1

  - Debrief leaflet will be sent after the interview with available sources of support which can be accessed
- Permission to audio record? + reason for recording
- Anonymity and confidentiality
  - Recording will be kept confidential, only accessed by the immediate research team / I am not a member of LWH staff
  - Reassure that any results published will be anonymous, with all names and other identifying details removed, so that no one will be able to identify you in the results.
- Any questions they have?
- Happy for me to begin recording?

1. Background and personal circumstances

"First of all, can I ask you a few questions about you and your home situation to understand a bit more about your background and personal situation which will help me to understand the 'bigger picture'"

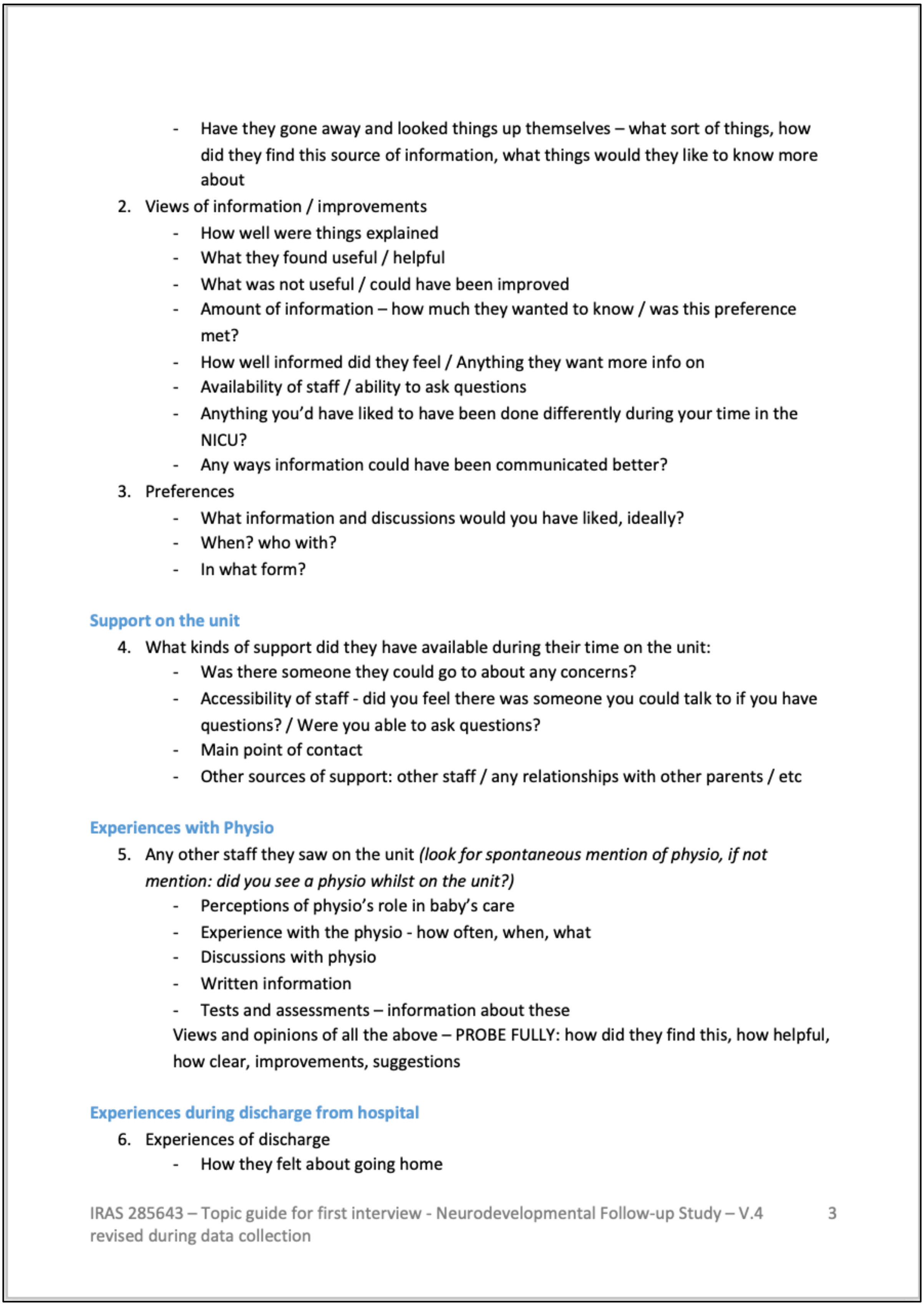
"Do you mind me asking…?"

- Parent age – at time of birth and now
- Household set up - who they live with, relationship to them, in which area of Liverpool
- Main daytime activity - (before having baby, if mother) - whether working/worked or not, details
- Baby details – ("a little bit about baby")- birth gestation, birth weight, singleton/twin *(Look for spontaneous mention of developmental risk Physio / scans / diagnoses - if they do: "that's really interesting, can we come back to that in a minute?" then probe once finished background section)*
- Other children - ("is [baby] your first child?") - details, did other children stay on the neonatal unit

Thank them for this information.
Introduce next topic…

Information on the neonatal unit about development

1. Any information given in the neonatal unit about [baby name]'s development?
   PROBE FULLY
   - Any conversations they had with staff / doctors / nurses about his/her development
   - Who, where, when
   - What sort of things discussions involved: tests, assessments, scans / results from these
   - Any other sources of information: leaflets, written information
   - Who they received this from, what form



   - Have they gone away and looked things up themselves – what sort of things, how did they find this source of information, what things would they like to know more about

2. Views of information / improvements
   - How well were things explained
   - What they found useful / helpful
   - What was not useful / could have been improved
   - Amount of information – how much they wanted to know / was this preference met?
   - How well informed did they feel / Anything they want more info on
   - Availability of staff / ability to ask questions
   - Anything you'd have liked to have been done differently during your time in the NICU?
   - Any ways information could have been communicated better?
3. Preferences
   - What information and discussions would you have liked, ideally?
   - When? who with?
   - In what form?

Support on the unit

4. What kinds of support did they have available during their time on the unit:
   - Was there someone they could go to about any concerns?
   - Accessibility of staff - did you feel there was someone you could talk to if you have questions? / Were you able to ask questions?
   - Main point of contact
   - Other sources of support: other staff / any relationships with other parents / etc

Experiences with Physio

5. Any other staff they saw on the unit *(look for spontaneous mention of physio, if not mention: did you see a physio whilst on the unit?)*
   - Perceptions of physio's role in baby's care
   - Experience with the physio - how often, when, what
   - Discussions with physio
   - Written information
   - Tests and assessments – information about these

   Views and opinions of all the above – PROBE FULLY: how did they find this, how helpful, how clear, improvements, suggestions

