

**Staff Perspectives of Working with Families of Children and  
Young People in Paediatric Residential Neurorehabilitation**

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## **ABSTRACT**

### **Background**

In the UK, paediatric neurorehabilitation services are encouraged to develop a collaborative working relationship with families. This relationship supports effective assessments, rehabilitation and the development of shared goals, interventions and evaluations. It also supports the transition of life after rehabilitation.

Children and young people with the most severe acquired brain injuries participate in intensive residential neurorehabilitation. Given the momentum to empower and integrate families, and the challenging context in which relationships between healthcare professionals and families takes place, data is sparse and disparate around this relational experience.

This study looked to understand what it is like for healthcare professionals to work with families of children and young people in a residential paediatric neurorehabilitation service and what enables or hinders collaboration.

### **Method**

15 participants who work at a residential paediatric neurorehabilitation service in the UK were interviewed. Participants were made up of members of the nursing team, psychosocial team, therapies team and assistive technologies team.

### **Results**

Interviews were transcribed and analysed using thematic analysis. Five key themes and 13 subthemes were identified, including intentions and hopes, assessment and understanding, what healthcare professionals do and what factors contribute to when things get stuck.

## **Conclusion**

The study suggests that the working relationship with families is important in order to create meaningful interventions and prepare families to life beyond the service.

Healthcare professionals attune to each family in order to join and create as good as working relationships as possible given very challenging contexts of grief, upheaval and stress. There are however a number of barriers to developing collaborative relationships.

This study puts forward a psychological stance to understand the experiences, barriers and enablers to collaborative relationships.

## CONTENTS PAGE

1.	<b>INTRODUCTION</b>	11
1.1.	Overview of Acquired Brain Injury	11
1.2.	Acquired Brain Injury in Children	11
1.2.1.	Injury Severity	11
1.2.2.	Impact on a Developing Brain	12
1.2.3.	Cognitive Reserve	13
1.2.4.	Location of Injury	13
1.2.5.	Additional Factors Affecting ABI Outcomes	13
1.3.	Prevalence of ABI	14
1.4.	Risk Factors for TBI	15
1.4.1.	Age	15
1.4.2.	Gender	16
1.4.3.	Race and Ethnicity	16
1.4.4.	Socioeconomic Status	16
1.4.5.	Risk Factors for Non-TBIs	16
1.5.	Neurorehabilitation	17
1.5.1.	Pathway, Categories and Policies in the UK	17
1.6.	Residential Paediatric Neurorehabilitation: A Level 1 Service	18
1.6.1.	What Works in Residential Paediatric Neurorehabilitation?	19
1.6.2.	Service Approaches	20
1.6.3.	A Focus on Families	21
2.	<b>LITERATURE REVIEW</b>	22
2.1.	Literature Review Strategy	22
2.2.	What Families Need and Want from PNR Services	24
2.2.1.	Information and Communication	24
2.2.2.	Trust and Rapport with Practitioners	25
2.2.2.1.	Facilitators of trust and rapport	25
2.2.2.2.	Barriers of trust and rapport	26
2.3.	Psychosocial Impact on Families	26
2.3.1.	Families Experience a Range of Emotions: From Admission to Discharge	27

2.3.1.1.	Emotional journey of parents	27
2.3.1.2.	Emotional journey of siblings	28
2.3.2.	Developing New Family Roles After a Child Sustains an ABI	28
2.3.2.1.	Developing new parental roles	28
2.3.2.2.	Siblings taking on a new role	29
2.4.	Gaps in Services	29
2.4.1.	Transitions	29
2.4.2.	Accessing Community Services	30
2.4.3.	Working with Adolescents	30
2.4.4.	Working with Children with Pre-existing Conditions	31
2.5.	HCPs Experience of Working with Families	32
2.5.1.	Navigating Expectations and Adjustment	32
2.5.2.	Experience of Endings and Discharge	32
2.5.3.	Tele-healthcare	33
2.5.4.	Making Services Work: Doing What it Takes	33
2.6.	Drawing on Psychological Theory	34
2.6.1.	Theories of Adjustment	35
2.6.1.1.	Stress-response models for understanding the crisis of physical illness	36
2.6.2.	Considering Wider Systems: The Ecological Model	38
2.6.2.1.	Ecological theory applied to paediatric ABI	38
2.6.3.	Attachment Theory	40
2.6.4.	A Psychodynamic Frame	41
2.7.	The Proposed Study and Research Question	41
2.8.	Clinical Relevance	42
3.	<b>METHOD</b>	44
3.1.	Ontology and Epistemology	44
3.2.	Methodology	45
3.3.	Research Method	45
3.3.1.	Practical Considerations During a Pandemic.	45
3.3.2.	Inclusion and Exclusion Criteria	45
3.3.3.	Choice of Method	46
3.4.	Recruitment	47

3.5.	Ethical approval	48
3.6.	Informed Consent	48
3.7.	Confidentiality and Anonymity	48
3.8.	Risk Assessment	48
3.9.	Withdrawing Data	49
3.10.	The Interview Schedule	49
3.11.	Analysis	50
3.12.	Reflexivity	51
3.12.1.	Personal Reflexive Statement	52
4.	<b>RESULTS</b>	54
4.1.	Overview	54
4.2.	Participant Characteristics	54
4.3.	Thematic Map	54
4.4.	Themes	57
4.4.1.	Intentions of Collaboration	57
4.4.1.1.	Access	57
4.4.1.2.	Developing useful interventions	58
4.4.1.3.	Preparation for next steps	59
4.4.2.	Understanding Family Needs and Expectations	60
4.4.2.1.	The circumstance: the family, the injury and the coping	60
4.4.2.2.	Expectations	62
4.4.3.	Attunement and Adaptation	63
4.4.3.1.	Joining strategies	63
4.4.3.2.	Strategies in rehabilitation	65
4.4.3.3.	Attuning to the family	66
4.4.4.	Things Get Stuck and Missed	69
4.4.4.1.	From the family	69
4.4.4.2.	From the professional	71
4.4.4.3.	From the service	73
4.4.5.	What Does or Could Help	77
4.4.5.1.	Personal practices	77
4.4.5.2.	Service practices	78

5.	<b>DISCUSSION</b>	80
5.1.	Overview	80
5.2.	Summary of Findings	80
5.3.	Research Q1: What is it like for Staff to Work with Families of CYP with an ABI in a RPNR Service?	81
5.3.1.	Expectations and Hopes from the HCPs	81
5.3.2.	Approaches to Working with Families	82
5.3.3.	Appreciating Family Individuality	83
5.3.3.1.	Mentalisation	84
5.3.3.2.	A Biopsychosocial Lens	85
5.3.4.	Common Dilemmas: Expectation Management with Families	87
5.3.5.	Common Dilemmas: Access	88
5.3.5.1.	Fathers	88
5.3.5.2.	Siblings	89
5.3.5.3.	The CYP	89
5.3.6.	Common Dilemmas: Responding to Emotional Responses	90
5.4.	Research Q2: What are the Enablers and Barriers to this Collaborative Work?	90
5.4.1.	Psychosocial Factors: Resources	91
5.4.2.	Practitioner Wellbeing	92
5.4.3.	Communication	93
5.4.3.1.	The communication environment	93
5.4.3.2.	Information exchange	93
5.4.3.3.	Attitude and listening	94
5.4.3.4.	Aligning and responding	94
5.4.3.5.	Communicating with specific groups	95
5.4.3.6.	Creating the preconditions for effective communication within a team	96
5.5.	Summary	97
5.6.	Implications for Clinical Practice	98
5.6.1.	Supporting Staff Mentalisation	98
5.6.1.1.	Information continuity	98
5.6.1.2.	Enabling smoother communication with families who don't speak English	99
5.6.1.3.	Enabling smoother communication with families with different	



world views or communication styles	99
5.6.1.4. Defining FCC approach	99
5.6.1.5. Supporting respite and protection for HCPs	100
5.6.1.6. Supporting HCPs' biopsychosocial understanding	100
5.6.2. Attending to Service and Practice Gaps	101
5.6.2.1. Resource gaps	101
5.6.2.2. Ambiguous loss	101
5.6.2.3. Fathers and siblings	101
5.7. Dissemination	102
5.8. Critical Evaluation	102
5.8.1. Methodology	102
5.8.1.1. Sensitivity to context	103
5.8.1.2. Commitment and rigour	104
5.8.1.3. Transparency and coherence	104
5.8.1.4. Impact and importance	104
5.8.2. Method	105
5.8.3. Limitations and Ethical Considerations	105
5.8.3.1. Recruitment	105
5.8.3.2. Alternative Recruitment	106
5.8.3.3. Generalisability	106
5.8.3.4. Missing Voices	107
5.8.3.5. Method	107
5.8.4. Researcher Reflexivity	107
5.9. Recommendations for Future Research	109
5.9.1. Investigating Further into Professional and Family Experiences	109
5.9.2. Outcomes	109
5.9.3. Considering Attitudes and Culture of Staff Abuse	110
5.9.4. Investigating the Gaps	110
5.9.5. Identifying Rehabilitation Capital	110
5.10. Conclusion	111
6. <b>REFERENCES</b>	112

7.	<b>APPENDICES</b>	157
	APPENDIX 1: Invitation Email and Poster	157
	APPENDIX 2: Application for Research Ethics Approval	159
	APPENDIX 3: Notice of Ethical Approval	172
	APPENDIX 4: Application to Organisation for Research Approval	175
	APPENDIX 5: Research Approval from Organisation	186
	APPENDIX 6: Initial Email After Participant Contact of Interest	187
	APPENDIX 7: Email with Information Sheet and Consent Process	188
	APPENDIX 8: Example Participant Interview Invites	196
	APPENDIX 9: Data Management Plan	198
	APPENDIX 10: Example Debrief Email and Letter	208
	APPENDIX 11: Example from Research Log	211
	APPENDIX 12: List of Initial Codes	212
	APPENDIX 13: Example of Codes and Quotes	216
	APPENDIX 14: Example of Grouping Codes to Initial Themes	218
	APPENDIX 15: Example of Mapping Themes and Subthemes	221

## **1. INTRODUCTION**

### **1.1. Overview of Acquired Brain Injury**

Acquired brain injury (ABI) is an umbrella term for damage to the brain that has occurred after birth and after a period of typical development. ABI can be categorised as arising from traumatic or non-traumatic means. Traumatic brain injuries (TBI) result of events where an outside force causes damage to the brain, such as road traffic accidents, assault or falls. Non-traumatic brain injuries include those that result from health conditions such as brain infections, strokes, hypoxia, encephalitis or meningitis (Entwistle & Newby, 2013; Lindberg, 2021; Menon et al., 2010).

### **1.2. Acquired Brain Injury in Children**

A child who sustains an ABI can be impacted in a wide variety of ways. Injuries can vary in aetiology with varying severity and locations to children and young people (CYP) at different ages in different environmental settings. This section will give a brief overview of the different factors that are considered in understanding ABIs in CYP.

#### **1.2.1. Injury Severity**

Severity of injury is one of the strongest indicators of outcomes, with the most research coming from TBI literature; there is a known need for more research into non-TBI outcomes (Stark et al., 2020). Severity of injury is mostly commonly assessed using a combination of clinical assessments; to identify risk factors such as loss of consciousness or post-traumatic amnesia. This often includes using the Glasgow Coma Scale. Injuries are then categorised into mild, moderate and severe (National Institute for Care and Health Excellence, 2014). Injuries are not static and can exacerbate, sometimes to the point of a second brain injury, due to the brain's inflammatory response and preventable factors such as hypoxia, hypothermia medication side effects (Morrison et al., 2013; Stark et al.,

2020). Outcomes are linked in a dose-like relationship with severity; higher severity means poorer outcomes.

Moderate to severe ABIs can impact CYP on multiple domains. They may face difficulties with their executive function, learning, memory, senses, movement, communication, and emotional sequelae. This can also lead to difficulties with self-esteem, low mood, anxiety and identity (Babikian & Asarnow, 2009; Di Battista et al., 2014; Entwistle & Newby, 2013; Stark et al., 2020; Treble-Barna et al., 2017).

### 1.2.2. Impact on a Developing Brain

The impact of an ABI can be more complicated given the developing nature of the brain in CYP. The brain becomes specialised for different functions at different stages of development from: pregnancy, early infancy, childhood to adolescence. The brain is not considered fully mature until approximately 25 years of age. Changes are underpinned by periods of neural expansion and pruning. Neural expansion is facilitated by a process of great plasticity and connection; millions of neurones fire new signals that start to connect and create wires, related to experiences (Hebb, 1949; Kandel, 2009). During adolescence, a process of topiary is undertaken. Connections related to experiences that are repeated are strengthened whilst those that are less relevant to the person are clipped, this is known as apoptosis. It's a case of 'use or lose it' (Alberts, 2008; Gogtay et al., 2004, 2006; Petanjek et al., 2011).

Given the developmental stages of the brain, the age a CYP sustains an ABI can determine different outcomes. Contrary to previous beliefs, recent research suggests that sustaining a brain injury earlier in life, before the age of three, is correlated to poorer intellectual, cognitive and functional outcomes. This is the 'double hazard' of paediatric ABI: the direct impact of the injury and then the impact the ABI has on brain development (Anderson et al., 2005, 2014). The long-term consequence of an ABI can be rather unpredictable for CYP and not be apparent for some time after the injury (Stark et al., 2020).

### 1.2.3. Cognitive Reserve

Cognitive reserve is a concept that encapsulates a broad range of factors that may make a person more able manage a brain injury, given pre-existing cognitive processes or compensatory mechanisms. Education, learning ability or disability, socioeconomic status and family functioning can impact this cognitive reserve. Cognitive reserve is less in younger children, due to a diminished opportunity to develop processes and mechanisms, thus linked to the greater impact of an ABI on younger children (Dennis et al., 2007; Fuentes et al., 2010).

### 1.2.4. Location of Injury

An ABI can be located to specific areas (focal) or spread throughout a broad area of the brain (diffuse). Considering focal areas of injury can be useful to help understand and summarise the impact of a brain injury, in terms of location and outcomes. For example, damage to the occipital lobes or the connections around the occipital lobes could impact visual perception and create difficulties in such areas as spatial awareness or facial recognition or experiencing hallucinations (Ffytche et al., 2010). Damage to different areas of the brain can elicit different outcomes, and a developing brain will have different areas forming at different rates (Anderson et al., 2019; Lezak et al., 2004). However, caution is warranted as it could be reductionist to identify the sequelae of brain injury to one area of the brain. Biomarkers are not well validated and there is evidence that ABIs are often both focal and diffuse (Ettey, 2018; B. Levine et al., 2006, 2013).

### 1.2.5. Additional Factors Affecting ABI Outcomes

Pre-existing difficulties with anxiety, anger, aggression or challenging behaviour are linked to behavioural difficulties post-ABI. In addition, children who have been given an ADHD diagnosis are linked to having poorer outcomes post-ABI (Bonfield et al., 2013; Catroppa et al., 2008; Cole et al., 2008; Narad et al., 2020).

Environmental factors are commonly cited as impacting outcomes post-ABI. The most robust factor being lower socioeconomic status affecting behavioural,

intellectual and cognitive outcomes (Anderson et al., 2006; Chapman et al., 2010; Crowe et al., 2012; International Paediatric Brain Injury Society & The Eden Dora Trust, 2016; Kline et al., 2017; Li & Liu, 2013; Taylor et al., 2002). This may be related to access to resources, enriched environments, financial and parenting pressures (Giza et al., 2009; McKinlay et al., 2016).

### **1.3. Prevalence of ABI**

It is difficult to ascertain the exact or consistent prevalence of people acquiring brain injuries. ABI encompasses a broad range of causes and research studies differ in their methods and inclusion criteria (Bruns & Hauser, 2003).

NHS England report an estimated number of children admitted to hospital a year for TBI being 35,000 (280 – 500 per 100,000). The majority of these admissions would be classed as mild TBI, with 3,000 being moderate and 2,000 severe (NHS England, 2013a; Trefan et al., 2016). It also reports that there are just under 5,000 cases of non-traumatic ABI's year, including non-traumatic coma, brain tumours and childhood stroke. These figures are contested in other literature, with estimates of 1,300 incidents of non-traumatic ABI each year (Forsyth & Kirkham, 2012). Putting this into a digestible context, The Child Brain Injury Trust report that a child acquires a brain injury every 30 minutes in the UK (The Child Brain Injury Trust, 2018).

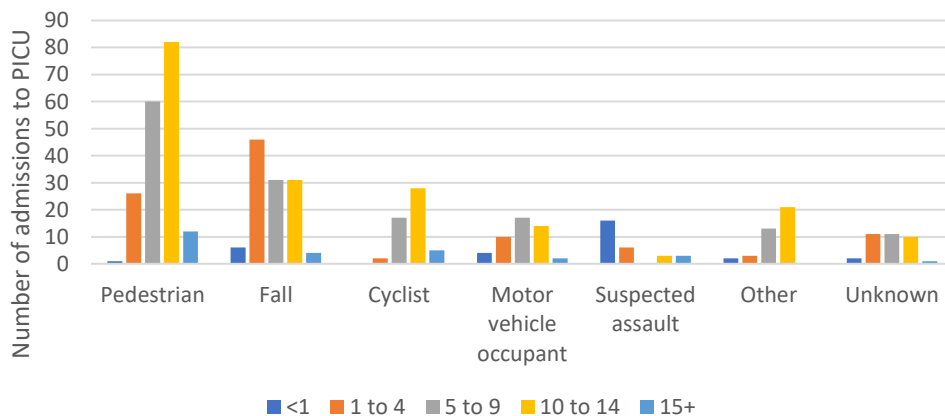
ABI is acknowledged as one of the leading causes of childhood death and disability worldwide. Within the UK, the rates of survival from an ABI in children under 15 has improved over time, due to advances in medical care. Paediatric death due to an ABI reduced from 15% to 6% between 1990 and 2004 (Barber et al., 2018; Feickert et al., 1999; Parslow, 2005; Sharples et al., 1990).

## 1.4. Risk Factors for TBI

### 1.4.1. Age

Age is a significant risk factor for TBI with peaks of incidence at infancy, adolescence and old age (Bruns & Hauser, 2003). Figure 1 shows a breakdown of causes of TBI in CYP who attended intensive care in the UK by age (Parslow, 2005). The highest number of incidents were caused by pedestrian accidents, falls and cycling accidents for children 1 year old or older. For infants below the age of 1, suspected assault was the highest cause of traumatic brain injury. These figures seem to be in correlation with the physical developments of children and the increase of activities (L. Levine & Munsch, 2014).

**Figure 1.** Causes of admission to paediatric intensive care units (PICU) between Feb 2001 and Aug 2003 in the UK



Note: Adapted from data in Epidemiology of traumatic brain injury in children receiving intensive care in the UK by R. C. Parslow, 2005, Archives of Disease in Childhood, 90(11), 1182–1187 (<https://doi.org/10.1136/adc.2005.072405>)

#### 1.4.2. Gender

Bruns & Hauser's 2003 also posit that males are between 1.3 - 2.0 times as likely to sustain a TBI, a figure is consistent with other studies (Annegers et al., 1980; Guerrero et al., 2000; Jager et al., 2000; Kraus et al., 1984; McKinlay et al., 2008; Nguyen et al., 2016; Tate et al., 1998; Wang et al., 1986).

#### 1.4.3. Race and Ethnicity

Race and ethnicity have also been found as a factor of risk. Higher incidents were identified in most race and ethnic groups (Black, Hispanic and Asian people) compared to white people, a rate found in both adults and children. The reasons for this difference are rarely explained (Brenner et al., 2020; Dewan et al., 2016; Langlois et al., 2005; Love et al., 2009).