Experiences during discharge from hospital

6. Experiences of discharge
   - How they felt about going home

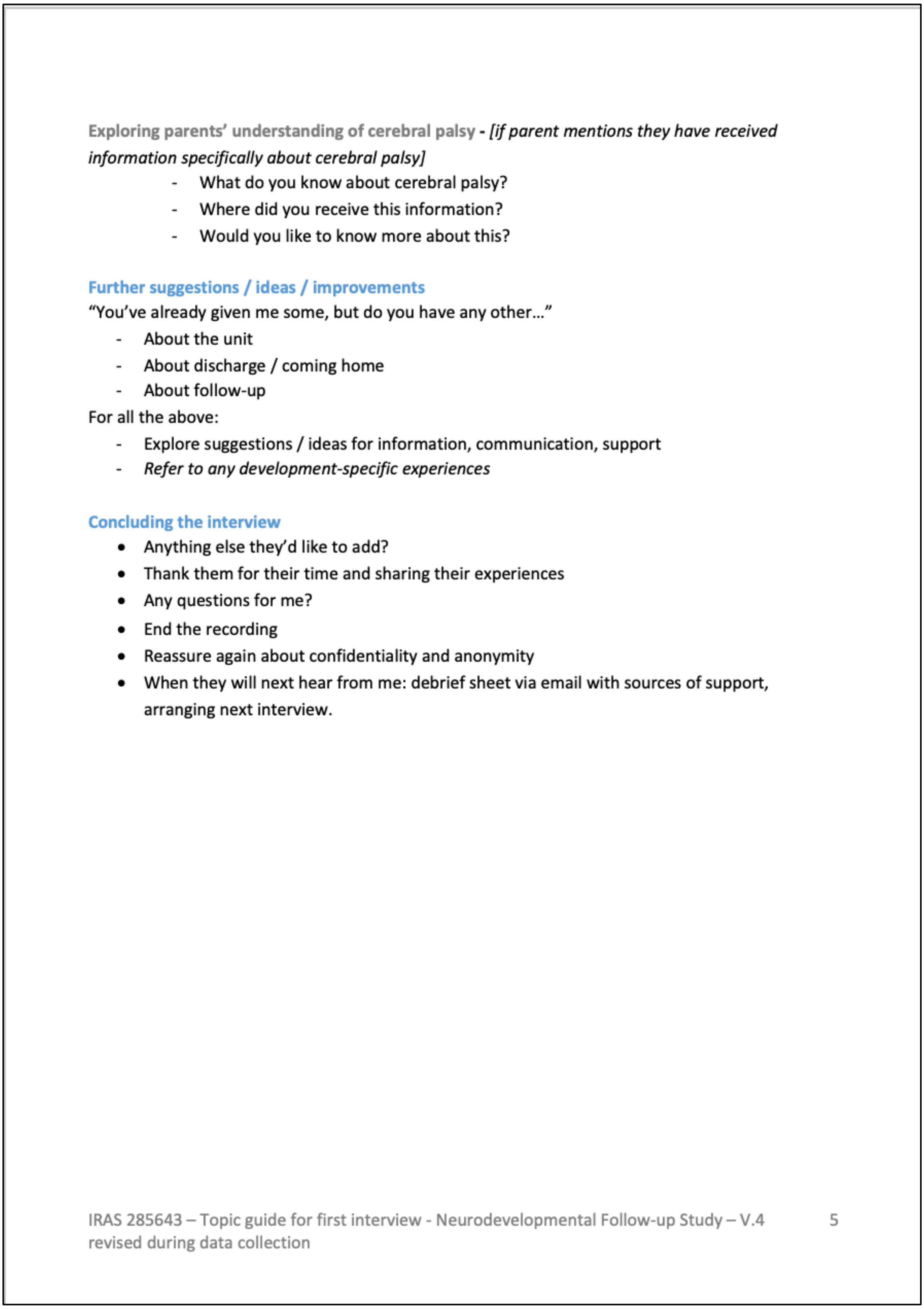
    - Any concerns / worries during this time
    - Were these addressed? – how / by whom / how well / any improvements
7. Information given during discharge
    - What form – verbal/written/videos
    - Who from, where, when
    - Views of this: how well was this explained / how helpful / how clearly explained / improvements

After discharge from hospital

8. Since you've come home, how have you found things?
    - Any problems or concerns?
9. Sources of support
    - Where, who, how can they contact
    - Point of contact at the hospital?
    - If they want more: Do you know where you can go for support? Who you can ask?
    - Are there areas where you would like more support? / What are these
    - Anything they've discussed with family / partner / friends? / what sort of things?
10. Home visits
    - Who from, when, frequency
    - Purpose of the visits, what they involve, any checks / assessments / tests
    - Discussions during home visits
11. Any information received from the hospital / from anywhere else since going home
    - Where from / when / what form / any other sources
    - Provided to them or accessed themselves?
    - Opinions of this / how useful? / was it helpful? / how clearly explained?
    - Improvements
    - anything else you want to know / lacking information on?

Upcoming follow-up – "thinking ahead now / about the future…"

12. Follow-up appointments scheduled
    - Do you know when [baby's name] is next being seen?
    - Any other follow-up appointments?
    - When will this be?
    - How was this arranged? Who with, when, where, how (verbal / letter / other)
    - How did you find arrangement of the clinic(s) / improvements
13. Information about what follow-up involves
    - What do you expect this to involve?
    - *If assessments mentioned:* what information did they receive about this / how clearly explained / improvements



Exploring parents' understanding of cerebral palsy - *[if parent mentions they have received information specifically about cerebral palsy]*

- What do you know about cerebral palsy?
- Where did you receive this information?
- Would you like to know more about this?

Further suggestions / ideas / improvements

"You've already given me some, but do you have any other…"

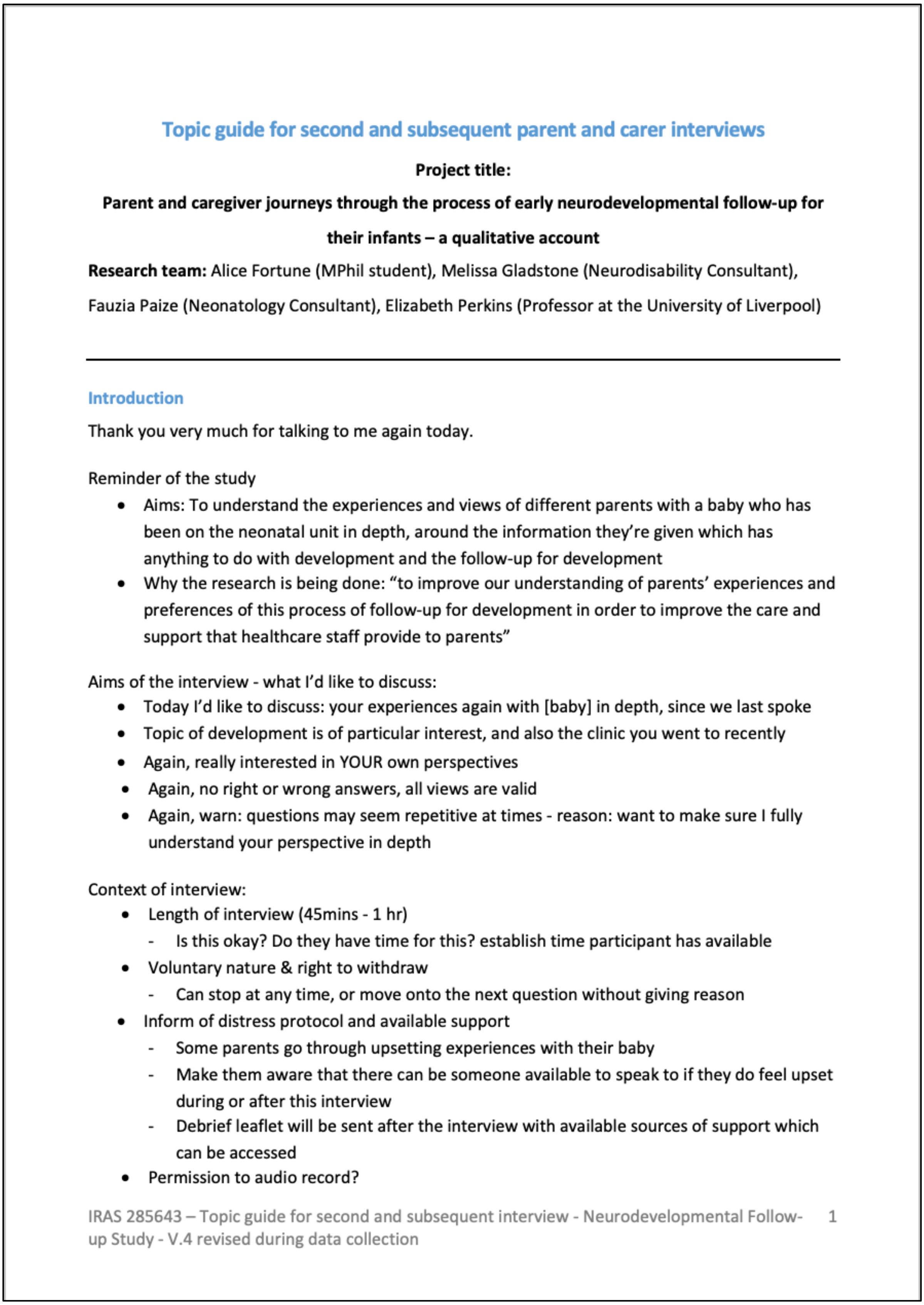
- About the unit
- About discharge / coming home
- About follow-up

For all the above:

- Explore suggestions / ideas for information, communication, support
- *Refer to any development-specific experiences*

Concluding the interview

- Anything else they'd like to add?
- Thank them for their time and sharing their experiences
- Any questions for me?
- End the recording
- Reassure again about confidentiality and anonymity
- When they will next hear from me: debrief sheet via email with sources of support, arranging next interview.



Topic guide for second and subsequent parent and carer interviews

Project title:

Parent and caregiver journeys through the process of early neurodevelopmental follow-up for their infants – a qualitative account

Research team: Alice Fortune (MPhil student), Melissa Gladstone (Neurodisability Consultant), Fauzia Paize (Neonatology Consultant), Elizabeth Perkins (Professor at the University of Liverpool)

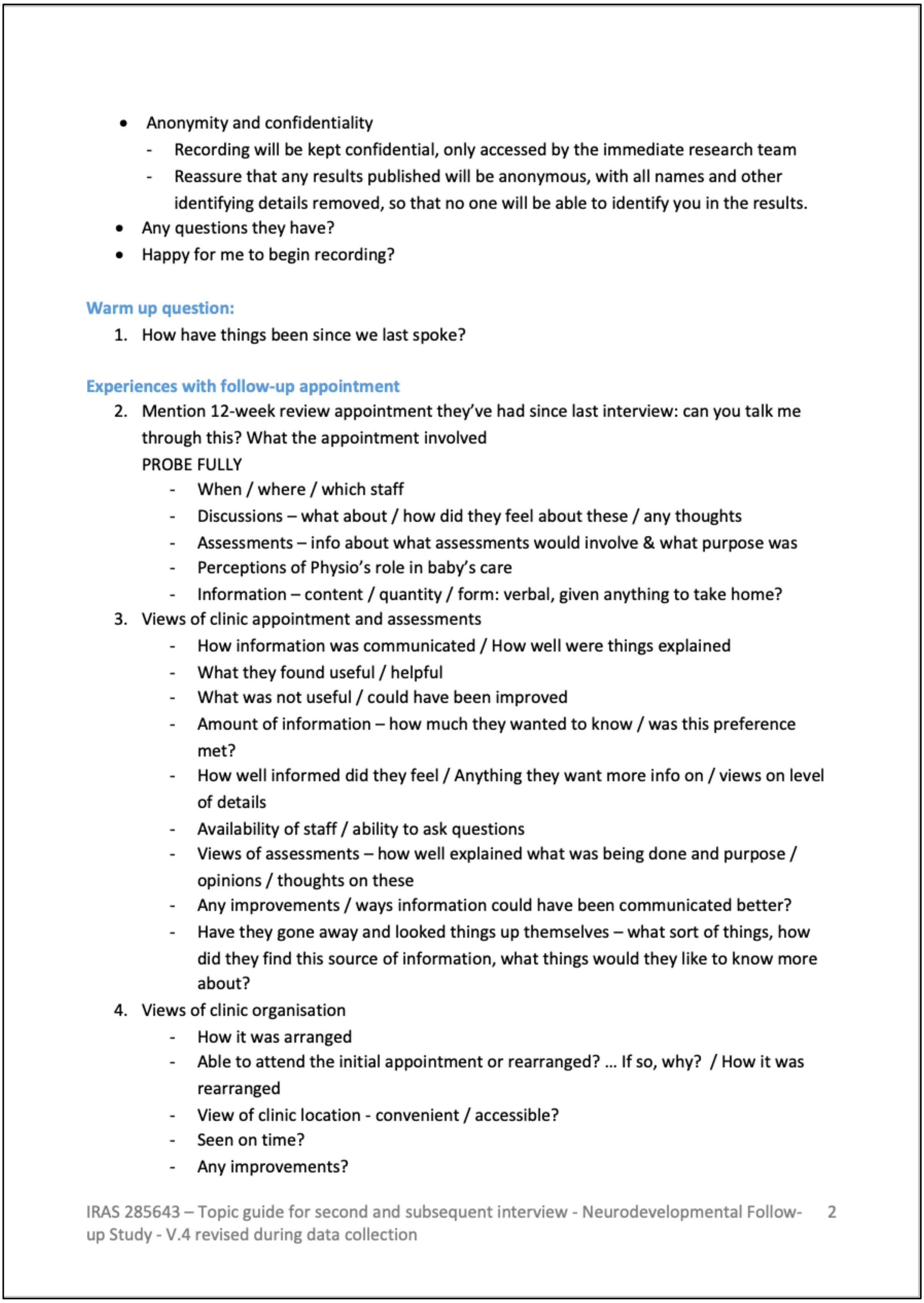
Introduction

Thank you very much for talking to me again today.