#### 1.4.4. Socioeconomic Status

It has also been posited that children who come from low socioeconomic status (SES) households may be more at risk of a TBI. Literature suggests this is due to a higher exposure to hazardous environments and lower supervision which increase risk (Amram et al., 2015; Hippisley-Cox, 2002; Murgio, 2003; Parslow, 2005).

#### 1.4.5. Risk Factors for Non-TBIs

Identifying risk factors for non-TBIs is a challenge and difficult to summarise. There are many different health conditions that can cause a non-TBI, each with different risk factors. For example: paediatric stroke has a similar epidemiological profile to traumatic injury, with males and black children having a higher rate of incidence, taking into account sickle cell disease (Roach et al., 2008; Tsze & Valente, 2011). This is then compared to risk factors for central nervous system cancers; where there is small and non-conclusive data that gender (being male), low birth weight and exposure to certain chemicals may increase risk (Kaatsch et al., 2001; McKinney et al., 1998; Schuz et al., 2001).



## 1.5. Neurorehabilitation

Neurorehabilitation is the broad name given to the package of support that is given to people who sustain an ABI, it brings together a range of different disciplines for a person's care. Given that each incidence of ABI can be so different and have such unique effects, the challenge of neurorehabilitation is to develop a package that meets the needs of each person (Menon, 2018; Royal College of Physicians of London & British Society of Rehabilitation Medicine, 2003; D. Wade, 2015).

### 1.5.1. Pathway, Categories and Policies in the UK

The pathway of care after a child sustains an ABI depends on the severity of injury and regional provision of services. Pathways generally start with admission to a general hospital's accident and emergency department. It is then recommended CYP are transferred to local specialist paediatric teams or regional paediatric neuroscience centres. This is in order to access a neurorehabilitation assessment with specialist teams for acute and ongoing support planning, either inpatient or outpatient (NHS England, 2013a, 2013b; Paediatric Best Practice Statements Short Life Working Group, 2018; Regional Acquired Brain Injury Implementation Group, 2014). Following stabilisation, patients are categorised from Category A: people requiring the most care needs, to Category D: people with the least care needs.

Care across the UK is provided on three service levels. Level 3 services are non-specialist rehabilitation teams that provide general rehabilitation support in acute and community care settings for Category C and D patients. Some Level 3 services offer specialist support for one type of condition, for example stroke, and are renamed as Level 3a. Level 2 services provide specialist regional services in hospital and community settings for both Category A and Category B patients. Level 2 services can be thinly spread, some services extend their support to wider areas, being re-branded as Level 2a. Level 2 and 3 services are commissioned by local Clinical Commissioning Groups (CCG). Level 1 services provide low volume, complex care for Category A patients that are beyond the

scope of the more localised services. Given their specialist nature, they may have several public funding streams from NHS England and local CCGs (British Society of Rehabilitation Medicine, 2019; Menon, 2018; NHS England, 2013c).

This pathway relies on a regional network system to cover the needs of CYP with ABI. It assumes there is standardised care, or at least equitable access to services. However, there are inconsistencies in local access to major trauma centres and rehabilitation centres and quality of specialist care (Hamilton et al., 2017; Hayes et al., 2017; Keetley et al., 2019). The All-Party Parliamentary Group on Acquired Brain Injury maps out the 27 major trauma centres in the UK, of which 16 accept child admissions, with only 5 being for children alone (Menon, 2018). The Children's Trust lists only 11 specialist rehabilitation services for children with ABI (The Children's Trust, 2018). Rehabilitation support is reported to be running at a shortfall of 10,000 beds, with NHS provisions reducing since 2013 (Knoester et al., 2008; Menon, 2018; Parslow, 2005).

#### **1.6. Residential Paediatric Neurorehabilitation: A Level 1 Service**

NHS England gives guidance on their expectations on what should be available in a Level 1, residential paediatric neurorehabilitation (RPNR), service. RPNR services are made up of multidisciplinary teams (MDT) consisting of a Consultant Neurologist, Junior Doctors, Paediatric Nurses, Dieticians, Clinical Psychologists (specialising in neuropsychology), Speech and Language Therapists, Physiotherapists, Occupational Therapists, Play Therapists, and a hospital education service (NHS England, 2013a; Wilson et al., 2009). Services also need to provide adequate spaces for professionals to do their work such as specialist therapy spaces, a school and areas for day to day living such as dining areas, leisure areas and outdoor spaces. The MDT require a lot of equipment and logistical support, thus supporting and administrative staff are integral (British Society of Rehabilitation Medicine, 2019; NHS England, 2013a). It is pertinent to note that it is the process in which MDTs work, rather than an MDT approach itself that can provide effective treatment (Fay et al., 2006).

Bespoke care plans are created for each CYP admitted to a RPNR service and consist of 4 or more therapeutic disciplines, education and rest time. The goals for each therapy would be collaboratively developed with CYP and families. The CYP will work towards these goals whilst their families begin to skill up in therapeutic approaches and care. An admission would be commissioned initially for 3-4 months but could be longer depending on circumstances (Braga, 2009; Braga et al., 2005; Kelly et al., 2019; NHS England, 2013c)

RPNR is costly, but deemed economically viable due to a reduction in community and health needs later in life and working capabilities of individuals (Turner-Stokes et al., 2015).

#### 1.6.1. What Works in Residential Paediatric Neurorehabilitation?

There is a scarcity of information about which elements of neurorehabilitation are most beneficial to CYP in RPNR. This is a proven task given the unique care plans and goals in rehabilitation for each person. There are some projects beginning to attend to this question, such as the development of the Paediatric Rehabilitation Ingredients Measure (PRISM) (Forsyth & Basu, 2015; Menon, 2018). In developing PRISM, five key areas were identified that paediatric neurorehabilitation (PNR) services should meet. PNR should: 1) Meet the needs of the body and physical function of the body 2) Facilitate the acquisition of skills, 3) Support emotional health and identity development, 4) Support adaptation, to allow meeting of psychosocial needs and equip CYP returning to the community and 5) Support knowledge acquisition, meeting informational needs of CYP and families (Forsyth et al., 2018).

There is some literature that shows neurorehabilitation to be effective and economically viable. The majority of this data is for adults, PNR data is sparser (Cullen et al., 2007; Forsyth et al., 2018; Semlyen et al., 1998; Turner-Stokes, 2007, 2008; Turner-Stokes et al., 2006; Turner-Stokes et al., 2015). For RPNR specifically, there is data showing its effectiveness in improving CYP's self-care, physical functioning and participation in education, but there's a general awareness of large gaps in data for the effectiveness of interventions (Davis &

Wales, 2017; Gordon & di Maggio, 2012; Wales et al., 2018, 2020; West et al., 2014). Some question rehabilitation's role for all the progress made during an admission, with validity concerns around the data for interventions (Forsyth et al., 2018; Forsyth & Basu, 2015).

Research has been funded to further understand the UK's PNR provision and evidence how effective it is (Forsyth et al., 2015).

### 1.6.2. Service Approaches

Traditionally, neurorehabilitation was delivered in a compartmentalised approach, where health professionals took a lead in treating and working with the children to improve functional outcomes, whilst parents and carers supported integration back into life (Braga, 2009). In the UK, PNR services are encouraged to develop a collaborative process with families / carers during their work with CYP in a family-centred way. This collaboration should be fostered throughout the rehabilitation process, including assessment, psychoeducation, developing shared goals, interventions and evaluations as well as negotiating discharge (NHS England, 2013c; Royal College of Paediatrics and Child Health, 2017). This move towards empowering families to work collaboratively with services has been a relatively new shift, taking place over the past two decades (Braga et al., 2005; Laatsch et al., 2007).

There can be many ways that services can work with family and caring systems. A breakdown of commonly used models in how paediatric rehabilitation services work with families was brought together by Hanft et al., 2012:

- **Collective Empowerment:** families have access to resources in an inclusive setting and their strengths are the focus of interventions; they have equal power to professionals.

- Family-centred: Concerns of families are considered and professionals encourage families to take a leadership role through formal and informal network of services.
- Family-focused: Family needs are identified in relation to the child's development and decisions are mutually agreed with families.
- Family-allied: Families are seen as a helpful resource to direct professionally led goals and interventions.
- Professional-centred: Care is child-focused and exclusive of the family, goals are arranged and delivered by professionals.

The collaborative approach is thought to have come from two main drivers: that it makes economic sense, reducing the need for professional intervention, and that it is more effective (Braga et al., 2005; Fisher et al., 2019). Integrating the family into neurorehabilitation efforts with children has shown to have cognitive and functional benefits for CYP and reduces the burden that parents / carers can feel in preparing for changes in their caring roles (Braga et al., 2005; Lawler, Taylor, & Shields, 2013; Lawrence & Kinn, 2013; Novak & Honan, 2019).

### 1.6.3. A Focus on Families

A family-centred approach means that attention to the impact on family systems is important. During the pathway to a RPNR, families will need to adapt to constantly changing environments impacting roles in the family, caring duties, expectations as well as a need to join relationships with healthcare, educational and social care professionals.

With the focus on the collaborative relationship between healthcare professionals (HCPs) and families, I was curious as to whether there had been any research in identifying the experience and important factors to developing this relationship.

## **2. LITERATURE REVIEW**

In order to learn more about the collaborative working relationship in RPNR a systematic literature search was conducted to identify experiences from both service providers and families.

### **2.1. Literature Review Strategy**

The literature review began by exploring the research of HCPs' and families' experience of working together in RPNR services. Scoping searches determined that this remit was too narrow and the search was broadened to look into the collaborative work experience in any PNR services.

The review was planned using the Population, Exposure, Outcomes, Type of Literature (PEOT) framework (Bettany-Salkitov, 2012; Khan, 2011). This framework seemed most appropriate as the literature review would be looking to capture qualitative literature. This is in contrast to frameworks such as the Population, Intervention, Comparator, Outcomes (PICO) framework, which are more slanted towards capturing quantitative research (Booth et al., 2016). Table 1 outlines how the PEOT framework was developed.

PsychINFO, Academic Search Complete, CINAHL and PubMed were the available online libraries chosen. Initial scoping searches were performed to develop a search strategy that would yield the most relevant literature. The libraries had variable abilities in their filters. Given the sensitivity needed for the search strategy it was decided to begin the search using broad search terms. Umbrella and 'MeSH' search terms were used in each library for: brain injuries, rehabilitation and qualitative research. This search yielded 1063 different pieces of literature.

**Table 1.** The PEOT framework used to plan the literature review.

Population	<p>In this study the population is three-fold. Breaking this down for a literature search this would mean capturing 3 populations in the search terms:</p> <ol style="list-style-type: none"> <li>1) CYP in PNR</li> <li>2) Families of CYP in PNR</li> <li>3) HCPs who work in PNR</li> </ol>
Exposure	<p>To capture literature in which the population are exposed to a part of the PNR pathway.</p> <p><b>Include:</b> Neurorehabilitation care: any part of the pathway to discharge, including hospital, residential or community services.</p> <p><b>Exclude:</b> School (not related to transition or working with neurorehabilitation pathways); military and prison as these are not related to the rehab journey.</p>
Outcomes	<p>The experiences of people in these positions.</p>
Type of Literature	<p><b>Include:</b> Reviews; Qualitative; Case Studies; Ethnographic, Phenomenological, Grounded Theory</p> <p><b>Exclude:</b> Quantitative Studies, Discussion, Letters.</p>

The 1063 results were screened manually using the PEOT framework (Table 1) and data was recorded on a spreadsheet, allowing a system for filtering. The data was initially filtered to identify papers that shared HCPs' experiences and perspectives in the PNR pathway, this yielded 12 papers. This was then broadened out to papers that included experiences of CYP and families which yielded an additional 16 papers.

The 28 pieces of literature are from different international, regional and time-specific contexts and focus on varying parts of PNR. Below I have given an overview of the data and themes raised. The collaborative relationship is not directly addressed in any of the papers but is implicit in their results. Some additional references cited in the literature were also added if relevant.

## **2.2. What Families Need and Want from PNR Services**

In interpreting the data below, it is key to hold in mind that needs in care are subjective to one's personal cultural, societal values and expectations as well as time dependent. Needs are not static and change as families adapt to different environments, contexts and developmental stages in individual and family lifecycles (Hallström et al., 2002; Heinemann et al., 2002; Lawrence & Kinn, 2013; McGoldrick et al., 2016).

### **2.2.1. Information and Communication**

A common experience cited in the literature is that families report they aren't given information readily and often have to go through a tedious process of making sure they ask the right questions to get the information they need. CYP and parents would like HCPs to give a prompt diagnosis and have information ready and accessible, such as: knowing what to expect and what activities CYP can do (Gagnon et al., 2008; Hermans et al., 2012).

The way that information is given was also reported as important. The location of information delivery and language used, particularly around safeguarding concerns, had an impact on CYP and families. When information is not clearly communicated, families must use more resources to press HCPs for clarity, requiring a 'strong backbone' (Rosigno & Swanson, 2011). In addition, poorly positioned communication can result in CYP and families feeling guilt, loss of hope, or that HCPs trivialise their pain (Aitken et al., 2004; A. Clark et al., 2008).

HCPs raised how services are set up affects communication with families. HCPs understood that parents would go to the professionals that they needed at any



particular moment but posited that families may see the MDT as one organism, that information will be filtered instantly to the wider team. In reality, information is not always shared amongst the whole team (Rashid et al., 2018). To support information sharing, teams communicated through frequently through team meetings, 1:1 meetings, orders and informal communications as poor communication and co-ordination can affect care continuity (Gan et al., 2010). High turnover of staff can also make things more challenging as this affects continuous care and knowledge is lost, putting more emphasis on families' own recollection when working with new staff (Lundine et al., 2019; Rashid et al., 2018). HCPs would like a co-ordinating professional to ensure smooth information delivery, supporting the care process and parents' experience (Swaine et al., 2008).

#### 2.2.2. Trust and Rapport with Practitioners

Developing rapport and a trusted relationship with HCPs was reported as important to CYP and families. Below I have outlined some of the facilitators and barriers that the literature implicitly outlined as impacting the building of trust and rapport between HCPs, CYP and families.

##### 2.2.2.1. *Facilitators of trust and rapport*

HCPs being available, attentive, competent and able to liaise with external non-clinical agencies, such as schools, are concrete ways in which trust and rapport can be developed with families (Gagnon et al., 2008). The skill of being able to communicate and undertake tasks flexibly, depending on families' needs, also helps to facilitate better relationships, attending to families with different needs. Cahill (2015) suggested that a standardised framework and experiential practice with actors in was helpful in supporting practitioners to reflect on and expand their practice, particularly around their position as an expert.

#### *2.2.2.2. Barriers of trust and rapport*

Although building a trusted and collaborative relationship with families is a key part of a HCPs role, it can sometimes be a difficult task to join with families effectively (Cahill, 2015).

A barrier to collaboration can be time. Some HCPs' involved with long-term care felt time constraints were a barrier in developing a rapport. There's enough time to attend to CYP's physical needs but not enough time to speak about personal matters with families, which can create ambiguity for families seeking support (Rashid et al., 2018). Another tension, particularly for newly qualified practitioner's, was being able to show professional competency and developing collaborative work (Cahill, 2015; Hanft et al., 2012; Øien et al., 2010). HCPs gender was reported as a factor that can affect rapport building with adolescents, for example: 75% of young women would be prefer a female HCP (Lindsay et al., 2016).

A lack of knowledge about brain injuries is also a barrier to the collaborative relationship and access to services. Johnson & Rose, 2004 highlight a series of cases where wider systems' poor knowledge of ABI's affected families' potential to benefit from clinical, social, financial and legal support.

### **2.3. Psychosocial Impact on Families**

The literature gave an insight into the psychosocial impact that having a CYP with an ABI has on a family. Although experiences are unique to each person and family, this summary of literature gives an indication of the different tasks required and emotions that family systems experience. The literature search did not pull up experiences within a RPNR service, however, it is very likely that CYP and families would have been through the reported services before their RPNR admission.

### 2.3.1. Families Experience a Range of Emotions: From Admission to Discharge

HCPs report that emotional responses are variable and dependent on each family's previous strategies for coping with stress and change. Identifying the unique ways that families will respond could help HCPs target their positioning of support (F. Brown et al., 2013).

#### 2.3.1.1. *Emotional journey of parents*

Immediately after the injury there can be waves of guilt, fear, apprehension, shock, feelings of helplessness, isolation and difficulties in being able to absorb information. Going to an intensive care unit elicits more uncertainty, in a medical, noisy environment. Parents described best-guessing potential outcomes from machines and staff, whilst acknowledging staff may also be uncertain. This experience can lead to a lack of confidence or knowing what to ask HCPs. Families reported that they have to make quick decisions for the CYPs care which can be stressful and anxiety-provoking. The move onto a general ward presents another adjustment. There is reduced support on the ward and it's more challenging to build relationships with busier staff.

Going home, parents can feel abandoned with a lack of support and lack of follow up. Families can be vigilant and protective over their children amidst the uncertainty of their child's needs. There can be a loss of confidence, guilt, anxiety and depression at this point. This can impact and put strain on family relationships, such as marriages, which aren't often recognised or supported (Aitken et al., 2004; Hermans et al., 2012; Kirk et al., 2015; T. Lee et al., 2017; Roscigno & Swanson, 2011). It's also reported that men manage their emotions differently in this context, particular when using denial as a coping strategy, which may lead to greater stress or difficulties (S. L. Wade et al., 2010).

### *2.3.1.2. Emotional journey of siblings*

Siblings of a child with an ABI can experience significant anxiety with the potential loss of their sibling. Some siblings reported a change in their day-to-day living, with their emotional reactions changing. Siblings also reported of being acutely aware of changes within the family which can lead to physical separations from their sibling and other family members. Separations can lead to disconnection in relationships which could particularly impact younger children who have more emotional and developmental needs (Bugel, 2011; Gill & Wells, 2000; Roscigno & Swanson, 2011; Sambuco et al., 2008; Tyerman et al., 2019).

### *2.3.2. Developing New Family Roles After a Child Sustains an ABI*

#### *2.3.2.1. Developing new parental roles*

Parents and carers are tasked to adjust their parenting role. They become a care co-ordinator: supporting for their child's health, education and social life. Parents reported this adjustment as a process of trial and error as they run on nerves or 'autopilot' reacting to the injury and each required task (A. Clark et al., 2008; Roscigno & Swanson, 2011). Parents described some changes to home life with a need for more rigid routines and anticipatory planning which requires time, education, finances, energy, creativity and support. Parents also have to prepare for when things become more challenging, e.g., when their children get distressed. Parents reported a lack of HCP support in this adjustment.

Parents have reported that social support is helpful in managing day-to-day living, such as helping with childcare, errands, cleaning and transport; however, they often lack the energy needed to be able to socialise or 'deal with' with people; knowing that people meant well but ultimately couldn't empathise to their situation fully. Peer groups and people who had been through similar circumstances were most helpful (Aitken et al., 2004; Roscigno & Swanson, 2011). Those that were able to develop support networks reported the need for their CYP to be comfortable and encouraged to be independent (Gagnon et al., 2008; Lindsay et al., 2016)

Navigating these changes in role and when to use different strategies was confusing both for families and professionals. HCPs empathised with the difficulties in trying to distinguish the effects of ABI on CYP's behaviour to other factors and realising previous parenting strategies may not being as effective as before. HCPs reported that supporting new approaches can be facilitated by building shared behavioural formulations, breaking tasks down and developing positive strategies (Bedell et al., 2005; Sohlberg et al., 2001). HCPs also noted the understandable protective nature of parents, which can sometimes create difficulties in co-ordinating care to support independence. (F. Brown et al., 2013).