Reminder of the study
- Aims: To understand the experiences and views of different parents with a baby who has been on the neonatal unit in depth, around the information they're given which has anything to do with development and the follow-up for development
- Why the research is being done: "to improve our understanding of parents' experiences and preferences of this process of follow-up for development in order to improve the care and support that healthcare staff provide to parents"

Aims of the interview - what I'd like to discuss:
- Today I'd like to discuss: your experiences again with [baby] in depth, since we last spoke
- Topic of development is of particular interest, and also the clinic you went to recently
- Again, really interested in YOUR own perspectives
- Again, no right or wrong answers, all views are valid
- Again, warn: questions may seem repetitive at times - reason: want to make sure I fully understand your perspective in depth

Context of interview:
- Length of interview (45mins - 1 hr)
  - Is this okay? Do they have time for this? establish time participant has available
- Voluntary nature & right to withdraw
  - Can stop at any time, or move onto the next question without giving reason
- Inform of distress protocol and available support
  - Some parents go through upsetting experiences with their baby
  - Make them aware that there can be someone available to speak to if they do feel upset during or after this interview
  - Debrief leaflet will be sent after the interview with available sources of support which can be accessed
- Permission to audio record?



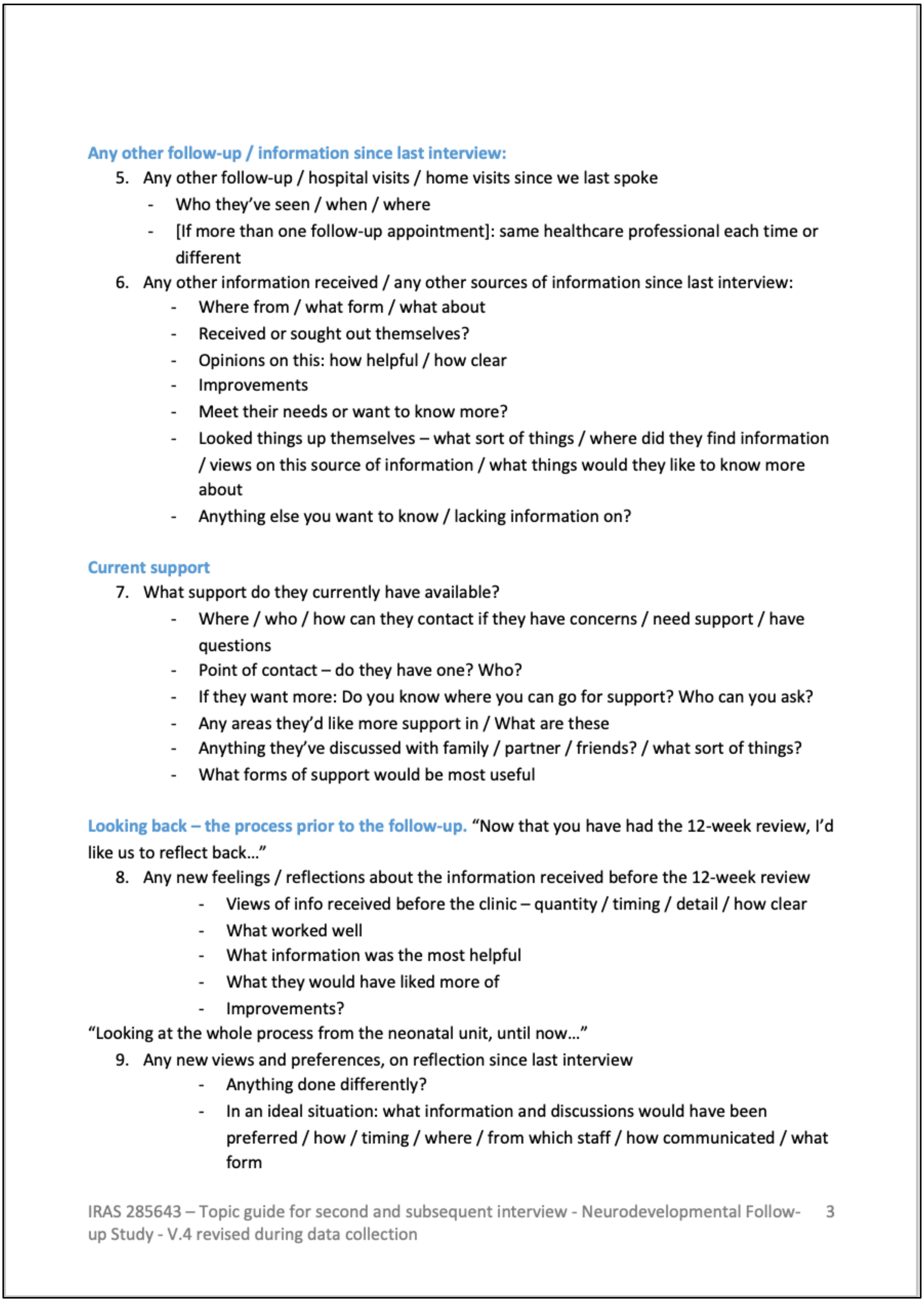
- Anonymity and confidentiality
  - Recording will be kept confidential, only accessed by the immediate research team
  - Reassure that any results published will be anonymous, with all names and other identifying details removed, so that no one will be able to identify you in the results.
- Any questions they have?
- Happy for me to begin recording?

Warm up question:

1. How have things been since we last spoke?

Experiences with follow-up appointment

2. Mention 12-week review appointment they've had since last interview: can you talk me through this? What the appointment involved
   PROBE FULLY
   - When / where / which staff
   - Discussions – what about / how did they feel about these / any thoughts
   - Assessments – info about what assessments would involve & what purpose was
   - Perceptions of Physio's role in baby's care
   - Information – content / quantity / form: verbal, given anything to take home?
3. Views of clinic appointment and assessments
   - How information was communicated / How well were things explained
   - What they found useful / helpful
   - What was not useful / could have been improved
   - Amount of information – how much they wanted to know / was this preference met?
   - How well informed did they feel / Anything they want more info on / views on level of details
   - Availability of staff / ability to ask questions
   - Views of assessments – how well explained what was being done and purpose / opinions / thoughts on these
   - Any improvements / ways information could have been communicated better?
   - Have they gone away and looked things up themselves – what sort of things, how did they find this source of information, what things would they like to know more about?
4. Views of clinic organisation
   - How it was arranged
   - Able to attend the initial appointment or rearranged? … If so, why? / How it was rearranged
   - View of clinic location - convenient / accessible?
   - Seen on time?
   - Any improvements?



Any other follow-up / information since last interview:

5. Any other follow-up / hospital visits / home visits since we last spoke
    - Who they've seen / when / where
    - [If more than one follow-up appointment]: same healthcare professional each time or different
6. Any other information received / any other sources of information since last interview:
    - Where from / what form / what about
    - Received or sought out themselves?
    - Opinions on this: how helpful / how clear
    - Improvements
    - Meet their needs or want to know more?
    - Looked things up themselves – what sort of things / where did they find information / views on this source of information / what things would they like to know more about
    - Anything else you want to know / lacking information on?