#### *2.3.2.2. Siblings taking on a new role*

Siblings reported they have to adapt their role in the family, being aware of their parents' additional stress and the change in their sibling's, and potentially their own, behaviour. A wide variety of sibling responses are reported, such as increased family responsibility, compassion led actions, sadness, empathy and pain (Bugel, 2011; Gill & Wells, 2000; Roscigno & Swanson, 2011; Sambuco et al., 2008; Tyerman et al., 2019).

## **2.4. Gaps in Services**

The literature review identified a number of gaps in services that CYP, parents and HCPs identified in the pathways of PNR care.

### **2.4.1. Transitions**

CYP, parents and HCPs reported in many different studies that there is insufficient support for CYP when they transition from hospital. A lack of communication, supporting knowledge and preparation was reported between all major stakeholders: schools, educators, clinicians, families and students. Support for transitions depends on service capacities and local policy framework (Berbaum, 2007; Bruce et al., 2012; Hartman et al., 2015; Mohr & Bullock, 2005; Richey, 2008; Rosenthal, 2012; Swaine et al., 2008). With a lack of support,

parents engage in a cycle of needing to advocate and explain everything to their networks; fighting strong social narratives about expectations of people post-ABI and making a case for adjustments for their children (Hermans et al., 2012; T. Lee et al., 2017; Roscigno et al., 2015). Consistent holistic support, collaboration and communication were key recommendations to help support transitions (Cheung et al., 2014; Gauvin-Lepage & Lefebvre, 2010; Richey, 2008; Rosenthal, 2012).

In the UK, Children's social care services have responsibility for this transition. Transitions could last several years after turning 18, which could be beyond the remit of children services. There is a movement advocating for trust-wide efforts to create a transitional-focused level of care (Colver et al., 2020).

#### 2.4.2. Accessing Community Services

The level of support that is given varies with nation, region and where families live in relation to the services. The further away families are from specialist services the more difficult it is to keep connected to specialist services. Following up and discharge planning, by an allocated professional, has been highlighted as a key support needed for families (Aitken et al., 2004; Hermans et al., 2012; Lindsay et al., 2016).

Even if laws and provisions are in place, perceptions and attitudes within the system can limit the potential to providing optimal environments for CYP with an ABI. Some parents reported they were willing to take a lead in finding, or paying, for appropriate services if attitudes were not good enough in public provisions (Hermans et al., 2012; T. Lee et al., 2017; Lindsay et al., 2016).

#### 2.4.3. Working with Adolescents

The literature reported service provisions for adolescents as inadequate. Adolescents are often bunched together with paediatrics for research and policy purposes (Swaine et al., 2008). Adolescents may be too old for paediatric

services but too young or not well supported enough in an all-age adult service (Lindsay et al., 2016).

Adolescence is a unique developmental stage with unique needs (L. R. Clark, 1998; Swaine et al., 2008; Zakus et al., 1985). Adolescents are more aware of their limitations, skills and what is happening to them. Socially, adolescents may want to conform with their peers, participate in activities and education and break away from family; a process that helps build identity and self-esteem process (Erikson, 1959; Feldman, 2018; Garcia Petro, 2014). Adolescent drives and activities are often not acknowledged in care plans and restrictions put in place by HCPs (Gagnon et al., 2008; Swaine et al., 2008).

It is recommended that services include the adolescent's perspective in care, acknowledging their difference in age, needs for independence and their environment. The sparsity of support for adolescents can be further vindicated by the hope that relationships built with HCPs in rehabilitation could continue after discharge transitions. This is both as an individual support and also as a relational tool to help parents keep their children engaged with the rehabilitation programme (Gagnon et al., 2008; T. Lee et al., 2017).

Ultimately, decisions on resources for adolescents depends on availability in local health systems, which is often low, highlighting a vulnerability for adolescents (Munce et al., 2014).

#### 2.4.4. Working with Children with Pre-existing Conditions

Concerns around CYP who have a pre-existing condition, such as a learning disability, was also pulled up in the review. McKinlay et al. (2012) highlighted how children may not receive a full assessment and all the required information and support. Assumptions around disability and ableism may affect the care of such children who have a brain injury.

## **2.5. HCPs Experience of Working with Families**

### **2.5.1. Navigating Expectations and Adjustment**

HCPs reported a challenge working with families' who have an expectation and focus on 'getting back to normal'. HCPs felt their expectation that life would not return to normal created a gap and tension in their working relationship. Language used in managing expectations was deemed important. Participant's shared examples in the literature: framing the future as 'different, but manageable', that life can get 'back to a routine'. HCPs were also careful around the use of words such as 'recovery' or 'outcomes' as to not communicate the idea of a static end point. Caution on language also touches on the way services construct their outcomes. If a service relies on outcome measures to determine disability or outcomes, there could be misunderstandings and underestimations of prognosis (Johnson & Rose, 2004; Rashid et al., 2018).

HCPs saw their role in supporting families to navigate and keep up with the pace of the care system (F. Brown et al., 2013; Rashid et al., 2018). In supporting family adjustments HCPs looked to provide education around ABIs, signpost families to counselling, support groups and external resources. This support is reportedly accessed through various sources and not neatly disseminated (Gan et al., 2010).

### **2.5.2. Experience of Endings and Discharge**

HCPs reported the rewards in the work were seeing families' adjustment, resilience and eventual discharge. Connecting on difficult matters and being able to collaborate on an uncertain journey together was cited as a rewarding experience (Lundine et al., 2019; Rashid et al., 2018).

HCPs also reported they don't see what happens next for the CYP and families. They have intense relationships, where they have held responsibility for CYP and families' safety and progress and then have no contact. This void of knowledge can be difficult. HCPs have felt that for adolescents, a follow up relationship could



support transitions, having built up trust in the hospital (Lundine et al., 2019; Swaine et al., 2008).

### 2.5.3. Tele-healthcare

The literature search picked up an article looking into HCPs' use of video-conferencing in a paediatric TBI service (S. L. Wade et al., 2019). This felt pertinent to include as this project was conducted during the Covid-19 pandemic, where online psychological interventions were offered as standard in many services (BPS Covid-19 Response Task Force: Adaptations to Psychological Services Group, 2020; DCP Digital Healthcare Sub-Committee, 2020).

Participants felt this way of working was beneficial for understanding home environments, joining families in a less threatening way and allowing easier participation. However, it can be challenging to work with younger children, avoid disruptions, particularly in larger households, and read non-verbal communication (Van Allen et al., 2011). Therapeutic alliance and compliance with the work were seen as equitable to face to face work (S. L. Wade et al., 2019).

### 2.5.4. Making Services Work: Doing What it Takes

It is challenging to deliver services that collaborate well with families given difficulties with service provisions, locations and system structures. In some examples, it was clear that services are focused in a crisis driven, medical model format with HCPs taking a 'do what it takes' philosophy. HCPs ability to be highly flexible and advocate were vital in being able to adapt services to work as conveniently as possible for families, perhaps masking service inadequacies (Gan et al., 2010).

## **2.6. Drawing on Psychological Theory**

In this section I will briefly detail a number of psychological theories and models that can be drawn upon to begin to understand and interpret factors relevant to making positive collaborative relationships between HCPs and families.

This could be described as beginning the process of formulation. Formulation is a term to describe the skill that psychologists use of lightly holding hypotheses of understanding drawn from information gathered in assessments, interactions, personal experiences, sense making and psychological theory. Psychologists draw upon many different types of psychological theories which can have their own unique ontological, epistemological and historic frame (Division of Clinical Psychology, 2011; Health & Care Professions Council, 2015; Johnstone & Dallos, 2014). When working with CYP with ABI, several models have been developed to help scaffold formulation building, such as SPECS, NIF-TY and the SNAP (Jim & Liddiard, 2016, 2020; Jim & Norton, 2015; Liddiard & Jim, 2015). These models generally consider a biopsychosocial understanding, appreciating a holistic contribution to understanding people's experience. They draw upon several psychological theories considering developmental, the brain, stress responses, adjustment, grief, relationship building, family functioning and wider system and societal functioning (Jim & Liddiard, 2020). Similarly, the literature review highlighted a number of different theories and models, providing a biopsychosocial view when all put together.

The theories outlined here are informed by the theories and models in the literature review. It is also pertinent to note that bringing together an understanding of theories that fit together can be inherently biased. A HCP's alignment to particular theories and models, or critique of them, can shape understanding, I hope to provide more context to my background in my reflexive statement to support the reader's critique (Section 3.12). I also want to highlight that some theories brought up in the literature are omitted, this is from my own understanding that those theories are not as relevant to the understanding of collaborative working relationships between HCPs and families.

### 2.6.1. Theories of Adjustment

The literature search highlighted families' experience of adjusting and coping to their child sustaining an ABI. HCPs perception were also garnered (Aitken et al., 2004; Brown et al., 2013; Clark et al., 2008; Lundine et al., 2019; Luzinat et al., 2020; Rashid et al., 2018; Tyerman et al., 2019). There was a strong consensus around the power of coping strategies as well as some papers discussing the role of grief in response to children in the family acquiring a brain injury.

The western psychology community has had several paradigm shifts in understanding parental response to disability, from psychodynamic and stages of grief theories to more contemporary approaches of positive psychology and cognitive adaptation. Stages of grief theory, applied to families of children acquiring disabilities still has weight within the field (Allred & Hancock, 2012; Kübler-Ross, 1969). Yates (2003) describes this application through the work of Horowitz (1993) where the idea of a 'normal' and 'pathological' stress response were outlined: a normal response includes a series of phases such as outcry, denial, intrusion until one reaches a point of getting on with life; a pathological response would include being overwhelmed, experiencing panic, exhaustion, somatic symptoms, avoidance and character change.

A different lens to think about what adjustment and coping is through a stress-response model. There are many versions of stress-response models, one of the most common cited in psychology education was posited by Folkman & Lazarus (1984). The model suggests that when someone identifies a stressor there is an initial cognitive appraisal: 'is something a threat or not?' Then a secondary appraisal 'do I have the resources to cope with it?'. If someone feels they have inadequate resources to manage or deal with the threat, they will experience some form of stress. It is this frame of understanding that I drew upon more when reading the accounts of stress response and coping outlined in the literature review. This alignment could be due to a move away from the idea of 'pathologised' responses detailed in the grief stage models. I have experienced in my clinical practice the use of the stress-response model to make hypothesis' about individual's inherent mental capacity to manage tasks, locating difficulties

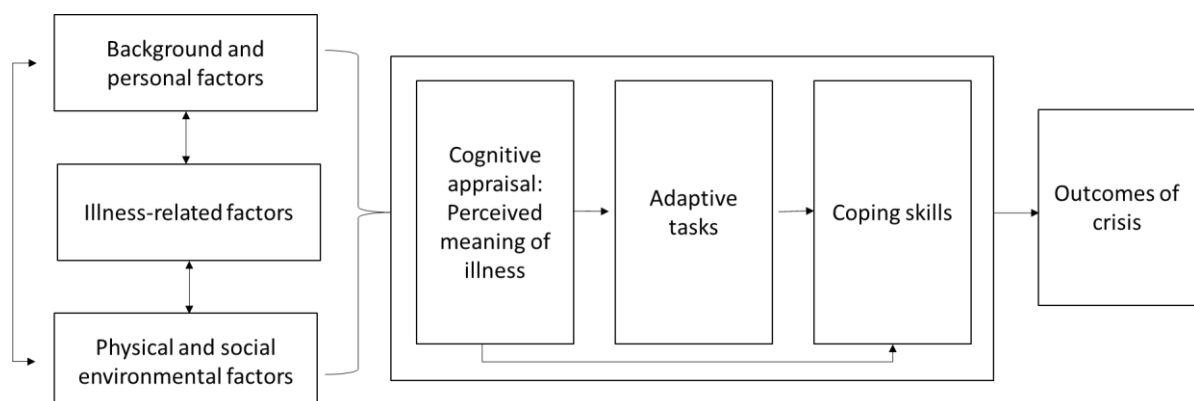
and challenges within individuals' resilience. I believe ensuring the language in realm of 'resources' allows room to think about wider aspects such as mental resources, financial resources, power resources, human resources which can bring the understanding of the problem into a broader realm than one's own resilience.

### 2.6.1.1. Stress-response models for understanding the crisis of physical illness

I found the Moos & Schaefer's 1984 crisis of physical illness model incredibly useful in expanding Folkman and Lazarus' theory. It aligns with my understanding of the theory, detailing more context and a biopsychosocial view that can inform where one's resources come from. The model takes into account a person's 1) background and demographics factors, 2) illness-related factors, such as the person's pain and symptoms and 3) physical and social environmental factors, such as managing hospital environments and relationships with HCPs.

Considering these factors can help us understand how one may appraise a situation, manage new tasks whilst also trying to cope (Figure 2). This model provides a platform to discuss these elements, which were raised in the literature review, in more detail.

**Figure 2.** A diagram of Moos & Schaefer's (1984) model for understanding the crisis of physical illness



Note: Re-drawn from Moos, R. H., & Schaefer, J. A. (1984). *The Crisis of Physical Illness: An Overview and Conceptual Approach* by R. H. Moos & J. A. Schaefer.

(<https://doi.org/10.1007/978-1-4684-4772-9>)

Coping is a broad construct that can include maintaining an emotional balance, self-image, personal relationships and preparing for the future. Three main categories of coping are posited which were all implicitly raised in the literature review (Folkman, 2001; Folkman & Lazarus, 1984; Moos & Billings, 1982; Moos & Schaefer, 1984):

- *Appraisal-focused coping*: this method of coping relates to cognitive-based reactions where one manages information by reframing or redefining the situation to relieve stress. This can include mental preparation, such as breaking down issues into one problem at a time and mentally rehearsing situations. Other cognitive reactions can include using avoidance or denial which can be a useful way to manage overwhelming situations, giving time to gather other coping resources.
- *Problem-focused strategies*: another method of coping is seeking information and support to gather more resources to enable more preparation and control in actions going forward.
- *Emotion-focused coping*: one can also manage stressors by trying regulate their emotions by holding onto to hopes or values of maintaining well for others, allowing emotions to discharge or resigning to acceptance.

The Dual Process Model of Bereavement (DPM) is a useful model to conceptualise the balancing coping and managing new tasks that families may experience. The model posits that people will experience oscillating stressors of loss and restoration orientations (e.g., new tasks) and as a result they will oscillate between different coping strategies. This dynamic process can elicit extreme ends of emotional coping, cognitive appraisals (both positive and negative) or problem solving (Stroebe & Schut, 1999, 2010).

Taking in mind the stress-response model, Moos and Schaefer posit that HCPs need to be able to interact flexibly with families. Practically this means that they

may need to repeat information, take on more responsibility at different times, allow emotional outlets and support mentalisation. They also suggest that staff's own reflections on their emotional state is important, as they too are going to face crises as they interact with families and will need to maintain their duty of care (Guldager et al., 2019a, 2019b; Moos & Schaefer, 1984).

### 2.6.2. Considering Wider Systems: The Ecological Model

The influence of wider systems and understanding ecological systems were commonly cited in the literature review (DeMatteo et al., 2008; Gauvin-Lepage & Lefebvre, 2010; Hermans et al., 2012; Johnson & Rose, 2004; Lee et al., 2017; Rashid et al., 2018; Roscigno et al., 2015). Although Moos & Schaefer's model is a biopsychosocial model, the interaction with wider social systems is not defined, being part of the umbrella term 'background and personal factors'.

Bronfenbrenner's ecological model can broaden this concept. The ecological approach acknowledges that people's lived experience will be situated and influenced by different layers of context in their life (Bronfenbrenner, 1977, 1995). This is in line with systemic theory that posits that reality is held in relation spaces: each of us are mutually influencing one another in a circular manner that feeds back into systems, rather than a single linear, cause and effect, way (Pendry, 2011; Rivett & Buchmüller, 2017).

The ecological model considers the child as an individual (their genetics, behaviour, physical body), the microsystem around them (their family and home environment), local community contexts in the exosystem and wider macrosystems of societal norms, politics and environments. This model can be used to map out the unique context of a person or family.

#### 2.6.2.1. *Ecological theory applied to paediatric ABI*

Informed by the literature, I have posited some ideas of how the ecological model can be applied to families in PNR contexts below.

At a microsystem level, a family's context can be important to understand their experience and ability to interact with influencing systems. A few papers in the literature review posited family system theories, such as life cycle and structural theories, can be used to help understand this context (Moreno-Lopez et al., 2011; Tyerman et al., 2019). Families in the PNR context will be forced to face unexpected transitions that will strain the implicit rules and roles that each family uniquely have. The challenge of a family is to adapt. Systemic theory posits that an inability to adapt, maintaining homeostasis, may cause distress or problems (Burnham, 1986; McGoldrick et al., 2016).

The experience of accessing services is variable for families. This is due to the unique circumstances of each family and the logistical, psychological demands that families have engage with to participate in PNR (A. Foster et al., 2012; Olin et al., 2010). These variable factors can be framed as 'rehabilitation capital', a capital determining how some families are able navigate and get more benefit from PNR services than others (Bourdieu, 1986; Guldager et al., 2018; Shim, 2010). It's suggested that higher rehabilitation capital is curated by larger, concrete, cohesive families that have wider access to supportive networks and potential for time building relationships with professionals and managing tasks (Bystrup & Hindhede, 2019).

At a more exo-system level, service provision, funding of services and local interpretation of laws can impact CYP's development. HCPs could be said to be situated in this layer. HCPs have an active role in supporting families to adapt and become ready for life going forward. HCPs influence and shape this new reality through their relationships with families and services. This posits second-order cybernetics view of professionalism, in contrast to first-order cybernetics, where health professionals were conceptualised as external and neutral to the system that they are working with (Cecchin, 1987; Palazzoli et al., 1980a; Yeates, 2009).

At a macro-societal level, we can consider the implementation of laws, policies and dominant societal attitudes and practices. For example, does the society we

live in make it easily accessible for people with disabilities to participate? The social model of disability posits that wider societal structures disable people from participating, which in the context of ABI can make things more challenging for the family, thus the need for further support (Oliver & Sapey, 1999).

It is a complex model to consider, holding many different influencing factors. Each person will have many different protective and risk factors in these influencing layers with some being more salient for neurorehabilitation, whilst some may balance out or become negligible (Gerring & Wade, 2012). Roscigno et al., 2015 demonstrates how the ecological model be used to help understand the influences in CYPs' transition back to school after an ABI.

I believe that the stress-response theories, contextualised by the ecological approach, highlighted in this section allows a framework to help understand the position and response of families coming into PNR services. However, it does not give too much theoretical detail on the relational aspects of families working with HCPs.

### 2.6.3. Attachment Theory

Clark et al., 2008, from the literature review, posited that attachment theory could be useful to help conceptualise parental responses after a CYP acquired a brain injury in seeking proximity to their children. I wondered if this idea could be expanded to consider how attachment theories could help describe interactions between HCPs and family members. Patricia Crittenden's iteration of attachment theory, the dynamic maturation model (DMM), came to mind in considering this.

Attachment theory suggests that infants adapt to their caring environments to ensure their needs are met. This is through relational strategies. These strategies are categorised as four different attachment styles: secure, insecure avoidant, insecure ambivalent and disorganised (Ainsworth et al., 1978; Silver, 2013). DMM posits attachment styles remain as protective functional templates throughout life, such as in the way people manage relationships, particularly at



times of stress. These strategies can change when alternative responses are on offer or it is safe to behave in a different way (Crittenden, 2006).