Current support

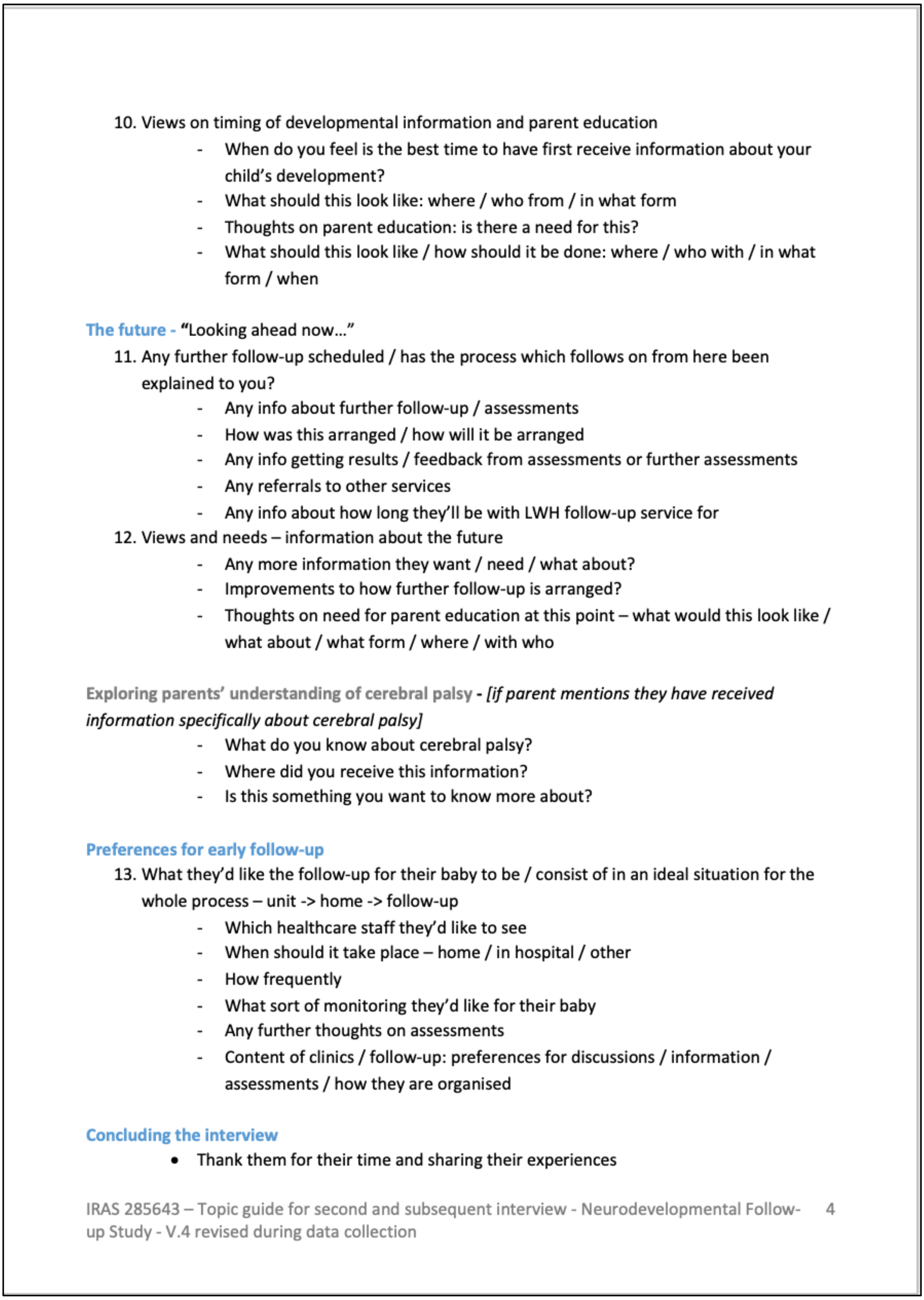
7. What support do they currently have available?
    - Where / who / how can they contact if they have concerns / need support / have questions
    - Point of contact – do they have one? Who?
    - If they want more: Do you know where you can go for support? Who can you ask?
    - Any areas they'd like more support in / What are these
    - Anything they've discussed with family / partner / friends? / what sort of things?
    - What forms of support would be most useful

Looking back – the process prior to the follow-up. "Now that you have had the 12-week review, I'd like us to reflect back…"

8. Any new feelings / reflections about the information received before the 12-week review
    - Views of info received before the clinic – quantity / timing / detail / how clear
    - What worked well
    - What information was the most helpful
    - What they would have liked more of
    - Improvements?

"Looking at the whole process from the neonatal unit, until now…"

9. Any new views and preferences, on reflection since last interview
    - Anything done differently?
    - In an ideal situation: what information and discussions would have been preferred / how / timing / where / from which staff / how communicated / what form



10. Views on timing of developmental information and parent education
    - When do you feel is the best time to have first receive information about your child's development?
    - What should this look like: where / who from / in what form
    - Thoughts on parent education: is there a need for this?
    - What should this look like / how should it be done: where / who with / in what form / when

The future - "Looking ahead now…"

11. Any further follow-up scheduled / has the process which follows on from here been explained to you?
    - Any info about further follow-up / assessments
    - How was this arranged / how will it be arranged
    - Any info getting results / feedback from assessments or further assessments
    - Any referrals to other services
    - Any info about how long they'll be with LWH follow-up service for
12. Views and needs – information about the future
    - Any more information they want / need / what about?
    - Improvements to how further follow-up is arranged?
    - Thoughts on need for parent education at this point – what would this look like / what about / what form / where / with who

Exploring parents' understanding of cerebral palsy - *[if parent mentions they have received information specifically about cerebral palsy]*