DMM could be conceptualised to consider how parents' own care and safety needs are at threat and how their attachment patterns could be enacted. These dynamics could play out in interactions during care. For example, a secure attachment pattern could elicit a story that one is worthy of care, reflect on feelings and working with the care system; whilst an avoidant attachment pattern may elicit a more turned away and autonomous approach, which may be less open to carers in the system (Dallos & Vetere, 2009). This could be a key theory in managing the tasks of emotional regulation as well as managing relationships within the care and social support system

#### 2.6.4. A Psychodynamic Frame

Clark et al., 2008 also highlighted the application of psychodynamic concepts of denial and defence in considering families difficulties. These are also posited in literature on coping (Folkman & Lazarus, 1984). Although, not a seasoned psychodynamic practitioner myself, I do believe these ideas could be useful to consider in the interplay of relationships between HCPs and families. Defence mechanisms look to identify where emotions, thoughts and urges go when they are too painful to look at, often cited as 'unconscious' ways of behaving. Within my frame of understanding, this can complement how people respond, given their templates of managing stress, related to attachment (Knox, 2003; Marčinko et al., 2020). Anna Freud identified 10 defence mechanisms that look to regulate painful experiences, the categorisation and nomenclature of these have developed over history; common examples include denial, splitting, projection, isolation, sublimation, reaction formation, introjection, displacement (A. Freud, 1936; Vaillant, 1992).

Object-relations is another useful psychodynamic concept to consider. It posits that each person has a unique take and relationship with the world (Fairbairn, 1954). People can hold an idea of who they think another person is, based on their object-relations and experiences of previous relationships, this is

constructed as 'transference'. A 'counter-transference' is the other person may get entangled in that idea, how they might respond to someone; seeing them as 'good' or 'bad' for instance (S. Freud, 1958; Granville & Langton, 2002; Jones, 2004). I felt this could also be important in considering dynamics that could play out in interactions during care between HCPs and families, where transference and counter-transferences could either enable or hinder the working relationship.

## **2.7. The Proposed Study and Research Question**

Given the recommendations that PNR services should collaborate with families, data is sparse and disparate around the experience of this working relationship. The literature review only identified 12 indirect studies from which to base information about HCPs experience of working relationships with families, none of which focused on RPNR. This thesis project provides an opportunity to look at the collaborative relationship in the context of a UK-based RPNR service.

Given the restrictions posed by the Covid-19 pandemic and difficulties in attaining appropriate ethical approvals, this study focussed on looking at HCPs perspective.

The thesis project was collaboratively developed between myself, the researcher, the University of East London and a RPNR service (the organisation). Through this collaboration the following research questions were developed:

- 1) What is it like for staff to work with families of CYP in a RPNR service?
- 2) What are the enablers and barriers to this collaborative work?

## **2.8. Clinical Relevance**

It is hoped that the data would yield an understanding of what it is like to work with families in an RPNR setting, the optimal circumstances and how HCPs manage dilemmas where these aren't available. This will add a new voice to the knowledge already in dissemination in a context that has not been investigated

before. The research will also be framed from a clinical psychology lens. This could provide a new way to connect and understand the experiences from HCPs.

It's hoped that the data generated could be used to expand knowledge of RNPR and support positive changes in structure of neurorehabilitation services, HCPs practice and attend to inequalities in care.

### **3. METHOD**

This section will describe the methodology and epistemological position of this study.

#### **3.1. Ontology and Epistemology**

The research question provides quite an ambiguous epistemological and ontological position for the research. The question implicitly values the contribution of consistencies found in exploring the natural world: Brains are real, they control bodies, cognitions, behaviours and can be damaged. It also implies that rehabilitation can have an observable impact in helping CYP recover function and that families, themselves, are a real definable construct. Taking this at face value may direct us towards a realist, positivist ontology, as we are acknowledging the reality of a world outside of ourselves. However, the investigative part of the question does not imply that knowledge of the outside world is consistently received or defined; this perhaps aligns more with a relativist epistemology, as it does not elicit a pure, or 'naïve' realist position.

Taking this convoluted stance, one has a choice of how to position this research. I believe it could be positioned under critical realist, interpretivist or critical theory positions, depending on one's intention.

The intended purpose of the study is to bring forward the experiences of working relationships with families, from HCPs perspective. The data could elicit descriptions of power dynamics and macro-level influences, which could fall under the remit a critical theory position and analysis; however, this is not the sole focus of the research and would perhaps be biased in focus. A broad interpretivism stance could also fit, but perhaps, on the other end of the spectrum to critical theory, it does not acknowledge wider contexts as much. It could also be posited that it would not hold a vigorous account of my own context and bias as the researcher. A critical realist approach may be most appropriate. This

posits a realist ontology, that there is a real definable world, but that this world can be perceived and accessed in different and partial ways.

In line with critical realism, the study acknowledges the complexity of the social world around a 'real' world outside of the mind, with an intention to draw knowledge for a causal change. The study accepts that the data received will be a representation of the real world, collected through the lens and methods provided by the researcher and the accessibility of the experiences of participants (Coule, 2013; Duberley et al., 2012; Pilgrim, 2014).

### **3.2. Methodology**

The research question and critical realist position inform a qualitative methodology. A qualitative methodology allows for a richer, in-depth, exploration of experiences which may well be missed or under-explored in a quantitative study. A quantitative methodology would direct the study to set out validated constructs for people to template or measure their experiences onto, deriving from a positivist position (Barker et al., 2015; Willig, 2013).

### **3.3. Research Method**

#### **3.3.1. Practical Considerations During a Pandemic.**

Consultations took place with service leads at a RPNR service to determine what methods would be practicable given the restrictions in place due to the COVID-19 pandemic (BPS Covid-19 Response Task Force: Adaptations to Psychological Services Group, 2020; NHS Health Research Authority, 2020). It was agreed that online or telephone methods of data collection would be the only viable option as unessential visits to the site were not permissible.

#### **3.3.2. Inclusion and Exclusion Criteria**

The inclusion and exclusion criteria for the study were structured on a scoping basis given the infancy of the published data in the field. I wanted to hear as

many voices as possible that have not been heard in the literature. The inclusion criteria agreed upon with consultants and my supervisor was:

*Any member of staff who works at the paediatric residential neurorehabilitation service who has time working with the families of the children and young people.*

This criterion included people in management positions, clinicians in the MDT as well as staff who work in the residences such as technicians and administrative staff.

The study was conducted in English. Participants therefore needed to be able to understand both verbal and written forms of English in order to participate and consent to the study.

### 3.3.3. Choice of Method

Prior to the study beginning, many different methods were considered. The study design had to be pragmatic and sensitive to the service context.

Online surveys were considered inappropriate. Surveys would allow for a larger breadth of questions and a larger sample, however, would lose a richness data that this study warrants (Saint-Germain et al., 1993). Online focus groups (OFG) were also considered. OFG's are an effective alternative to face-to-face groups and would allow data to develop in a collaborative way. This could bring out richer data than a 1:1 interview with a context-naïve researcher joining participants from a 'cold' relationship. As an interviewer, I would be positioned more as a facilitator to enquire on emerging themes and observations coming from the group and support synergy (Broyles et al., 2011; Fern, 1982; Kitzinger, 1994; Morgan, 1996; Reid & Reid, 2005; Tates et al., 2009)

As the study drew nearer, I was informed by service consultants that there had recent been some challenging relationships between HCPs and families which had affected the team in different ways. This was important to raise as

participants may not have control who is in the OFGs, which could mean that due to power differentials or frayed relationships, participants may be silenced or acquiescent. In addition, participants would not be anonymous in the OFG and confidentiality more at risk of being broken than in a 1:1 interview (Barbour, 2008; Côté-Arsenault & Morrison-Beedy, 2005; Hennink, 2007). Given this context, it was agreed that the study would allow participants to choose how they contribute to the study. Participants would be given the option of participating via 1:1 interview or with other HCPs of their choosing if that was more comfortable.

Participants that opted for a 1:1 interview could decide if they would like to have a conversation either through MS Teams, or over the phone. If two or more participants chose to interview together, the conversation would be over MS Teams, due to being the only resource available that could facilitate conference calls. This format would be considered a joint interview. Joint interviews would provide some of the benefits I was looking for in using focus groups: to support and prompt one another whilst allowing a safe space to talk openly (Polak & Green, 2016).

### **3.4. Recruitment**

During the service consultation I was able to agree a plan to recruit staff who work with CYP and their families.

An easy-to-read advertisement was produced and attached to an introductory email (Appendix 1). These were circulated by a small group of line-managers to staff by email as well as pinned up physically on staff notice boards and highlighted at ward handovers. Potential participants were able to contact me via my university email or a mobile phone number that I procured for sole use of the project. As this provides a top down delivery of information about the study, the language used had to be careful, so that it was not delivered through a frame of coercion from a position of power (Mauthner et al., 2002).

During consultation I was advised that a small incentive could help recruitment efforts. Through the university I was able to procure £100 in amazon vouchers

and it was agreed with the organisation that one £5 voucher per participant would be offered.

### **3.5. Ethical approval**

Ethical approval was sought and received from the University of East London Ethics Board and the organisation's research committee (Appendix 2-5).

### **3.6. Informed Consent**

On receiving contact from potential participants, an email response was sent thanking them for their interest and laying foundations for potential times to meet (Appendix 6). A separate email was sent detailing consent procedures and an information sheet (Appendix 7). Once arranged, an electronic calendar invitation was sent with some guidance to the logistics of the conversation (Appendix 8).

### **3.7. Confidentiality and Anonymity**

At the beginning of each conversation, I re-iterated the confidentiality and anonymity information outlined in the information sheet to ensure consent. Ensuring confidentiality and anonymity is understood can help reduce anxiety, misrepresentation, identification and potential exploitation (Finch & Lewis, 2003; Richards & Schwartz, 2002).

A data management plan was produced to manage safe storage and anonymisation of data (Appendix 9).

### **3.8. Risk Assessment**

As part of the ethical approval submission, a risk assessment was also performed (Appendix 2). The most prominent risk was being able to provide a safe, covid-secure, private environment for participants if they were unable to find one themselves. The service would support me finding an appropriate space for participants if this was needed as well as any technical support.



Uncomfortable and distressing topics could be brought up in conversation that could cause embarrassment, shame, stigmatisation, discrimination or anxiety of over-disclosure. Moderating the conversation would be vital for this. I was able to practice moderating and participating in joint interviews and interviews with peers before the study began in order to help to develop these skills.

Breaks, pauses and stopping the interview and groups was an absolute right. In addition, a debrief email was circulated to participants after the conversation which signposted them to my details and local support should they want to reach out about anything discussed or study as a whole (Appendix 10).

### **3.9. Withdrawing Data**

Participants had the right to withdraw from the study which was stated in the information sheet (Appendix 7). Data could be withdrawn within 3 weeks of the conversation, before any of the data would be analysed. However, if a participant who participated via a joint interview wished to withdraw, the process is more difficult as data is produced in an emergent way with other participants (Sim & Waterfield, 2019). I had planned to discuss with the participant what they would like to withdraw and determine what could be withdrawn immediately and what would need consent of others.

### **3.10. The Interview Schedule**

The study used semi-structured interviews as they allow participants to express their perceptions and experiences, whilst maintaining focus on the research subject. I did not want to use structured, standardised, interviews as I did not want to assume the direction of the conversation. At the other extreme, an unstructured interview would perhaps allow too much of a broad scope. A semi-structured interview, veering more towards the unstructured end of the continuum was constructed to allow room for unexpected tangents in the conversation that could be explored, whilst also allowing room for the interviewer to bring the subject matter back to the research question (Brinkmann, 2014; Ryan et al.,

2009).

The interview schedule was structured using a funnel approach of questions: from broad introductory questions to more focused ones. This felt like a suitable format both for 1:1 interviews and joint interviews (Plummer-D'Amato, 2008; Ryan et al., 2009; Thompson & Chambers, 2012). Questions were written in consultation with my supervisor informed by gaps and information from the literature review. The questions focused on understanding participants role and context, where they interact with families, their perception of their duty to work with families and then narrowing questions to understanding what enables or hinders their work and relationship with families.

The questions were piloted on opportunistic participants within my family network who were nurses and social workers. This helped ensure that the questions were focused and made sense, in addition to practicing interviewing skills (Ryan et al., 2009; Turner, 2010). I hope that practicing helped me develop a relaxed demeanour of interviewing to enable a comfortable conversation for participants where they felt they could control what they say (Ryan et al., 2009; Yeo et al., 2014). Opportunities to reflect on the interview environment and how the questions are received was planned throughout the study (Frith & Gleeson, 2012)

### **3.11. Analysis**

The analysis was conducted using a reflexive thematic analysis (RTA). This section will detail the reasons for that choice.

Discursive or grounded theory approaches seemed inappropriate as the intention of research is not to provide a theory to build upon or investigate the dynamics of group conversations (Willig, 2013). Interpretative phenomenological analysis (IPA) seemed more appropriate as the study was seeking to understand participant's phenomenological experience and acknowledge experiences are located in contemporary and historic contexts. IPA also looks to explore the unique experiences of an individual from the bottom up and seek to see if this broadens across a group of homogenous people (Eatough & Smith, 2017).

Although IPA offers a good framework for this analysis, the participants are unlikely to be homogenous. I was also concerned that an IPA approach puts too much focus on the person's experience of phenomena and perhaps reduces the opportunity to be reflective as a researcher about the context and structures that surround participants' descriptions. With the study taking a critical realist approach and potentially having a mixed method of data collection there could be difficulties, epistemologically, with an IPA approach. There are examples of adapted IPAs that blur theoretical and epistemological approaches that elicit both the themes of groups and individuals, but from my perspective it perhaps risks blurring the focus of analysis (Palmer et al., 2010; Tomkins & Eatough, 2010).

Reflexive thematic analysis (RTA) was deemed the most appropriate way to approach the analysis. RTA is a flexible method of analysis that can bring together a story of themes from an overarching group, which could include individual differences. RTA is an analytic method, rather than an approach that is held within an epistemological frame. Using RTA, I would elicit a reflexive, interactive and socially situated coding of work which would be iterative and recursive. This study provided a 'latent' RTA, offering a reflective discussion around the themes from the data. This is in contrast to a 'semantic' RTA that focuses more on participants' direct words (Braun et al., 2014; Braun & Clarke, 2019).

### **3.12. Reflexivity**

A key part of this research is acknowledging the context in which it is taking place. Detailing the researcher's context is important for readers, and the researcher, to critically reflect on how the data has been generated and interpreted.

In preparation of the study, I practiced conversational cues to help ensure that I reduced my impact in directing interviews. I also planned to use a reflective diary to help my epistemological reflexivity during the course of the research; to notice what knowledges and world views are implicitly drawn upon during the course of research. Another useful construct is that of personal reflexivity, where I can offer

readers some personal context to understand my world view and consider what assumptions I may have (Madill et al., 2000; Willig, 2013).

### 3.12.1. Personal Reflexive Statement

I am a white Jewish male, in his early thirties, who has only lived in the UK; growing up in North Manchester and spending most of my adult life in London. Coming from a 3<sup>rd</sup> generation immigrant, Jewish, family and my mother leaving the family at a young age, I have always had a sense of the different layers of social and personal context that can affect peoples' wellbeing and lives. This sense and view of the world has been solidified theoretically through my work experiences and clinical psychology training. A lot of my immediate and wider family work in the public sector, predominantly in nursing, social work and teaching. There was a strong narrative that helping people was important and that understanding realities about the world and medicine was a way to do this, in addition to helping success and survival.

My family have a deep appreciation of public services, particularly the NHS; this is in the context of several family members having physical and learning disabilities. However, recent funding cuts and changes to public services have made life more difficult and pressured recently. My role within the family meant that I was quite distant from supporting family members with disabilities. As I have grown older, I have realised that those sub-systems were quite isolated in building their support structures. This is something I have felt guilty about and something I perhaps want to change in my current and future family.

I was also brought up with the pressures realities associated with public sector work which I have experienced in my own career; identifying relational and systemic aspects of work that make life harder or easier. This was solidified more in pre-training work experiences where I was working in a systemic way to improve practice and relationships in a social care service. These experiences position me quite close to the subject of staff experiences in the public sector.

I am also aware that this study will be heavily influenced by the fact it is part of a clinical psychology doctorate programme. Explanations and conclusions from this study will be directed towards knowledges privileged by psychological principles, which in themselves are contextually-situated (Brennan & Houde, 2017).

## **4. RESULTS**

### **4.1. Overview**

This chapter presents the findings of the analysis. It will outline who participated in the study and map the themes generated from interview transcripts. The themes will be discussed in turn with illustrating quotes from the data.

### **4.2. Participant Characteristics**

15 people participated in the study. Two of the participants opted to be interviewed together whilst 13 participants opted for a 1:1 interview. Ten interviews were conducted using video conferencing software (MS Teams), four were conducted over the phone. Data were collected between December 2020 and February 2021 with interviews lasting between 28-61 minutes (mean = 46.8, mode = 43). Participants were from a range of different professionals from the MDT with representatives from the nursing team, therapies team (occupational therapy, speech and language therapy, physiotherapy), psychosocial team (social work, psychology) and the assistive technology team. There were 12 female and three male participants.

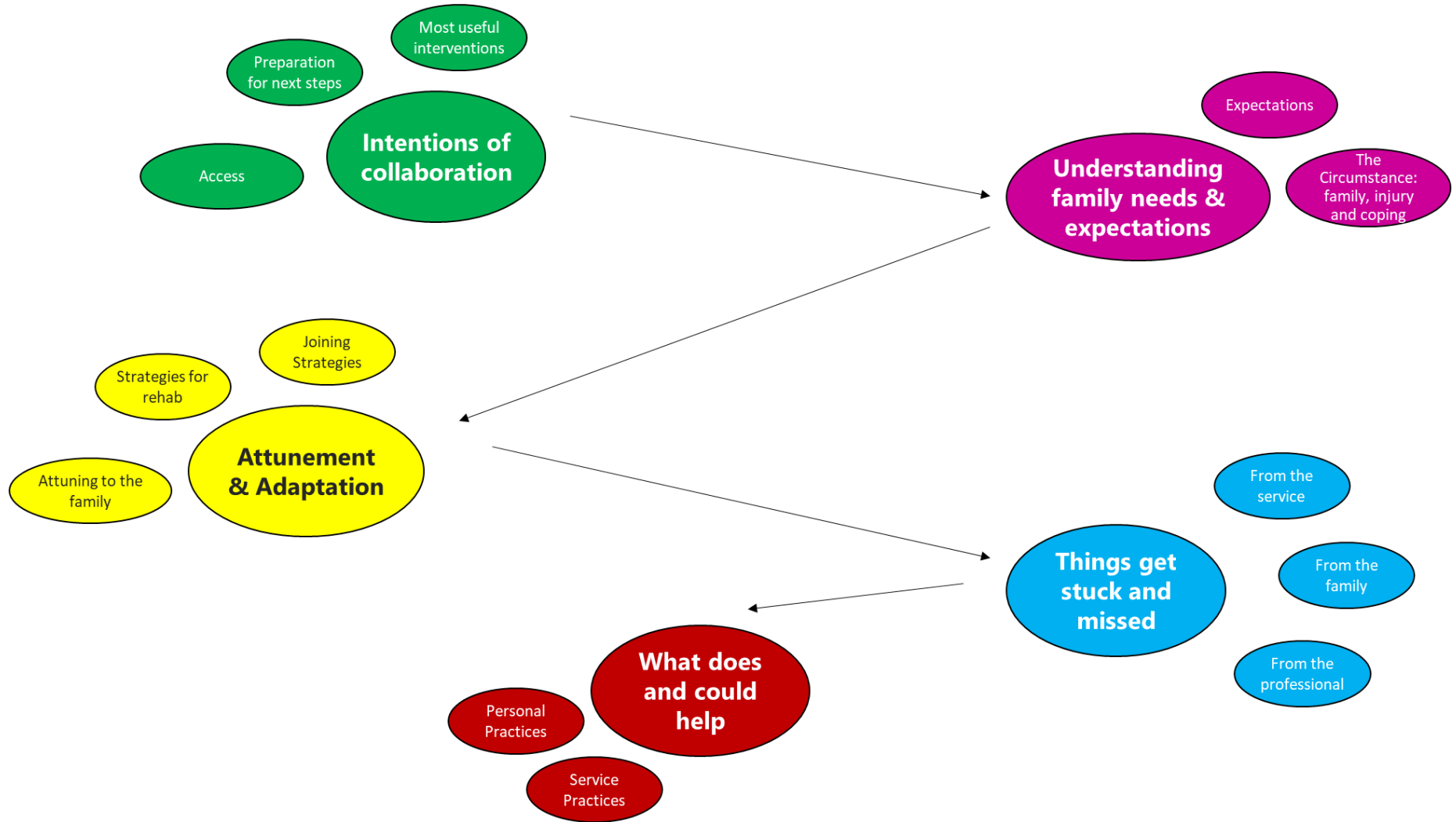
### **4.3. Thematic Map**

The analysis process adhered to Braun and Clarke's six steps method of thematic analysis. Time was spent getting familiar with the data through transcription and reading. Once transcribed, the data were coded for the first time and collated into draft themes. Themes were then reviewed and defined. A visual thematic map was used to help refine the theme development (Braun et al., 2014; Braun & Clarke, 2006).