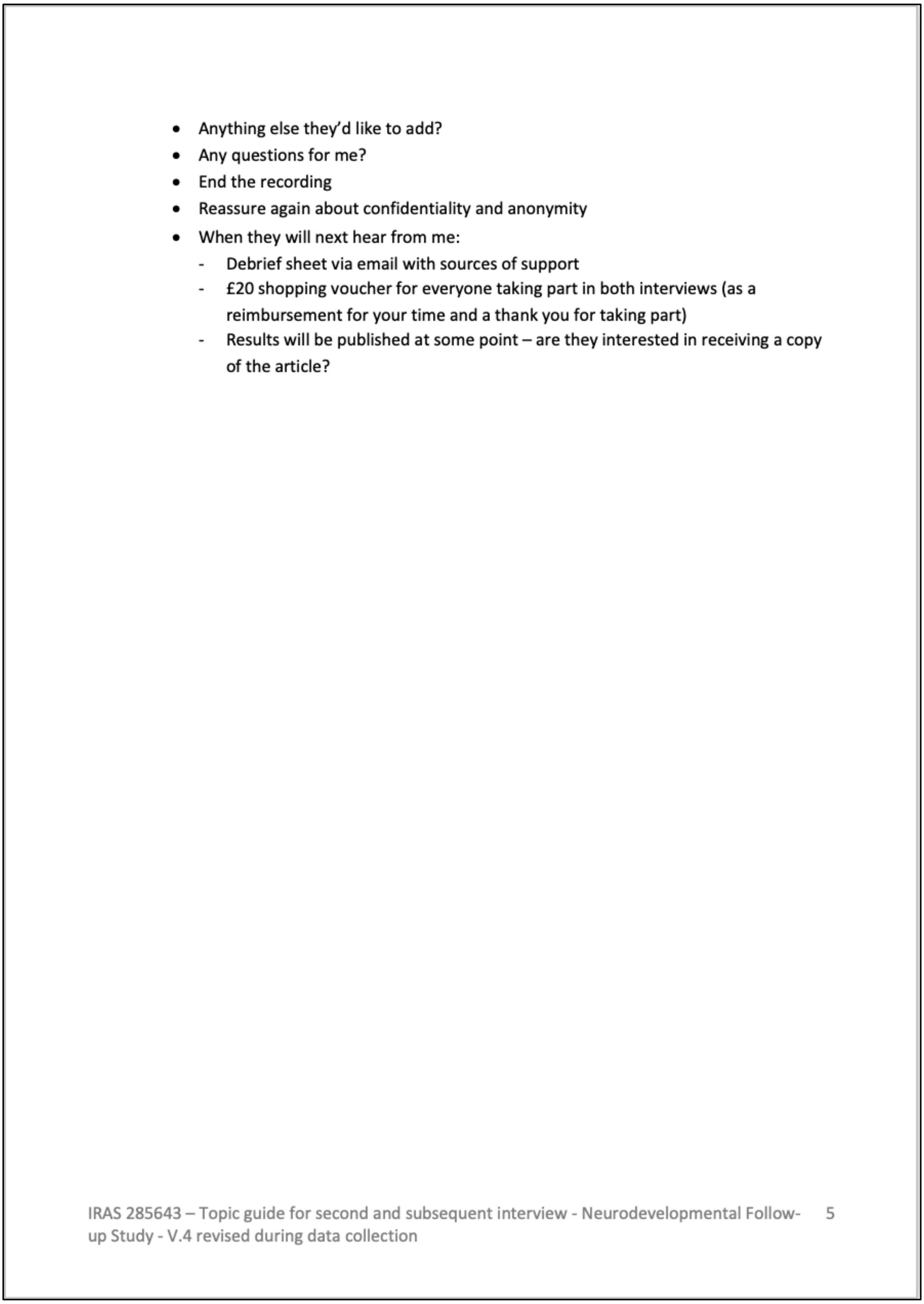
- What do you know about cerebral palsy?
- Where did you receive this information?
- Is this something you want to know more about?

Preferences for early follow-up

13. What they'd like the follow-up for their baby to be / consist of in an ideal situation for the whole process – unit -> home -> follow-up
    - Which healthcare staff they'd like to see
    - When should it take place – home / in hospital / other
    - How frequently
    - What sort of monitoring they'd like for their baby
    - Any further thoughts on assessments
    - Content of clinics / follow-up: preferences for discussions / information / assessments / how they are organised

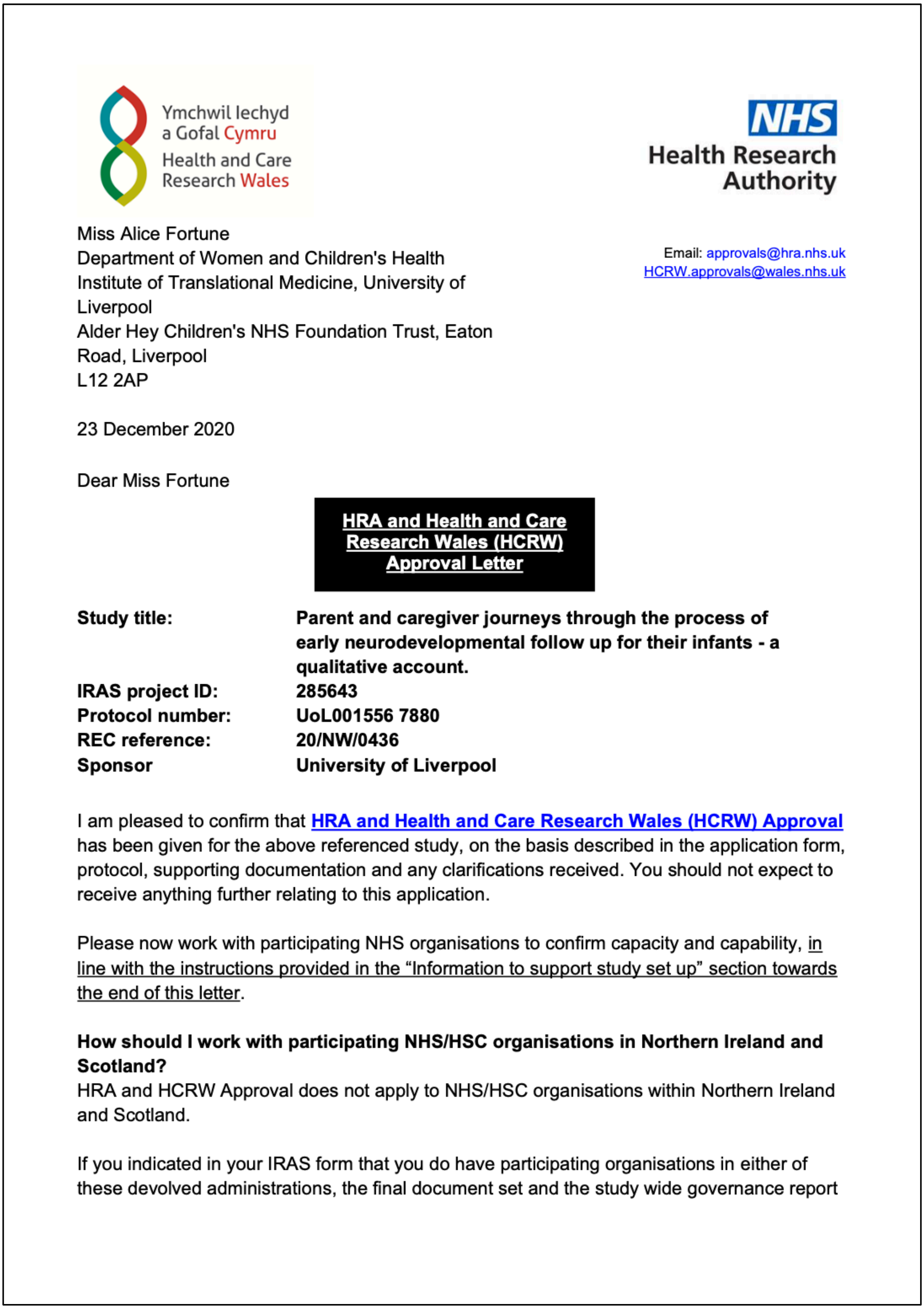
Concluding the interview

- Thank them for their time and sharing their experiences



- Anything else they'd like to add?
- Any questions for me?
- End the recording
- Reassure again about confidentiality and anonymity
- When they will next hear from me:
    - Debrief sheet via email with sources of support
    - £20 shopping voucher for everyone taking part in both interviews (as a reimbursement for your time and a thank you for taking part)
    - Results will be published at some point – are they interested in receiving a copy of the article?