Figure 3. shows the resulting, refined, thematic map. There are 5 themes and 13 sub themes. The themes link to one another: from the staff's intentions and hopes for relationships with families, to the assessment and understanding of

what they believe would impact a families' involvement and the ways practitioners adapt to facilitate a productive relationship. The themes then move on to when and why some relationships with families may get stuck and what could help to manage those difficulties.

Figure 3. Thematic Map





## 4.4. Themes

### 4.4.1. Intentions of Collaboration

All participants highlighted that relationships with families were integral to rehabilitation work. A good relationship and collaboration enable them to do their job effectively. The intention for a collaborative relationship varied on participants' role, the age of the CYP and perception of what life would be like for the family once they left the organisation. In this section I have highlighted three overarching themes HCPs highlighted collaborative relationships can enable: access, useful interventions and preparation for next steps.

A good working relationship was described as one where the HCP and family would have reciprocal roles and the family would feel comfortable enough to voice their needs and opinions on treatment.

*'I think one of the big things for me that kind of indicates good rapport is when they're comfortable telling you something that their dissatisfied with about thing you're doing know what I mean?' (P4: 86-88)*

*'I guess it would feel like there is a reciprocal flow of information and sharing and a feeling of working together on something' (P10: 138-139)*

#### 4.4.1.1. Access

Participants stated that without the family interventions can't get done, particularly for CYP who have more severe injuries, are under 16 or are unable to consent to treatment or plans. A good relationship with the family enables access to CYP. The relationship can also act as conduit to accessing wider networks in order to develop relationships and interventions outside of the service, such as with schools, health and social care systems. There is a clear sense that the time for intervention in the service is very short and the relationship going well with the

family enables the staff to trial a wider variety of interventions as well as access more areas of the CYP's life to support.

*'where you've got that good therapeutic relationship or good rapport with them is generally much easier to have any conversation, whether it's a you know, a, a good conversation about progress or a more challenging conversation' (P2: 78-80)*

*'Oh gosh, it's pretty integral to everything, really. I think if that breaks down, so does everything else. It says it's a central thread that needs constant, continual, sort of sensitive awareness, really.'* (P11: 91-93)

#### 4.4.1.2. Developing useful interventions

Participants wanted to seek out the most useful way to apply their professional knowledge, this requires an openness to families' knowledge and warrants collaboration with families to learn about the CYP to create a best fit intervention.

*'I have a strong belief that, as much as I'm a professional and I have my professional knowledge, they know their child really well, like they know them through and through... I'll talk through the different treatment options because there's often not one route that you can go down and kind of talk about the evidence behind the treatment options and then the parent will often go 'Well, what do you think?'* (P1: 37-45)

*'I think it's about, as a staff member, it's about involving the parents as much as we can and listening to the parents and trying to make sure that what they want for their child is able to be put in place and if it can't be put in place, it's about finding an in-between'* (P15: 523-526)

#### 4.4.1.3. Preparation for next steps

The relationship with families is a conduit to support families' preparation for life after the service. Participants believed that the rehabilitation offers several opportunities to equip for their child's care once discharged. This includes time to process what has happened, skilling up core care competencies and supporting parents to take on a co-therapist role to facilitate their CYP's independence. The relationships also provide an opportunity for staff to provide a positive relationship template that families can bridge to local services with the confidence of how to navigate and advocate for themselves. There is a clear sense that the participants felt a duty to prepare families as services in the community are not as cohesive and available, requiring more work from the family to co-ordinate.

*'So those relationships are really key, and I think we're also almost role modelling or trying to allow parents and families to have good experiences with professionals and showing them that they can trust professionals and we can work together.'* (P10: 84-86)

*'But we also know that it's very unlikely that anyone will come to them in the way that we do for the rest of the child's life and is able to support them, So we really do have to empower them to become the lead professionals in their child's care onboard a lot of those therapeutic responsibilities'* (P6: 171-174)

*'They're the kind of key worker that's coordinating and everyone. So, I think skilling them up. Yeah, 'cause it can feel a bit like falling off a cliff.'* (P7: 71-72)

#### 4.4.2. Understanding Family Needs and Expectations

All participants had an acute sense that they will be forging relationships in uniquely difficult circumstances with each family. Identifying needs and navigating expectations were posited as key actions that the interviewees had to perform.

Participants spoke about what factors they thought would impact their relationship with families prior to their admission. There were two distinct themes, the family's circumstance, 'where the family are at', and expectations.

##### *4.4.2.1. The circumstance: the family, the injury and the coping*

Participants empathised how much families are having to juggle on their arrival to the organisation. Families are likely to have experienced a period of trauma, hospitalisation and are then put under the spotlight in a care setting where a large number of HCPs are involved. It can be overwhelming and there can be a lot of demand to tell their story repeatedly.

Participants posited various aspects what make it harder (than hard) to join families in a collaborative working relationship: 1) Being in a process of grief, 2) The cause of injury (and what else had happened?), 3) The injury characteristic, including: when it happened, what type of injury it was, its severity and the age of CYP. These factors help the team hypothesise family experiences so far and where they may be 'at' on arrival to the organisation. It was recognised that each family will come in with a unique circumstance, a unique way of managing things and a unique support network. A number of different coping styles were mentioned: some people manage by gathering information, engaging with the work whilst other's may be at a point of being completely overwhelmed or managing by being in a state of 'denial'.

*'I think some families are in a completely different place to others, and some people have different styles of coping and I think that can really affect how your relationship is with that family. Some families' way of*

*coping, at the moment, and it won't always be like that... there's certain topics they don't want to go to. So sometimes we provide like psychoeducation and for some families that is great and they really want to learn, so that they can kind of have the knowledge and they feel that that then skills them to kind of advocate in the future, whereas other families that's way too much and they don't want to do that' (P7: 161-168)*

*'Yeah, there are families that are very anxious, which is totally understandable. It depends on what stage they are in in their coping. Some parents are still under denial stage. Some parents are on the acceptance stage' (P12: 76-78)*

Social circumstances also have a key role to play in enabling a collaborative relationship with staff. If there are factors that will affect a family's ability to be on site or be available to join sessions, this will impact the collaborative relationship and possibly outcomes. This could be due to living far away, having other children and family members to care for, having a family where carers are separated or employment responsibilities. In addition, in the context of the pandemic, there has been a reduced ability for more family members to be on site with their children. This has increased the need for families to be able to access and use technology.

*'I think some of it comes down to the parents' availability. If they're able to come and join and be there in the sessions versus if they have to work, then you know that's harder' (P3: 141-143)*

*'Like some parents if they've not got supportive employer, or if there's a single parent and they're trying to manage life at home and life also, in rehab they can't always physically be around all the time, or when their child in therapy sessions they may be doing working from at the same time so, there's a lot. There's a lot that restricts parents, which in turn restricts our ability to develop a good rapport with them'. (P8: 159-163)*

Families are involved in the dual tasks of re-organising their lives whilst engaging in the rehabilitation programme. Depending on each family's capacity, there may or may not be space to embrace some of the support offered by the organisation, this was predominantly raised by the psychology team.

*'I feel, psychology and the emotional side of things, just isn't the primary need. They don't have housing, you know. They don't feel well themselves. They barely eating or showering. Sometimes I just feel that level of psychological support, they're just not really in the place'*  
(P10: 342-345)

#### 4.4.2.2. Expectations

A family's journey to the RPNR comes with expectation. Participants reported one of their main roles working with families is managing expectations to help work collaboratively.

Participants felt families' expectations are informed through their previous experiences in healthcare, perceptions of specific roles, their own culture of care, expectations of how health services work, hopes for treatment and how the organisation has been pitched to them: either by the referring hospital or the organisation's own social media.

Participants reported some examples to highlight these factors. Families' culture of care can affect collaborative positioning, for example: some families manage care within the family system, keeping HCPs involvement to a minimum, whilst others position HCPs as experts who should direct all the work. Racism, poor prognosis or care in earlier experiences of healthcare were highlighted as factors that can negatively affect expectations and trust in HCPs. Perceptions about specific professional roles, formed from direct experience or societal and cultural narratives, also impact willingness to work with some HCPs.

*'...one of the most important things is setting expectations and expectation management... if you ask most parents quite soon after their child sustained a brain injury, you know 'what are your expectations of the Organisation?' is that they're looking for a miracle cure.'* (P6: 92-102)

*'It can be tricky because I think there's a little bit of, um this overpromised expectation you know for some of the parents. We have a reputation.'* (P4: 195-196)

*'What has their experience been with professionals already? You get families with such different experiences... you have families that have been told their child isn't going to survive or you have families that feel like they've had a brilliant experience of support in the hospital setting and I think how much they've kind of trusted professionals before or been able to develop relationships with professionals before can then impact how they're feeling in terms of doing that again'* (P7: 181-186)

#### 4.4.3. Attunement and Adaptation

One of the most consistent findings in the data is that the participants take an active role in their day-to-day work to try and facilitate a relationship that would be good enough. Some strategies were commonly used by participants whilst others were more garnered from personal style and experience. In this analysis I have broken down these relational strategies to those used for 'Joining', 'Rehabilitation' and 'Attunement'.

##### 4.4.3.1. *Joining strategies*

One nurse found that having a structured checklist for an initial assessment was a useful way to get to know the family under a familiar 'health' style interaction. Following on from this, participants spoke about the need to give families time before introducing themselves and clarifying their role.

Participants use their initial interactions to take a lead from the families, to get to know them. Learning from the family in the first sessions of therapies were seen as joining actions to help foster the rapport.

Nursing and therapist staff noted that concrete actions, doing what you say you would, or going the extra mile, was an important aspect to join with families: it demonstrated their care for the CYP and family as well as their knowledge, competence and professional role.

*'...all these new people are all trying to get their initial documents signed off and forms and all these different things going on. I think sometimes, it can be a bit overwhelming... so then you end up kind of thinking, 'actually, if I'm not involved on the day of admission, I'll give him a day or two before I start to actually try and engage with them.'*  
(P8: 195-199)

*'One of the things that just stood out to me, that he said was the most helpful, was that was that thing I mentioned earlier of like: if you said you do something, you do it' (P7: 402-404)*

*'I kind of want them to know that I will go the extra mile. I think I have a sense of the loss that they've experienced and the trauma that they've been through, and I feel that if there's anything I could do that would even demonstrate to them that I'm here and I'm willing to go the extra mile for you' (P5: 166-169)*

Participants spoke about some of their more unique and personal ways of joining with families. Participants' own social characteristics were often used to lubricate relationships with families, this could be initiated by families or the professional. Participants shared examples where families who were not from the geographical area of the service would pick out differences in staff to connect with. Participants also shared using human commonalities to find connection as well as bringing



humour and energy to the family when meeting them. Sensitivity, intuition, experience and awareness were key in knowing when and where to utilise these strategies.

*'And maybe I play up to it, Yeah, you'll have families, maybe, they're from another country, they'll say, 'Oh, when did you move here? Have you found it?' That type of question. I'm reluctant to say I'm that different or from this major ethnic minority, but I'm what I'm saying is people can, I guess they're looking for anything that you might have in common, even if it's not the same difference' (P10: 307-311)*

*'...as a male nurse I seem to have had quite good rapport with a lot of dads, I don't know if that's just typically because there's just not many male staff on the team and obviously they just want someone to chat to, that maybe isn't a woman sometimes.'* (P8: 179-181)

*'You generally use humour anyway, and so maybe if that's the way the parent would engage as well, then it becomes more of a shared experience' (P5: 337-338)*

#### 4.4.3.2. Strategies in rehabilitation

HCPs also have strategies to support the relationship in rehabilitation. Goal setting allows an opportunity for HCPs to attend to expectations. HCPs can 'dual plan' and 'scale back', allowing a co-ordinating conversation where the therapist can empathise and understand the family's needs and hopes whilst also keeping grounded to what is possible right now. Part of this is being open and honest with their professional expectations but not denying the family's hope and the possibility that they could be wrong. Those with experience spoke about miracles happening and you could never say never.

*'Alongside practicalities and having to be real about "OK, well we want something to happen. We're gonna have to have this chat no"' and it's*

*about... I often use phrases of sort of dual planning, so rather than concretising anything which we can't because we don't have, we don't have a sort of magic wand to look into the future and know what's gonna happen or how they will recover or what their needs will be' (P11: 271-275)*

*'I, kind of scale things back and break things into smaller chunks rather than thinking about like the big picture or long term. And then another one is another sort of line that we use is like dual planning' (P1: 122-124)*

Across all the professions there was a sense around timing and prioritising. Knowing where the family were in their ability to engage with the rehabilitation process and their circumstance meant that how and when the teams intervened have to be adaptable. For example, for some families the team would take on more caring and therapeutics duties to allow parents time to process what has happened and gradually bring them in to their new caring roles, whilst others may be able to be involved straight away. Modelling the need to take breaks and have some respite was also a role highlighted from the HCPs, to help maintain carer wellbeing.

*'Sometimes parents are happy to take the lead, but sometimes they're not that confident to do it. So that's when we have to intervene and give them enough support so that they will be or they feel confident in doing it on their own the next time that they're going to do it' (P12: 48-50)*

#### *4.4.3.3. Attuning to the family*

Participants reported to keep in touch with where families were at and adapt their communication and approach to varying situations. This involved both team and individual practices.

On a practical level, HCPs need to be understood. Participants highlighted how they adapt their communication styles, be it adapting their accent or breaking down medical terms. Professionals also ensure that they re-visit information that would be assumed to ensure that important information has not been missed.

*'Sometimes if a family I'm working has demonstrated to me that it is a challenge to them, that I have an accent, or they would be more trusting if I use medical terms, for instance, and that's what I'll use, and vice versa, the opposite. It's about the knowledge sharing in the best delivery, communication style that they need'. (P11: 491-495)*

When, where and how the participants communicate with families is very flexible depending on the situation. All participants spoke about families bringing concerns to them in informal or unexpected settings and that this needs time. In some circumstances conversations elicit emotional outpouring that need time and empathy to contain. A couple of interviewees described naming what they perceived was going on for the family, which helped the process of attunement for both family and HCPs. Using the family's language was mentioned by one interviewee as imperative as it ensures that their experience is held in the way they make sense of it.

*'It could look like me coming in very jovial and just being a bit jokey and leaving again or I could end up spending hours sitting down and, you know, on day one hearing half their life story – You know it's very much like you go in, ready to: eyes open, ears open, active listener and responsive and adapting your communication skills styles, not only to the young person but to the family' (P11: 175-180)*

*'She literally just shouted and screamed at the video screen for the call for about over an hour, but I think even though I just sat there and supported her and I didn't judge that' (P8: 236-238)*

*'I think sometimes naming it and saying, 'oh, I've notice that when I say this, it seems like that's not a comfortable thing to say' (P10: 105-106)*

Bringing important or difficult conversations to families was also highlighted. Participants described how their approach is informed by their own intuition, of where the family are at in that moment, and the information shared by the wider team, to understand any other contexts that may be going and who may be best placed to have the discussion. Some participants described the importance of a team approach to ensure a consistent and reliable message being communicated to families.

*'...the more people that you involved and the more complicated it got, and then there was risk of miscommunication and she would use every single word you said she would use it later, so you had to be really clear, really consistent, which is why certain staff are allocated to be the first point of call' (P6: 508-511)*

One interviewee described the uncomfortable feeling you sometimes get when you are not yet attuned to a family and sometimes it takes an element of bravery to go towards a family to get on the same level and understanding.

*'In the back of your head you have these clients, and at first I feel like, "Oh yeah, there's that one again, I'm going to avoid the", and actually what I've learned is those ones that you get that feeling, those are the ones you've gotta go like. "Oh there they are". And instead of like your instinct saying "run, get out of the room", No, they haven't seen me yet. Now, that' like "no. I'm gonna put myself right in front of them". Like that's what you gotta do' cause that's the ones, I feel like that's the ones where you have a real game to make' (P4: 158-164).*

Keeping families, who are not as available or engaged in the rehabilitation, updated also needs carefully attuned communication, if it is videos, emails or the occasional check in.

*'...they could generally only visit on weekends for short periods time. So I tried to email them at least three times a week and then I would, for the weekend, when I knew they were coming I would print out some photos of things that you've been doing in therapy and just so that they felt up to date with his journey' (P5: 109-112)*

#### 4.4.4. Things Get Stuck and Missed

Although effort is put into adapting and attuning approaches to ensure smoother collaboration with families, there are still times where the relationships can get stuck or break down. Participants also highlighted some relational elements may get missed in the RPNR context. I have broken this theme into three elements of where participants reported these difficulties came from: 1) The family, 2) The professional and 3) The organisation.

##### 4.4.4.1. *From the family*

Participants felt that there can be some barriers to the collaborative relationship that stem from the family.

A recurring experience was HCPs not being able to read responses from the family. This could present itself in not being able to understand people's facial expressions, body language or communication of conflicting messages, for example, when something positive is said in a negative way. This was challenging as HCPs are unable to read where the family is at and can stifle their ability to adapt their approach, making attempts to connect feel lost. Similarly, if a family remains rigid about their expectations, this can put a barrier up in developing work together.

*'...little bit harder if they're quite reserved. And like, kind of, I always wonder what they're thinking when I'm doing all sorts of crazy things with their children.' And they're not giving me much feedback with their facial expressions or anything.'* (P3: 213-215)

*'And when you can't read the parent it's really unnerving. And that was definitely a shared experience amongst the team as well because everyone will come back and be like "I don't know what she's thinking", "I don't know if she's happy if she is sad, if she is struggling with this, what's going on?"* (P5: 351-354)

Families' management of their care roles changing, with HCPs in positions of power, were also raised. This dynamic could present itself in small ways where HCPs are scolded for doing daily routines a different way, for example dressing CYP in the 'wrong clothes'. The power differential could also have more impactful consequences for the collaboration, such as families feeling unable to share what's really happening due a fear of what the consequence would be for their admission, parenting role or child. This could impact HCPs attempts to adapt to families' needs. Powerful examples were raised around safeguarding, where HCPs may act to ensure safety but are received as being judgemental or restrictive. This can compound previous bad experiences of public services.