Appendix F: Ethical approval by the Health Research Authority (HRA)



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Miss Alice Fortune
Department of Women and Children's Health
Institute of Translational Medicine, University of
Liverpool
Alder Hey Children's NHS Foundation Trust, Eaton
Road, Liverpool
L12 2AP

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

23 December 2020

Dear Miss Fortune

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**Parent and caregiver journeys through the process of early neurodevelopmental follow up for their infants - a qualitative account.**
IRAS project ID:	**285643**
Protocol number:	**UoL001556 7880**
REC reference:	**20/NW/0436**
Sponsor	**University of Liverpool**

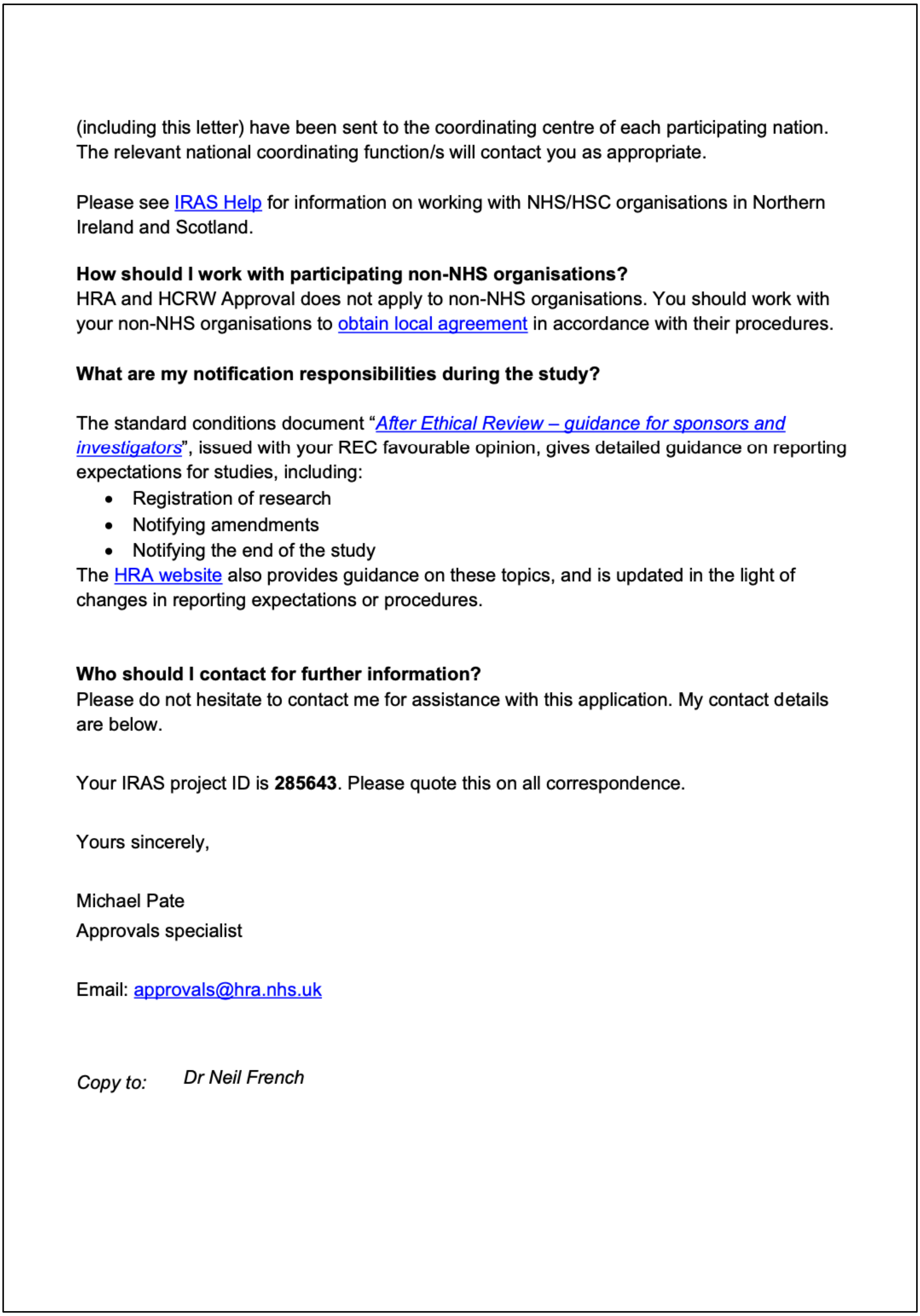
I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report



(including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

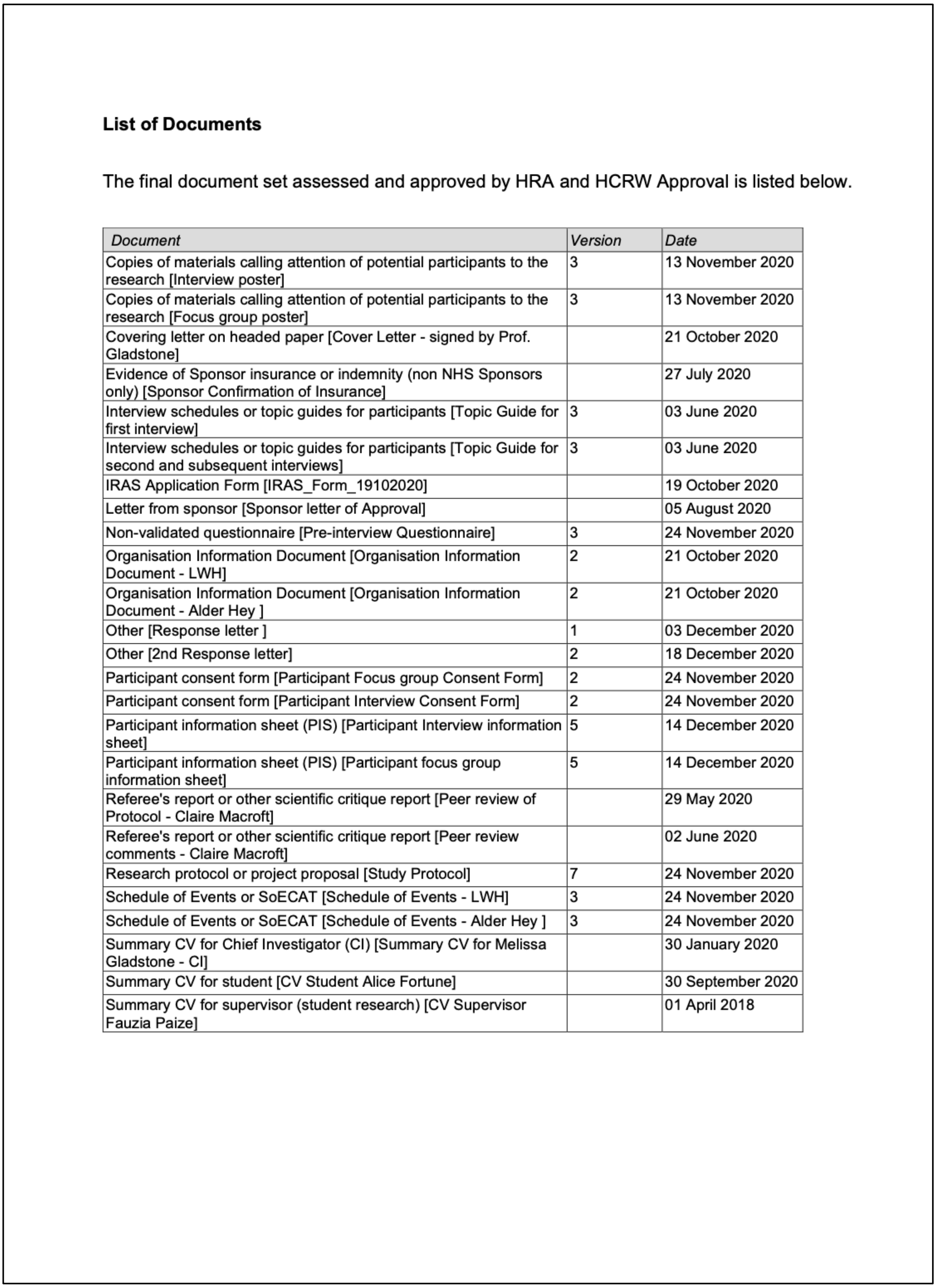
Your IRAS project ID is **285643**. Please quote this on all correspondence.

Yours sincerely,

Michael Pate
Approvals specialist

Email: approvals@hra.nhs.uk

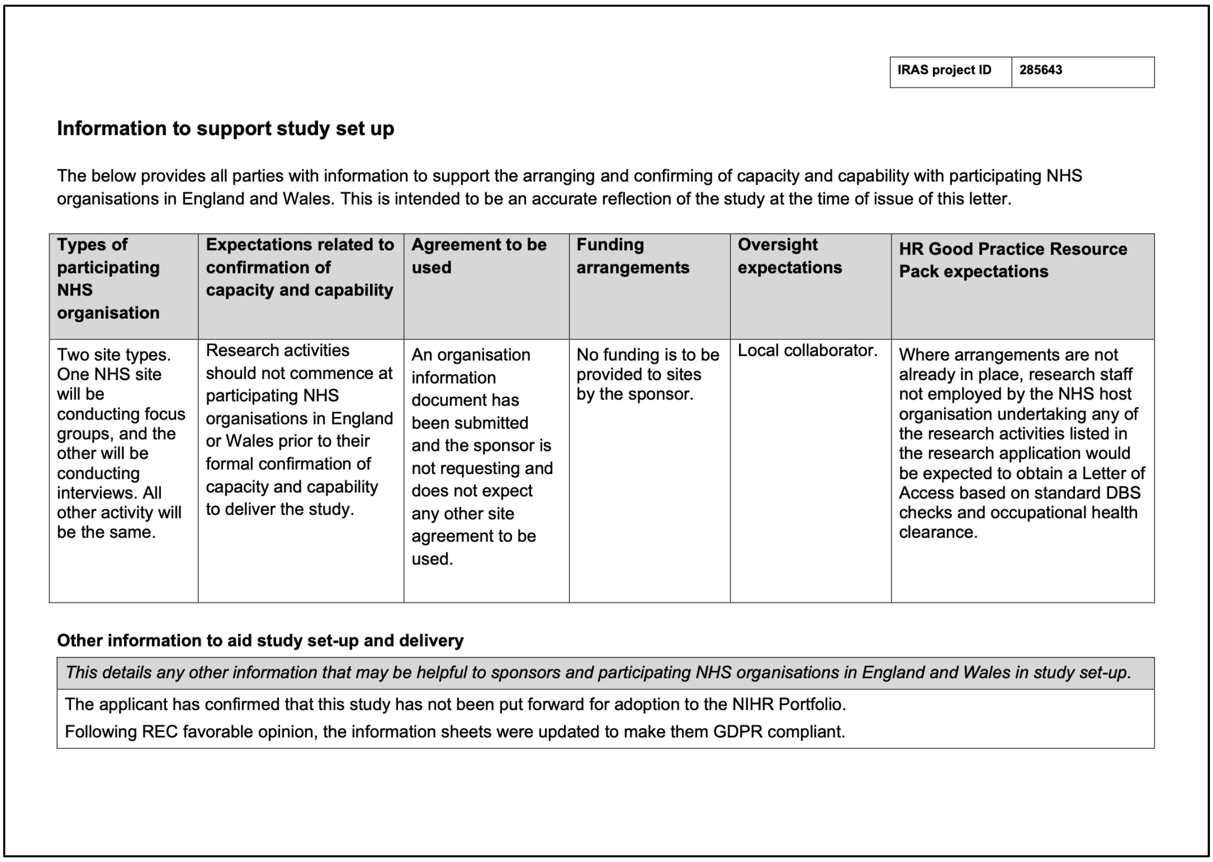
Copy to: *Dr Neil French*



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Interview poster]	3	13 November 2020
Copies of materials calling attention of potential participants to the research [Focus group poster]	3	13 November 2020
Covering letter on headed paper [Cover Letter - signed by Prof. Gladstone]		21 October 2020
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Sponsor Confirmation of Insurance]		27 July 2020
Interview schedules or topic guides for participants [Topic Guide for first interview]	3	03 June 2020
Interview schedules or topic guides for participants [Topic Guide for second and subsequent interviews]	3	03 June 2020
IRAS Application Form [IRAS_Form_19102020]		19 October 2020
Letter from sponsor [Sponsor letter of Approval]		05 August 2020
Non-validated questionnaire [Pre-interview Questionnaire]	3	24 November 2020
Organisation Information Document [Organisation Information Document - LWH]	2	21 October 2020
Organisation Information Document [Organisation Information Document - Alder Hey]	2	21 October 2020
Other [Response letter]	1	03 December 2020
Other [2nd Response letter]	2	18 December 2020
Participant consent form [Participant Focus group Consent Form]	2	24 November 2020
Participant consent form [Participant Interview Consent Form]	2	24 November 2020
Participant information sheet (PIS) [Participant Interview information sheet]	5	14 December 2020
Participant information sheet (PIS) [Participant focus group information sheet]	5	14 December 2020
Referee's report or other scientific critique report [Peer review of Protocol - Claire Macroft]		29 May 2020
Referee's report or other scientific critique report [Peer review comments - Claire Macroft]		02 June 2020
Research protocol or project proposal [Study Protocol]	7	24 November 2020
Schedule of Events or SoECAT [Schedule of Events - LWH]	3	24 November 2020
Schedule of Events or SoECAT [Schedule of Events - Alder Hey]	3	24 November 2020
Summary CV for Chief Investigator (CI) [Summary CV for Melissa Gladstone - CI]		30 January 2020
Summary CV for student [CV Student Alice Fortune]		30 September 2020
Summary CV for supervisor (student research) [CV Supervisor Fauzia Paize]		01 April 2018



IRAS project ID	285643

Information to support study set up

The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
Two site types. One NHS site will be conducting focus groups, and the other will be conducting interviews. All other activity will be the same.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An organisation information document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No funding is to be provided to sites by the sponsor.	Local collaborator.	Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
The applicant has confirmed that this study has not been put forward for adoption to the NIHR Portfolio. Following REC favorable opinion, the information sheets were updated to make them GDPR compliant.