*'He had an incident that needed to be recorded; he had flipped out the sling and she had, against advice, had tried to hoist him on her own. And what that kind of resulted in was a breakdown of trust between her and the care team... [Parent:] "If I don't do this then you don't think I'm safe and then I can't lift my own child from bed to chair, so the powers all with you, crack on will ya"* (P11: 387-405)

*'...she brought it up with a couple of our staff members and was like 'Oh well I don't understand why he's signed off and I'm not'. So it then caused problems with us because we were like, 'right? OK, we need to " try and manage this situation' in terms of explaining to her*

*why she hasn't been signed and ultimately it was because it wasn't safe for her to be signed off: to be allowed to do medication because you know, she was getting confused sometimes with the dosages that she needed to give'. (P15: 474-480)*

Participants spoke about getting caught up in the middle of family conflicts which can be a difficult place to be. This situation was raised in the context of staff being subject to verbal and physical abuse.

*'The teenage boy became verbally and physically aggressive with his sister and mother in the room, so I had to intervene and check on them. But as soon as that young teenager saw me, he right away refocuses his attention and anger towards me and just wanted to hit me.'* (P12: 183-186)

#### *4.4.4.2. From the professional*

The working practice of HCPs can also impact the relationship. One interviewee highlighted work pressures meant that they were sometimes unable to provide enough time to engage with some families.

*'The only times when it hasn't been what I'd hoped it would be, I think, is when I haven't put in the time needed to really build that relationship properly. And so usually, it's meant that the parent hasn't understood something or they've missed something along the line because I haven't explained it properly or I haven't made the time to find out properly how they're working with what I'm suggesting... I think it's just when it's very busy. Yeah, we've had a bigger caseload and lots of other meetings...'* (P3: 230-242)

A few interviewees spoke about the fact delays in being able to communicate with people who speak a different language meant that you often had times when your interaction, particularly around safeguarding issues, were not easy to

explain quickly. The fluidity of relationship and speed of information transfer would be impacted. The experience of working with interpreters can also be variable; some helping foster a good working relationship, whilst others create a chasm between the HCP and the family, with the interpreter having intermediary conversations.

*'...with a parent that didn't speak English as a first language; to explain that their management seizures wasn't that great: they were just going off and getting water and chucking it in the child's face and which is quite concerning practice whereas... we could easily try to bring about change, rather than wait for the next day where the interpreter's in' (P8: 308-312)*

Some participants highlighted that the personal impact of the work can affect collaborative relationships. Participants shared that they can get flustered when conversations become challenging and may avoid having certain conversations with families. Some participants reported times when families were abusive towards HCPs which was particularly challenging and led to relationship breakdown. One participant reported that seeing families not pushing to get all the support they deserve could be disappointing and sway their positioning in the relationship. One participant also commented that endings were challenging.

*'I also then got a bit flustered... and then was trying to like pad around the conversation rather than being direct and I think we kind of got somewhere in the conversation, but then also just parked it... because of that experience I put off that revisiting it' (P1: 273-276)*

*'[The team] were having daily conversations with this mother and family, they were being utterly abused by the mother and they were shouted at, they were called names, they were told that they weren't allowed to look after her. And a lot of it was all because she was going through so much personally with her own health as well as the*



*fear of what was going to happen to her once her daughter was discharged from us and she was taking it out on us....' (P6: 478-484)*

The data also provided anecdotal experiences of who HCPs may miss in their interactions with families. Fathers were frequently raised as a family member that participants did not have a good collaborative relationship with. Some participants explained that this could be due to mothers commonly being the parent on site whilst others suggested there was a natural tendency to connect with and read mothers easier. One interviewee said they generally connected with fathers more and that was a male nurse. Some participants raised their concern that support for siblings is missed; siblings are not often on site. One participant reported a tendency to rush siblings into some type of support when they are on site, but this can be misplaced as the siblings just want to spend time with their family.

*'The dads.... in my experience tend to go one of two ways that they're either fully engaged, really on board... or they struggle coming to terms and become quite defensive about things and take on quite authoritarian type role and almost become difficult to work with' (P6: 328-332)*

*'I just think there are more mothers than fathers at the service playing that role but not unique to the service. I hope that's not too controversial, (P10: 269-271)*

*'Interestingly, something I've noted myself, it's kind of embarrassing to say, is I find it a lot more natural and easy to connect with the moms than the dads.' (P14: 192-193)*

#### *4.4.4.3. From the service*

Sharing information through the MDT was one of the most important themes in the data, however, lapses of information sharing does happen and can have

consequences for the staff - family working relationship. Two prominent examples came through the data: 1) Staff not being privy to what happened to the family in other areas of the team 2) Staff being unaware of what other members of MDT were communicating to a family regarding a specific issue. These led to poor staff positioning and communication, with poor timing and inconsistent, confusing messages to the family. If the first interactions with families are clumsy, chaotic or disorganised, this can have negative effects to the family's impression of the service and ongoing relationship.

*'it was only after [an attempted collaboration] did we then know what happened a couple of days previously about the sling and how she had then felt that she had been accused of bad mothering really, from the care staff, and you know she is dealing with a lot of guilt in herself' (P11: 408-410)*

*'...it's about coming together as a team to be able to build that relationship with the parents and make sure that we're all in the same boat and we're all saying the same thing because otherwise of course, you're going to get conflict between some of us staff' (P15: 429-432)*

The MDT consists of practitioners who are predominantly white, living in a specific area in England. A few practitioners highlighted that curiosity around families experience of the service may be missed which could limit attunement and adaptations. In addition, there can be a tension working out who, in the MDT, is best positioned to have a conversation with a family, for example: social workers lead safeguarding concerns but may not be best placed to have that conversation, given potential perceptions of their role. Another tension described was when one discipline felt that another discipline needed to do a particular piece of work to lubricate their own ability to work with the family, for example, brain injury education needs to take place in order to progress, which requires more open communication through the team.

*'I felt I really needed to advocate for them in the team and help the team think about what it was like being at some of those meetings for them. No one else in the meeting room look like they did, having an interpreter there hearing all of their personal business, thinking about what they could understand' (P13: 597-600)*

*'I think when you when you bring a social worker into that conversation, it has all these different connotations for families when it's never quite clear how they may take that on, especially if it's not a very significant safeguarding concern' (P9: 230-233)*

*'It's not that we're saying 'no' when we won't work with their child, 'cause I think then they [other professionals] hear 'no, we're not helping', I think it's important to explain 'We've met them with the child. Have done an assessment. Based on where they are now, we're actually a lot lower down rungs of the ladder than where you want us to start' (P10: 218-221)*

An interviewee highlighted how some basic needs are sometimes facilitated by families connecting with one another onsite, creating a community. If the cohort of families are not well connected, simple things can be missed which can add more stress to the family and relationship.

Some participants spoke about wider organisational policies and priorities. Participants experiences of witnessing or receiving abuse highlighted an imbalance of the organisations attention to staff needs. It was also mentioned that it takes courage to speak up when having difficulties with a family.

*'I think it's having the courage, as a staff member, to sort of speak up and say 'oh I'm struggling to deal with this family member' or 'I wasn't sure what to say in this situation. Can you help me?' I think it's important for us, as staff, to be kind of acknowledging when we're*

*struggling and actually say 'no, I need help with dealing with this parent or family member' (P15: 508-513)*

*'And we had some really challenging discussions as a team around the ethics of that and that if it was a parent that didn't have a significant mental health difficulties, would we accept that kind of behaviour? Because it was abusive, what she was doing, and we all agreed that we wouldn't. But because of this situation because the mother's mental health issues, she was just allowed to continue speaking to staff in the way she did' (P6: 517-521)*

The commissioning structure also has an impact on the collaborative relationship. Time for admission is very short which can lead to difficulties in prioritising what can be done on site and arranging what can be set for discharge; resources across the country vary and ordering specific items is more challenging since Brexit. It was also noted that work with families was not actually commissioned for in the psychology team, which again perhaps is interpreted that supporting families' mental wellbeing is an additional aspect of work not yet considered by the organisation.

*'Now, when it comes to parents, there isn't anything in the funding contract that says we do have to provide therapy. It's all about providing support for children'. (P10: 197-199)*

*'So, if he needs this in the community it's gonna need ordering and the EU/ Brexit has made that even more challenging, those things need to go in now, but the conversation to them to agree for it is a sensitive one. So it's this balance between, you know, being aware of their emotional needs and where they're at, and potential kind of risk to their mental health' (P11: 265-270)*

#### 4.4.5. What Does or Could Help

Participants raised some ideas of what does or could help soften or untangle stuck moments.

##### 4.4.5.1. *Personal practices*

Participants spoke about the different ways that they manage and get through stuck moments. Some participants spoke about actively focussing on their primary task of the CYP's rehabilitation in helping them navigate the difficult moments, helping to regulate their emotions and work out what they would like to say. Participants also spoke about acknowledging difficulties and emotions you, in order to address them.

*'I guess at that point I focus on the child and on my previous experience and know that it is the thing that needs to be tried' (P3: 292-293)*

*'...sometimes you just have to set aside your personal emotions in dealing with difficult situations, you have to prioritise the safety of the child and families' (P12: 113-115)*

Participants spoke about how their experience had developed their approach. Through experience participants had built up skills to navigate difficult conversations, showing empathy whilst also maintaining boundaries and respect to how they could best help. One participant spoke pragmatically that part of their role in this context is accepting that you don't know what it's like for families and not knowing can help empower you to focus on your role in that moment. In addition, experience tells you that the ruptures will happen, but there will be opportunities to attend to them.

*'I think I was a bit clumsy on doing that when I first started, but I think with practice we've become a bit more skilled talking to parents about some of those difficult concepts' (P13: 571-573)*

*'So I think I was quite naive when I got into this. Like you, you start thinking well 'Why would a parent do that?' and I never ask myself that anymore.... It's like I have no idea what they're going through, who am I? I can't possibly know that 'cause I've been around long enough now to know that not everyone reacts to it like me, and obviously this is so different' (P4: 363-367)*

#### 4.4.5.2. Service practices

Shared spaces to discuss difficulties with families were important to a number of participants, citing informal debriefing conversations with management and the psychology team as helpful. This could help practitioners vent or make sense on what happened. Sharing also allows opportunities to reframe what happened as a shared experience and not located with your relationship with the family. It also provides opportunities to learn how others have managed to position themselves better with a family, sharing solutions.

*'I think just having that kind of shared experience is useful in terms of knowing what really didn't work and what maybe did work, but also in terms of not taking it personally 'cause I think if you're building relationships and it's not going well, it can be hard not to take it personally, but actually, if you can kind of have it as more of a shared experience with, it's easier to reflect on and see the kind very real reasons why that parent is putting up those barriers and actually their issues are huge and you can understand it when you reflect on.'* (P7: 380-384)

The current provision of safeguarding training was cited as useful. One participant also felt specific training in managing difficult moments and

relationships with families would be useful.

*'I think that safeguarding training is really, especially, when they just joined us in their entering sort that level one training which is half a day; the way we demonstrate empathy for families and trying to put across where that careful balances between safeguarding and being supportive or protective, to give them those tools' (P9: 669-672)*

Additional ideas included developing more formal spaces or protocols to discuss relationships with family's, rather than it being discussed when things go wrong; it would be a more normalised and less brave thing to bring forward. One participant also suggested a who's who book of the key team for the family could support their joining the organisation.

## **5. DISCUSSION**

### **5.1. Overview**

This chapter will discuss the overall findings of the research. It will summarise the main points from the results and look to answer the two research questions.

### **5.2. Summary of Findings**

The research looked to explore two research questions:

- 1) What is it like for staff to work with families of CYP in a RPNR service?
- 2) What are the enablers and barriers to this collaborative work?

The results of this study suggest that working with families of CYP in a RPNR service is important to create opportunities to make meaningful interventions and prepare families and CYP to life beyond the service. HCPs expect the relationship with families to be challenging as they recognise they're meeting families in extremely difficult circumstances and identified a wide variety of factors that could impact their working relationship. There is a concerted effort by HCPs to learn, adapt and attune to each family in order to join and create as good as a working relationship as possible. Many different skills and strategies to attune to families came through the data.

There are times when relationships become stuck, rupture or breakdown. Participants located contributing factors from service structures, team organisation, individual professionals or from the family themselves. Relationship ruptures and breakdowns can have an impact on the team, professional and family wellbeing. Challenges to the relationship could also have some impact on the outcome of the work done in the organisation, particularly around building up caring and advocacy skills for parents and carers.



In addition to answering the research questions the results also elicited some ideas that participants would like to implement to help enable better relationships or outcomes.

### **5.3. Research Q1: What is it like for Staff to Work with Families of CYP with an ABI in a RPNR Service?**

In this section I will look at the results of the study in answering the first research question, situating the data in previous literature and psychological theory. Some common dilemmas are also included in this section as they were framed as expected elements of HCPs' roles. I have structured this section into highlighting how staff set up working with families and common dilemmas that they face.

#### **5.3.1. Expectations and Hopes from the HCPs**

HCPs hoped that their relationship with families would enable access to the CYP, supporting further understanding of the CYP, development of interventions, liaison to local systems and preparation for life beyond the organisation. These hopes are in line with general goals of RPNR: to recover previous skills, acquire new skills and promote CYP's appropriate level of self-independence (Royal College of Paediatrics and Child Health, 2017; Wales et al., 2020; Wilson et al., 2009).

HCPs' work in RPNR is explicitly defined by the short time frame of the residence, the collaborative nature of the MDT and the reality of what services are available in a CYP's local community, to continue the work that is started in RPNR (Hamilton et al., 2017; NHS England, 2013a; Wales et al., 2020). HCPs' balance these factors when developing interventions whilst also holding the uncertainty of outcomes (Kelly et al., 2019; Menon, 2018; The Children's Trust, 2018).

### 5.3.2. Approaches to Working with Families

In the first chapter, I introduced the idea of different forms of how services may work with families in rehabilitation settings (Hanft et al., 2012; NHS England, 2013c; Royal College of Paediatrics and Child Health, 2017). The data from this study has led to suggest that discrete descriptions of collaborative approaches are perhaps naïve to the experience in this context. This section will look into family-centred approaches in more detail, considering the data generated in the study

Literature suggests that family-centred care (FCC) is a tricky concept to define. There are a number of different nuanced ideas and practices of what could be involved in it (Mikkelsen & Frederiksen, 2011; L Shields, 2015; L Shields et al., 2012). If a service is able to develop a discrete definition of FCC, HCPs can have difficulties practicing it due to a lack of resources and skills which can negatively impact families; particularly those that have different cultures and needs to the general service provision. Data from this research suggests that the HCPs in this organisation are aware of these dilemmas and are able to provide a fluid approach to developing relationships and FCC, depending on each unique family and where they are at, at any specific time.

There are perhaps more resources within this organisation, being a specialist service that serves national and international patients with several funding streams. This increased resource may allow staff to lean into more active roles than those described in other FCC research (Coyne, 2015; M. Foster et al., 2010). Within FCC, the negotiation of roles between HCPs and families is an important aspect. The data in this study did not bring up the way that the roles are negotiated and I wonder if perhaps this represents how roles are mostly informed by the MDT and HCP intuition. An open negotiation with families is recommended as a way to facilitate FCC more smoothly (Coyne, 2015; Harrison, 2010).

The fluid positioning that participants described echoed the hierarchy of FCC published by Hutchfield (1999). Hutchfield developed a model which describes the flow of a working relationship that moves from parental involvement, participation and partnership to FCC, where the staff would be more hands off and a consultant to the expert family. I posit that perhaps this is the process the HCPs work with families in this context, which is influenced by a number of biopsychosocial factors and an 'ideal' idea of a working relationship that was elicited in the data: to join with families to develop the most useful interventions, support families to engage with care tasks and be ready for life outside the organisation. However, it was acknowledged that some families will not get a to a place where they will be able take the reins of care by the end of their time in residence, this could be due to practical arrangements or emotional readiness. Different professions will be working in different stages of the FCC hierarchy with each family; some may be at a point of parental involvement, whilst others will be stepping back to a consultant role.

### 5.3.3. Appreciating Family Individuality

Previous literature has shown that identifying and understanding family individuality was the highest priority for HCPs and this was echoed in this study (Coyne et al., 2013). Participants understood that they would be meeting families at different stages of the CYP's rehabilitation journey accompanied by their own emotional reactions, coping strategies, adjustments and expectations. This is in line with previously highlighted literature (Aitken et al., 2004; Kirk et al., 2015; Roscigno & Swanson, 2011).

This study shown a light on the effort that the participants go to identify 'where families are at'. Participants' assessment for understanding families' context came from informal and formal settings such as: hospital referral information, information from the wider team and their own interactions with the family. It is suggested that a systematic process of interactions between families and the wider team to assess and react is integral in working with families to help build up trust and keep in touch with families' individual needs (Coyne & Cowley, 2007;

Sarajarvi et al., 2006). Most participants felt that they were not trained in this flexible practice of 'in-the moment' assessment and reaction and reflected that this practice relied on natural abilities or experience.

In this section I will outline two concepts that I believe to be integral to this process: mentalisation and a biopsychosocial lens.

### *5.3.3.1. Mentalisation*

In reviewing the data, I understood HCPs 'assess and react' approach as coming alongside mentalisation theories. Mentalisation is a term used to describe the mental activity of perceiving and interpreting internal mental states. Mentalisation encompasses the idea of mind mindedness, your attunement to others' internal world, and mindfulness, the attunement to your own internal world. Mentalisation is posited as a part-innate ability which is curated through life, particularly early social environments and attachment relationships with primary caregivers. Thus, although positioned as an individual quality, it's development is inherently influenced through interpersonal and wider system interactions (Bateman & Fonagy, 2019).

Mentalisation is not theorised as a consistent ability that is carried with people. It is a constant process of cognitive checking in with automatic reflexives, your own needs and others' needs, recognising or controlling external indicators and understanding and naming internal states. It is part of normal functioning that people experience temporary lapses in mentalisation due to stressful situations. When blocked, people can fall back on 'pre-mentalised ways of thinking' which can lead to difficulties engaging with alternate ideas, acknowledging the external world, other people's perception or get a good grasp of understanding what is happening to themselves. A quicker recovery to re-engage in mentalisation processes can be due to secure attachment styles and a general sense of security. It is therefore important for clinicians in health services to be able to hold families' mentalisation capabilities in mind in the way that they work, as not addressing them could result in relational difficulties (Allen et al., 2008; Bateman

& Fonagy, 2013; Bateman & Fonagy, 2019; Bevington et al., 2013; Jarvis & Polderman, 2011).

Although not framed in this language, the data around parents' experiences made me consider if mentalisation capabilities are impacted by the stressful circumstances of having a child with an ABI and being on the PNR/RNPR pathway of services. I also felt that participants accepted these differences in peoples' ability and their hope was to create a secure environment for families, to enable a smoother and more productive transition in caring roles. It is my understanding that this creation of a secure and empathic environment supports the re-engagement of mentalising processes which will be key for the parents' own wellbeing and ability to develop their new 'care co-ordinator' roles for their CYP (Sharp & Fonagy, 2008). This process of curating a secure environment will be different for each person and family and in itself is a mentalisation process. HCPs engage with each person, looking for cues and information, holding in mind where families' internal states may be at in order to best position themselves.

HCP's mentalisation capabilities relies on support from wider systems to cultivate mentalisation development. In the context of work, the environment should be safe and secure to support their ability to be curious and interested in each family they work with. Service structures can also support family's security, for example: ensuring basic needs are met (Bateman & Fonagy, 2019). It is my opinion that part of developing and cultivating mentalisation in practitioners is the promotion of taking a biopsychosocial view, which was apparent in the data. This can help practitioners understand the holistic picture of factors that may be impacting parents and families' internal states.

#### *5.3.3.2. A Biopsychosocial Lens*

It was apparent in the data that participants viewed families through a biopsychosocial lens. This helps support them to understand and attune to families. The biopsychosocial lens includes consideration of social

circumstances, expectations, the CYP's injury, parent's own mental health and coping strategies.

Participants implicitly referenced that families go through stages of grief. During the interviews I only managed to ask a few participants where that theory comes from and there was no clear answer. I wonder if the language around stage-theories of grief is ingrained within this context due to the way professionals are trained or perhaps it is more widespread across western society (Elisabeth Kübler-Ross Foundation, 2021; Stroebe et al., 2017).

There was also reference to some families not being able to process their grief during their time in RPNR. This perhaps could relate to ambiguous loss theory. Ambiguous loss describes a loss that is unclear and does not have a concrete end (Boss, 2000, 2007). In paediatric ABI, there may be periods where families will not know how their CYP may present in the future or if they will survive, leading to a prolonged period of ambiguity. This ambiguity can block grieving processes, or mentalisation, and lead to family members experiencing anxiety, depression, and relational distress (Kreutzer et al., 2016).

There was a clear sense and empathy that HCPs ask a lot from families: to process what has happened, to grieve whilst also engaging in preparation for the next stages of their life. HCPs shared experiences of being at the end of different reactions from families on different days, this in line with the idea of 'oscillation' from the DMP. This process of oscillation requires curiosity from staff to understand what is going on each day (Stroebe & Schut, 1999). The data also supported the idea that pre-existing coping strategies held by families and individuals can lubricate or create challenges to the working relationship with the HCPs (Guldager et al., 2019a)

HCPs took in mind systemic, injury and environmental influences on understanding a family's position. Again, a specific idea of where this approach comes from was not directly known. From my perspective, these ideas fit in well

with ecological theory and Moos and Schaefer's model for understanding the crisis of physical illness (Bronfenbrenner, 1977, 1995; Moos & Schaefer, 1984).

#### 5.3.4. Common Dilemmas: Expectation Management with Families

The literature review posited that gaps in expectations between HCPs and families can create a tension in the working relationship. The review focused on expectations around prognosis, recovery and the language that HCPs use (Johnson & Rose, 2004; Rashid et al., 2018). This study supports this experience; participants spoke about the careful balance of ensuring clarity and honesty to their professional expectations around recovery, but balancing that with maintaining a sense of hope for the family (Bray, 2015; Perrow, 2013). This study adds more information around the strategies used to manage expectations. Participants engaged in 'scaling back' and 'dual planning' strategies whilst keeping open that miracles and unexpected things happen. This is in line with the idea of providing 'reasonable hope'. Reasonable hope is a construct that directs attention to what is within reach. It deflects away from what may be unattainable but keeps in the realm of hope that is open, uncertain and influenceable (Weingarten, 2010).

This research broadens the understanding of where HCPs believe families' expectations come from as they enter the RPNR context. Participants demonstrated that they consider the pre-admission contexts which would influence a family's expectation such as culture, previous experiences of healthcare and specific HCPs and the context in which the referral is made. Curiosity of pre-admission contexts is a well-founded part of assessment in therapeutic practice in mental health, particular for systemic-orientated practitioners who seek to understand how different levels of systems influence families and individuals (Palazzoli et al., 1980b; Reder & Fredman, 1996).

There are many reports of families feeling their needs are not met during the acute hospital phase and understandably may set the tone for expectations of HCPs and settings coming into RPNR (Aitken et al., 2004; Coyne & Cowley,

2007; Gagnon et al., 2008; Hermans et al., 2012; Kirk et al., 2015; Roscigno & Swanson, 2011). Research has shown that expectations from healthcare systems can be also be influenced from the political landscape, trust in the government, peoples' privilege and power in society, experience of discrimination, age, education and the number of interactions with the health system (Bowling et al., 2013; Rockers et al., 2012; Roder-DeWan et al., 2019; Sturgeon, 2014).

The data also highlighted how different professional disciplines may be perceived differently to each family. Research highlights how and where people may determine their opinion or expectation of a profession, such as from previous experience, their ability to access that profession and media (Legood et al., 2016; Patel et al., 2018; Sheppard, 1994). Within this research, this was mostly raised by social workers and psychologists.

#### 5.3.5. Common Dilemmas: Access

The data in this study re-iterated that the focus in this context was on the child's progress and the relationship with the family could be seen as a conduit to access and understand the CYP. However, the wellbeing of the wider family is key for the longer term success of interventions and wellbeing. Access to the wider family was noted as lacking in some circumstances, particularly around fathers and siblings. The focus of HCPs attention and relationship seemed to be with the most available family member, a pertinent factor in the context of the pandemic. In addition, access and working relationships were often dependent on the CYP themselves, and their age and capacity.

##### 5.3.5.1. *Fathers*

A number of participants found fathers were less available on site. This was due to the way the family held their roles or other social factors, such as employment or caring duties. Some participants reflected on their assumptions of gender roles, where they implicitly saw mothers in leading child care. Only one



participant said they found working with fathers easier, and that was a male nurse. Perhaps these experiences highlight the multiple levels of hegemony that influence fathers' participation in the RPNR journey. These ideas are in line with research findings of father's experiences of children with disability or undergoing cancer care. Fathers reported their difficulties in balancing their role in the family, employment, social expectations of their emotional response, social expectations of disability and developing new perspectives and adjustments (Musumeci & Santero, 2018; Neil-Urban & Jones, 2002; Pancsofar et al., 2019; Schippers et al., 2020).

Another barrier to working with fathers raised by participants was around the way that fathers cope. Literature suggests that fathers do cope differently to mothers after their child sustains an ABI. Fathers experience more distress earlier in the process and perhaps use denial defence strategies more (F. Brown et al., 2013; Narad et al., 2016; S. L. Wade et al., 2010).

#### *5.3.5.2. Siblings*

This data also highlighted that siblings are also affected by a CYP's ABI, as reflected in the literature review (Bugel, 2011; Bursnall et al., 2018; Tyerman et al., 2019). Participants queried if the RNPR is the best place for HCPs to work with siblings. Siblings visit the site during their free time, weekends and the holidays, and may want to spend it with their family. For RNPR, it seemed working with siblings is opportunistic and depends on the time in the school year that a CYP's admission is, how far away the family live and resources of the family.

#### *5.3.5.3. The CYP*

Some participants, particularly social workers, highlighted the dilemmas and adaptations that the different levels of CYP's capacity and age had to the way that they worked with families. The data echoed a lot of the literature around adolescents, where older CYP should be encouraged to be part of the decision-

making process, which a good relationship with families can lubricate (Gagnon et al., 2008; T. Lee et al., 2017). This process of participation is a careful balance of abiding by legal frameworks such as The Mental Capacity Act (2005), The Children Act (1989), Gillick's Competence and the ambiguous 'zones of parental control' (Department of Health, 2015; Griffith, 2016). This balancing act, particularly in an environment with rapidly changing circumstances, can be very confusing (Akerlele, 2014; Fenton, 2020). Within this data it seemed social workers take on the burden of clarifying the legal frameworks, which in some circumstances can break relational ties or double workloads when plans change due to CYP regaining the capacity to make decisions.

#### 5.3.6. Common Dilemmas: Responding to Emotional Responses

Throughout the data there was an expectation that HCPs could take the brunt of emotional responses from families. I perceived the data as suggesting that the HCPs saw themselves as a safer object for families to express emotions towards, framing this within psychodynamic ideas of transference. There were examples where one may be able to perceive defence mechanisms in play, such as denial, emotional displacement and projection. It seemed that many participants were able to describe that they are generally able to keep a distance from emotions being played out and hold on to a curious stance. However, there could there were instances and stories where they may become more entangled in the projections and emotions pushed onto them, a form of counter-transference. It can be challenging to recognise these moments.

#### **5.4. Research Q2: What are the Enablers and Barriers to this Collaborative Work?**

In this section I will look into the study results that answer the second research question, situating the data in previous literature and psychological frames of understanding. I have separated the main points into three categories: psychosocial factors (particularly resources), practitioner wellbeing and communication.

#### 5.4.1. Psychosocial Factors: Resources

A prominent aspect that can impact the collaborative relationship is the availability of resources, locally and within the family. This perhaps goes back to the concept of rehabilitation capital (Guldager et al., 2018).

This study highlights that parental availability was frequently cited as a factor that impacts the working relationship with HCPs. Parents' availability can be impacted by having other children who need support, geographically being far away, work flexibility and family dynamics. In addition, the idea of being mentally unavailable came up due to managing many issues at the same time such as housing, benefits and education in addition to parental coping. Families who have more resources and availability to be able commit to the RNPR placement may have more capacity and time to participate in and develop a better relationship with HCPs.

The data also pulled out some of the meso and exo-system considerations. HCPs consider the resources that the families local community offers to help navigate the priority of what needs to be done in RNPR, whilst the resources are there. The UK provisions of services are disparate, perhaps due to a lack of understanding of need in commissioning groups, and this will impact how HCPs in RNPR work (Menon, 2018; The Children's Trust, 2018).

Each field and organisation in health has its unique context in which a different combination of family circumstances will allow mobilisation of cultural or personal capital (Scambler & Newton, 2011). This study does not have the detail or scope to detail what that is but does begin that conversation in the setting of RNPR.

#### 5.4.2. Practitioner Wellbeing

The projection of emotions towards staff can reach a threshold that could meet abuse and greatly affect practitioners' wellbeing and ability to perform their professional tasks or collaborate with families.

Abuse is not a novel experience in healthcare, with 15% of NHS staff experiencing physical violence and over 26% of NHS staff experiencing bullying, harassment or abuse from patients, relatives or other members of the public (NHS Staff Survey, 2021). The UK government have begun developing a violence reduction strategy which posits a 'zero-tolerance' approach to verbal and physical abuse to HCPs, backed up by new laws for tougher penalties for those that are violent (Assaults on Emergency Workers (Offences) Act 2018, 2018; Department of Health and Social Care, 2018b; Hancock, 2018).

Within this context, a zero-tolerance approach and acting powerfully with the new laws seems a difficult concept to imagine and perhaps counter-intuitive to what HCPs want to achieve. HCPs know that they are trying to engage families in restorative work whilst they process grief or change, it is known the relationship could be very difficult with lots of emotional defence mechanisms in play. Thus, in this context, I wonder if there is a blurring between what is acceptable and what is deemed abusive. This lack of clarity could lead to delays or missed opportunities for the organisation to step in to protect staff and their dignity. This dilemma has been identified in other contexts, such as in nursing, dentistry and GPs, where a perspective of 'it's part of the job' was posited and need for better identification of abuse warranted (S. Lee et al., 1999; Merivale, 2020; Oxtoby, 2021)

### 5.4.3. Communication

The need for good communication is threaded throughout the data and the literature review for all staff-professional, inter-discipline and inter agency relationships (Hartman et al., 2015; Johnson & Rose, 2004; Lundine et al., 2019; Rashid et al., 2018).

Poor communication can impact patient safety and outcomes, and is an improvement area for the NHS (Patient Safety Initiative Group [PSIG], 2018). The PSIG report defined communication as a context-dependent social interaction which can be influenced from six specified areas. Below I have used these six areas to align and structure what had been said in the data.

#### *5.4.3.1. The communication environment*

Participants noted that time is a key factor in their ability to enable relationships. The majority of participants reported their ability to be flexible with their time to meet families' needs. However, one participant highlighted a high caseload reduced their capacity. A high workload is a key determinant in HCPs ability to build relationships, with reduced time to communicate, as well as impacting HCPs' wellbeing (Greenglass et al., 2001; Nicholls & Pernice, 2009; J. Singh et al., 2020). Although uncommon in this cohort, 52% of NHS staff feel they are unable to meet all the conflicting demands of their time at work (NHS Staff Survey, 2021).

#### *5.4.3.2. Information exchange*

The study data framed that HCPs give information in a sensitive and empathic way, informed by professionals' understanding of what needed to be said, when and by who (F. Brown et al., 2013; Roscigno & Swanson, 2011). However, this is a biased overview, from the HCPs perspective. The literature review cited that there was often a gap between the way professionals gave information and the needs of families. These studies were predominantly in acute hospital settings

where time and resources may be very different to the RPNR setting (Gagnon et al., 2008; Hawley, 2003; Hermans et al., 2012).

#### *5.4.3.3. Attitude and listening*

The PSIG report (2018) outlines that clinicians should show respect, commitment, positive regard, empathy, trust, receptivity, honesty and enable collaborative focus on care. From my perspective, HCPs in this study sought to bring these to their practice. Being honest, open and attuning to each family was most frequently mentioned which requires active listening and professional integrity.

#### *5.4.3.4. Aligning and responding*

The data suggested that when HCPs are unable to read a family member's communication their efforts to attune and adapt their approach are hindered. Throughout the data there were no committed ideas from HCPs to why this may be. Some postulated that it could be around cultural expectations of healthcare or perhaps a feature of their coping process.

A misalignment of cultural communication could also explain these experiences. We are all grounded in our own culture's interpretation of behaviour and their meaning; perhaps a mismatch of communication interpretations is being played out (Qureshi & Collazos, 2011; N. N. Singh et al., 1998). Singh et al 1998 cites examples of how non-verbal communication such as greetings, eye contact and silence can be misinterpreted and cause tension or misunderstandings in a therapeutic relationship.

The data also highlighted how healthcare's culture around safety was also a point of misaligned communication; particularly around safeguarding and reporting processes, a common practice to assess adverse events and near misses (Doupi, 2009; Larizgoitia et al., 2013). Although this is a professional process of due diligence, it can be received as a negative judgement on parenting.

Participants reported bringing different parts of themselves to support alignment with families, for example: gender, accent, sense of humour or place of origin. This brings to mind the idea of multidimensionality and 'cultural borderlands': each person and family have unique contextual variables on multiple dimensions providing multiple opportunities for connectedness (Falicov, 1995; Rosaldo, 1993). These borderlands may also hinder communication, for example, an accent being misunderstood or a jarring sense of humour.

#### *5.4.3.5. Communicating with specific groups*

The data highlighted examples of participants providing provisions for working with parents with learning disabilities and who spoke a different language; requiring time to create bespoke materials and access to interpreters.

When working with families who speak a different language, barriers came up in different areas for different professions. Nursing professionals highlighted difficulty in managing quick, in the moment, information exchange which can affect the relationship, particularly when there are safety concerns. Perhaps this issue was less prominent prior to the pandemic as other family members may be present to interpret, a practice not recommended but deemed appropriate in some circumstances (NHS England & Primary Care Commissioning, 2018; Rimmer, 2020; Zendedel et al., 2018).

HCPs from therapies and the psychosocial team felt the quality of interpreters affected their relationship. Interpreters are positioned in healthcare to be the conduit between HCPs and patients or families, whilst holding responsibilities of safeguarding, whistleblowing, confidentiality and consent (NHS England & Primary Care Commissioning, 2018). The quality of interpretation is difficult to assess. Some authors and guidance suggest that interpreters should be neutral to facilitate the integrity of HCPs communication (Hadziabdic & Hjelm, 2013). Other authors highlight the complexity of an interpreter's role, where they need to navigate: the discourses of healthcare, different turns of language and their

meaning, different cultures of healthcare, their own relationship to the person, the different power dynamics in the moment, what may have happened before and the changing dynamic that their presence will make (Kaufert & Putsch, 1997; Tribe & Tunariu, 2009). Given this, there is a specific skill of working with interpreters, the British Psychological Society collated research and literature to provide guidelines for working with interpreters. A useful tool within this report was considering the 'mode' of interpretation required in each moment for example: a word for word interpretation, contextual explanations or advocacy (British Psychological Society, 2017).

#### *5.4.3.6. Creating the preconditions for effective communication within a team*

The data and literature review highlighted that a lack of communication between the team can lead to relationship ruptures. This can lead to team members being misinformed and inconsistent messages being delivered to the family.

Participants were already practicing recommendations highlighted in the literature review, such as frequent meetings and electing a co-ordinating professional to enable better communication (Gan et al., 2010; Lundine et al., 2019; Rashid et al., 2018; Swaine et al., 2008). However, this may not be enough for the demand on the MDT to be fully informed in a 24 hour, residential service that cares for CYP with complex and changing needs.

Good information continuity can save repetition, confusion and also help practitioners position themselves (Haggerty et al., 2003; Infante et al., 2004; Nair et al., 2005). Information continuity has not been researched much within the area of neurorehabilitation, with most research centring around the experience of GPs and primary care (Freeman & Hughes, 2010; Hustoft et al., 2019). Haggerty et al., 2003 provides a useful account of how informational continuity varies in terms of the service and roles within that service.



## 5.5. Summary

In this section I have tried to apply context and psychological theory to interpreting and situating the data yielded from the study. Participants work in a flexible way that can be described in as an iterative FCC model that appreciates the individuality of each family; this relies on HCP's ability to mentalise and attune to families whilst appreciating the biopsychosocial context in which their relationship takes place in. Participants strive to ground expectations of rehabilitation work into the realm of 'reasonable hope'.

This biopsychosocial view can hold several psychological theories. Theories of grief were very pertinent to frame participant's experiences such as the dual model of bereavement, the crisis of physical illness and ambiguous loss. Psychodynamic theories of defence mechanism can be used to describe the balance and projection of emotional coping. An ecological view of influencing factors support understanding contextual determinants that that could impact the relationship and families' participation, such as previous experience and rehabilitation capital.

Participants also identified communication and practitioner wellbeing can impact their work. Co-ordinated communication and information continuity among all stakeholders is key in enabling collaborative relationships. Service and societal structures could impact HCPs ability to work with some family members. The uncertainty around the thresholds of the expected playout of defence mechanisms and received abuse can also put up barriers to relationships.

## 5.6. Implications for Clinical Practice

Having named and framed the results of the study, this section looks to identify some potential interventions to support clinical practice in the future.

### 5.6.1. Supporting Staff Mentalisation

In order to have the capacity to mentalise, the working environment needs to be secure (Luyten et al., 2020; Steinmair et al., 2020). If HCPs don't feel safe then their ability to provide a relational safe space for families will be shut down as their capacity for mentalising may be blocked. Mentalisation takes and receives from attunement, which requires information, time for reflection and energy (Allen et al., 2008). This sub-section looks to outline some ideas that could support HCPs ability to mentalise.

#### 5.6.1.1. *Information continuity*

Better information continuity could support efforts for HCPs to be attuned to families' circumstances. The unique 24 hour setting of RNPR and potential for rapid changes in the field of severe ABI in CYP presents a unique context with its own needs and potential solutions to continuity that need to be explored more. An audit of where gaps in communication occur could be a useful way to locate areas of communicative improvement. Given current provisions of communication and note taking systems I wonder if an openness with families about the restraints of communication could be helpful to situate, or plant the seed, for when these difficulties arise. Unfortunately, knowledge around potential technological advances for information continuity is beyond the remit of this research, and is not yet on the horizon in recent reports (Department of Health and Social Care, 2018a).

#### *5.6.1.2. Enabling smoother communication with families who don't speak English*

Barriers to communication were identified when working with families that speak a different language. Nursing staff have dilemmas of understanding families in the moment. Families having more power to access interpreting services could help in this manner, being able to communicate on their terms and needs.

Therapeutic staff spoke about the quality of interpreters being a barrier. I wonder if training with or working closer with interpreters, or interpreting service providers, could support understanding of interpreter's 'mode' and skill of practice. This could improve practitioner awareness and skill of working with interpreters as well as creating more clear channels of mutual feedback.

#### *5.6.1.3. Enabling smoother communication with families with different world views or communication styles*

I posited the idea that a misalignment of world views and communication styles could be a barrier to collaborative relationships. It is unrealistic to expect HCPs to be culturally aware or competent to all the world views of families they work with and understand communication minutiae that could help them attune better. Perhaps supporting open curiosity and seeking support from networks that are linked to a family could help HCPs become more co-ordinated. This idea is inspired from my personal experiences of working with chaplaincies in acute hospital. Chaplains can take up roles of consultant, advocate, bereavement counsellor and as they negotiate different cultural barriers between healthcare and religion (Flannelly et al., 2006).

#### *5.6.1.4. Defining FCC approach*

The FCC approach of RPNR services is not well defined in the literature review or data of this study. Perhaps an overt FCC framework, such as that proposed by Hutchfield (1999) that integrates the service resources can help HCPs in their positioning with families. It could give words to the process that already happens

and perhaps allow a more open line of communication and clearer distinction of roles with families.

#### *5.6.1.5. Supporting respite and protection for HCPs*

The study highlighted that there was a blurring around support for when HCPs are subject to abuse. There is perhaps a need for HCPs' to feel equipped, supported and know how to position themselves when they do receive abuse. Working parties and audits could help identify how HCPs feel with current support to help to create a working model of what should be done when. This could be developed into an easy to reach document. Models would depend on the culture and resources in each individual service. The provision of mental health days could also be useful, giving validation that taking time to attend to mental wellbeing is important for HCPs' role. Traditional construction of sick days can make it ambiguous if taking days off to attend to mental health is included (Mental Health Foundation, 2017).

A system-psychodynamic frame could also be useful to consider the development of a culture shift to enable exploration of emotions held in teams (Obholzer & Zagier Roberts, 2019). However, this relies on having a space where people can be brave enough to bring these difficult feelings. I have been inspired by the brave space framework, a concept from social injustice fields which could be a useful template to consider this (Arao & Clemens, 2013).

Some participants raised that there was no formal training on managing challenging or conflicting moments with families and that a standardised training in this could be useful as a baseline to equip them.

#### *5.6.1.6. Supporting HCPs' biopsychosocial understanding*

It was clear from the data that participants had a clear understanding of the multiple layers that could affect a family which was well supported by management and the psychosocial team. However, each HCP will have different

knowledges and experience from which to access this understanding. Perhaps ensuring resources around supporting a biopsychosocial lens could support a common approach to understanding families. This could be through presentations on biopsychosocial frameworks, such as SPECS, NIF-TY and the SNAP (Jim & Liddiard, 2016, 2020; Jim & Norton, 2015; Liddiard & Jim, 2015), or easy to access resources or worksheets.

## 5.6.2. Attending to Service and Practice Gaps

### 5.6.2.1. *Resource gaps*

The understanding and awareness of a context specific rehabilitation capital could help services and practitioners position themselves better, as well as provide guidance to what specific provisions are needed to attend to service gaps and support social equality for families.

### 5.6.2.2. *Ambiguous loss*

Throughout the data there was an acceptance that some families may not be able to process their grief. Being able to describe this process through the lens of ambiguous loss allows the potential for an intervention to help families manage with this. This may or may not be within the knowledge base or remit of services but perhaps partnership with organisations that are well versed in working with families in this limbo of grief could help practitioner positioning. I wonder if validating and attending to this process could perhaps help families take more of the caring reins whilst they manage.

### 5.6.2.3. *Fathers and siblings*

The research highlighted how different HCPs can have different relationships with different family members: particularly with mothers, fathers and siblings. This is important clinically as to identify which parts of the family may be missed in the work and relationships. I don't believe this is necessarily a call for RPNR

services to provide interventions for everybody, but perhaps an awareness. This could allow for signposting for more appropriate services, or perhaps an open curiosity to the wider team to know who is joining better with certain family members and using that positioning flexibly.

## **5.7. Dissemination**

It is my intention to disseminate the results of this study, an action that is supported in clinical psychology training that is often not delivered upon (Evans et al., 2018).

This thesis, in its current form, will be added to the University of East London's Research Repository and made available online. I will also offer to share the thesis to participants and the organisation that partnered the study. Given this is a long piece of work and can be inaccessible, I would intend to offer a short summary of findings as well as a presentation.

I also intend to publish the research in a peer reviewed journal and present it at an international conference. An abstract has already been submitted to International Brain Injury Association's Virtual World Congress on Brain Injury. This was submitted with the support of partnerships that I have forged with my thesis supervisor and the organisation, although options remain open for disseminating in other ways as well (Callahan, 2020). The literature review could also be published in a separate piece.

## **5.8. Critical Evaluation**

### **5.8.1. Methodology**

I stand by my decision to undertake this research using a qualitative methodology. The method was led by the research question and allowed a rich exploration of participants' experiences. However, there can be some pitfalls in using qualitative methods; assessing the quality, or validity, of the research is

one. Ideas for assessing validity varies between creating sets of criteria that one must meet or demonstrating the research's impact on the world (Lincoln & Guba, 1986; Spencer & Ritchie, 2012; Stiles, 1993). There is not enough space to review the different validity frameworks in this thesis. One useful model was published by Lucy Yardley who highlighted four criteria research must meet: 1) Sensitivity to context, 2) Commitment and rigour, 3) Transparency and coherence and 4) Impact and importance (Yardley, 2000).

#### *5.8.1.1. Sensitivity to context*

As a practitioner I have not worked in RNPR, thus I needed time to understand the context. Prior to the project beginning, I spent a lot of time talking to practitioners about what would work for the study, such as recruitment practice and spaces to talk. Given this took place during the peak of the COVID-19 pandemic this included considering which online platforms would be best suited for participants. This context building allowed me to position myself in a flexible way to join people in comfortable ways, taking into consideration working shifts and access to different technologies.

Due to the pandemic, the timeline for this research project was vastly reduced and I am aware this may have impacted the sensitivity to context. For context, the study's proposal, literature review, data collection and write up was completed in the space of 9 months, there would usually be 18 months or more. Therefore, certain elements of the study may have been rushed. For example, if there were more time, I believe I may have looked into a second question in the literature review, to gain understanding around the literature on FCC. The data led me to perform an ad-hoc narrative review around FCC for the discussion, but being closer to this context would have created a richer foundation for discussion.

The lack of time also reduced the opportunity to build infrastructure for self-reflexivity. I was able to build in time for self-reflection in a more ad-hoc way through an events diary (Appendix 11) but more structure would have supported

closer attention to my positioning, power and the sociocultural context during the study.

#### *5.8.1.2. Commitment and rigour*

I was open and flexible to facilitate as many interviews as possible during the data collection period. I provided my availability to potential participants and was committed to carve out time to when was most suitable for them. During the interviews, I ensured that I kept to the remit detailed in the information sheet and balanced the conversation between allowing participants to speak freely and being more directive to the topic, if needed.

I kept the process of analysis close to the protocols outlined in the thematic analysis literature (Braun et al., 2014; Braun & Clarke, 2006). Codes were developed into initial themes through four different iterations, from: grouping in a word document, mapping on a mapping software, re-organising again in a word document and consolidated again during the write up (Appendix 12 - 15)

#### *5.8.1.3. Transparency and coherence*

I hope that I have also been able to convey my thought process throughout the study, acknowledging that I will have my own unique access to and perceptions of the world. Within this critical evaluation I will also provide an additional self-reflexive statement to highlight the personal impact of delivering this research.

#### *5.8.1.4. Impact and importance*

I believe that this research can have an impact on clinical practice. I don't believe that any of the points raised in the research are particularly novel, but it does offer them in the context RPNR.

The ultimate hope from this would be that people in positions of power would be able to use the data from this study to inform positive change in services, not only



in RPNR but other similar services; through development of policy, practice within services or support for staff. The research also has the potential to inspire further research and validate working experiences of HCPs.

### 5.8.2. Method

The method used for this study was a pragmatic choice given the pandemic restrictions and not knowing the team. Participants were able to participate in a flexible way; they were given a choice of when they would like to talk, if they would like to speak with others, over the phone or via MS Teams.

### 5.8.3. Limitations and Ethical Considerations

#### 5.8.3.1. *Recruitment*

The recruitment strategy meant that I was one step removed from potential participants. I was reliant on a network of professionals that I had built prior to the study to help disseminate advertising emails and posters. I am therefore unaware of which groups of professionals were privy to knowing about the project or how it was described to them beyond the words in my emails and posters.

The recruitment may have also been biased as my thesis supervisor has a role within the organisation. This may have skewed who decided to participate; with some participants perhaps feeling a duty to participate and others being more cautious of participating. Although safeguards were put in place to separate me from the organisation and anonymise all data prior to sharing draft thesis chapters, there could have been concerns of confidentiality being at risk.

The study ended with recruitment of participants from four separate teams: therapies, psychosocial team, the nursing team and assistive technology team. Many key professionals from the MDT were missing, therefore, this research does not represent the full MDT.

### *5.8.3.2. Alternative Recruitment*

A more direct way of advertising the study could have helped with recruitment. It had been hoped that I would be able to virtually join wider team or organisation meetings, giving me the opportunity to describe the project in person. This could have provided opportunities to discuss the study safeguards, widen the recruitment pool and enquire if there were other ways to facilitate conversations that may have appealed more to people.

If the research were not restricted due to the pandemic, I would have liked to have spent more time joining with the organisation, visiting and understanding the context more. This could have facilitated a more comfortable, direct, joining and bespoke method of advertising, potentially expanding the representation of the MDT in the research.

### *5.8.3.3. Generalisability*

Although this study investigates the experiences of people working in a unique context in the field of ABI the results can have applicability to theory and practice in wider spheres. The study focuses on HCPs' working relationships with families which is a common experience in healthcare and is situated within the same cultural context of laws, systems and experiences of UK healthcare. Therefore, many of the experiences, barriers and enablers may resonate to professionals in other contexts.

However, the misuse of knowledge could present an ethical issue of epistemic injustice (Fricker, 2007). I am particular mindful around the disparity of resources between different services and the impact of applying knowledge from this service directly into different contexts. In addition, I am mindful that study does not represent the whole MDT, nor have the power to make claims on the experience of specific professions in the RPNR context.

#### 5.8.3.4. *Missing Voices*

This research highlights the experiences of HCPs. It does not represent the voices of people that HCPs work with and is therefore a biased picture of collaborative relationships in RPNR.

#### 5.8.3.5. *Method*

Due to the pandemic, the research was advertised and performed using remote methods. Online and phone interviews had some pitfalls. I sometimes struggled to pick up specific cues in non-verbal communication and conversations were interrupted due to bad connections and non-protected spaces during the conversation. This has been highlighted in other research (N. Brown, 2018; Lo lacono et al., 2016).

In proposing this study, I had hoped that I to be able to facilitate focus groups. The one joint interview brought rich information that was generated in synergy from the participants. Facilitating more joint interviews or focus groups could have generated more unique, richer data, closer to the context of the participants.

#### 5.8.4. Researcher Reflexivity

An exploration of my personal journey during the study is important to consider. It allows for transparency of potential biases or influences of my contributions (Willig, 2013).

In starting the data collection, I was aware that, being slightly removed from the participants' context, I may build assumptions of the professionals' experiences; based on my own experiences working in MDTs, hospitals and care settings. I was also aware that I was slightly uncomfortable with the role of being this 'external researcher' and the power and position it may hold. Initially, this was a struggle for me and I found myself leaning towards trying to create a 'peer' like atmosphere in the interview, making inferences to my own experience. On

listening back to the first interview I was able to pick this up. Keeping focused on the open-endedness of the questions helped me reduce skewing the conversation that way.

Early on in the interviews I was aware of some very difficult stories coming into the conversation, particularly around verbal abuse towards HCPs. I felt the dilemma that HCPs are left with, I particularly related to an example of being verbally abused by a parent, who themselves were in distress, having been in that position myself. I was able to talk to my supervisor about how to manage that kind of moment. It was useful to discuss practical ways to help let the conversation flow whilst being containing. Through the research process and listening to different experiences of abuse towards HCPs, I was able step back and think about the different stakeholders involved and where responsibilities lie, rather than the dilemma of the individual practitioner in those moments. I hope that the recommendations of this research could help validate or ease these dilemmas for HCPs.

I undertook all the interviews and transcribed them with the aid of MS Teams and MS Word's transcription function. This process of listening, transcribing, editing and formatting the interviews helped me get embedded with the material. I was also able to discuss some of the initial themes with my supervisor in an ad hoc conversation which helped to develop wider ideas from the content. I was also aware that the way I constructing themes, through causal links, may well be influenced by my training in psychological formulation.

## **5.9. Recommendations for Future Research**

The findings from this study could inform quite a few areas for future research. Some suggestions are highlighted below.

### **5.9.1. Investigating Further into Professional and Family Experiences**

Given that this study only captured a small section of the MDT, further exploration is warranted. There could be merit in furthering the current study. Perhaps when the pandemic restrictions are reduced, there could be a more comprehensive recruitment drive bringing forward different voices and broader experiences within the MDT. Perhaps research looking at the experiences of a more homogenous HCP sample, from specific disciplines, would hold more power as well.

It would be very interesting to be able to cross reference the experiences shared in this study with families. Other studies were able to speak to different stakeholders in the relationships and I think there could be a key development in this area of work (F. Brown et al., 2013; Lundine et al., 2019). For example, research looking into families' experience of how HCPs balance their communication, could facilitate a more holistic picture in RPNR settings.

### **5.9.2. Outcomes**

One aspect of the results that was unclear were the varying reports that a poor relationship will have an impact on outcomes. More research in this area, perhaps qualitatively looking at outcome measures, may give more of an indicator of this. Identifying specific outcome measures is quite a challenge in this context: What would one measure? Who would report it? Unfortunately going into detail in this area is beyond the remit of this thesis. However, I am aware this dilemma is being addressed by several parties in general and brain injury rehabilitation: advocating for context sensitive outcome measures that encourage

a shared review of outcomes and empowerment for families and CYP (An & Palisano, 2014; Hanna & Rodger, 2002; King et al., 2011; McCauley et al., 2012).

#### 5.9.3. Considering Attitudes and Culture of Staff Abuse

I think there is some weight to further explore attitudes around abuse towards staff. Further research in this area could help pin point more acutely how organisations, commissioners and policy makers can best protect staff.

#### 5.9.4. Investigating the Gaps

This study highlighted gaps in relationships, such as those with siblings, fathers or families that speak a different language. I believe that more research to help clarify these gaps could be warranted. For example, research could look into who in the family is the primary contact and why that might be, where siblings fit in and identifying points at which families who don't speak English are losing their opportunity to communicate with staff. I imagine this would be unique to each service setting, but clarifying and building up data to the gaps highlighted could help to develop useful interventions.

#### 5.9.5. Identifying Rehabilitation Capital

Further data to clarify which elements of rehabilitation capital are most mobilised in the RPNR setting could also help clarify what services can do to help bring more equity to families' experience in their residential placement. This could be achieved via a similar approach to Guldager et al., 2018 who used a mixed methods approach of observing and interviewing patients and relatives. The research looked into participant's bio-socio-cultural background and current experiences in their interaction in services and decision making.

## **5.10. Conclusion**

This thesis presented a thematic analysis of the experiences of HCPs working with families of CYP in RPNR. The study suggests that the working relationship with families is important in order to create meaningful interventions and prepare families and CYP to life beyond the service. Overall, the findings conclude that there is a concerted effort by HCPS to learn, adapt and attune to each family in order to join and create as good as working relationships as possible given very challenging contexts of grief, upheaval and stress.

Even with all the efforts HCPS make to facilitate good working relationships, there can be relationship breakdowns, ruptures and gaps in their family relationships. These barriers can come from service structures, team organisation, individual professionals or from the family themselves. These barriers could have an impact on the wellbeing of stakeholders and the outcomes of the rehabilitation.

This study puts forward a psychological stance to understand the experiences, barriers and enablers to collaborative relationships. The study also supports further research into this area, supporting interventions for positive change.

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## 7. APPENDICES

### APPENDIX 1: Invitation Email and Poster

Participate in Research: Experiences of Working with Families Project

[REDACTED]

Thu 19/11/2020 14:36

[REDACTED]

📎 1 attachments (113 KB)

Working With Families Research Poster.docx;

Dear all,

Please find attached an invitation to participate in a research project looking into experiences of working and building relationships with families of children who are in residence at [REDACTED]

**What would you need to do?**

Have a conversation with me by phone or video call about your experiences of working and building relationships with families (no more than an hour).

**Each participant can get a £5 amazon voucher as a thank you!**

If you are interested in participating, contact [REDACTED]

All the best

[REDACTED]

# Research Project



## EXPERIENCES OF WORKING WITH FAMILIES OF CHILDREN AND YOUNG PEOPLE

### Who am I?

I'm [REDACTED] A Trainee Clinical Psychologist.  
This project has been developed as part of my doctoral degree in clinical psychology.



Photo of researcher

### What's this Project About?

Working and collaborating with families is an important part of the rehabilitation of children and young people with a brain injury.

What is often missing from research is how do you build those relationships? What skills do you use to help with working with families? What gets in the way of that?

### Who am I asking to participate and why?

People who work with families of children who are in [REDACTED]

Working at [REDACTED] means that you are working with a range of diverse families from [REDACTED] who have children with different injuries at different ages. The work you do on a daily basis may help answer those questions above.

The hope is that study could help develop support for staff working with families, which could improve the experience of building those collaborative relationships.

### What would you need to do?

Have a conversation with me about your experiences of working with and building relationships with families (no more than an hour).

This could either be 1:1 or as a group interview with yourself and colleague(s) if that is more comfortable. This conversation would be either over the phone or online (using Microsoft Teams)

### As a Thank You...

*Each participant will receive a £5 amazon voucher*

### How do I get involved?

Contact me, [REDACTED]

## APPENDIX 2: Application for Research Ethics Approval

### UNIVERSITY OF EAST LONDON School of Psychology

#### APPLICATION FOR RESEARCH ETHICS APPROVAL FOR RESEARCH INVOLVING HUMAN PARTICIPANTS (Updated October 2019)

##### FOR BSc RESEARCH FOR MSc/MA RESEARCH FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING & EDUCATIONAL PSYCHOLOGY

#### 1. Completing the application

1.1 Before completing this application please familiarise yourself with the British Psychological Society's [Code of Ethics and Conduct \(2018\)](#) and the [UEL Code of Practice for Research Ethics \(2015-16\)](#). Please tick to confirm that you have read and understood these codes

1.2 Email your supervisor the completed application and all attachments as ONE WORD DOCUMENT. Your supervisor will then look over your application.

1.3 When your application demonstrates sound ethical protocol, your supervisor will submit it for review. By submitting the application, the supervisor is confirming that they have reviewed all parts of this application, and consider it of sufficient quality for submission to the SREC committee for review. It is the responsibility of students to check that the supervisor has checked the application and sent it for review.

1.4 Your supervisor will let you know the outcome of your application. Recruitment and data collection must NOT commence until your ethics application has been approved, along with other research ethics approvals that may be necessary (see section 8).

1.5 Please tick to confirm that the following appendices have been completed. Note: templates for these are included at the end of the form.

- The participant invitation letter

- The participant consent form

- The participant debrief letter

1.6 The following attachments should be included if appropriate. In each case, please tick to either confirm that you have included the relevant attachment, or confirm that it is not required for this application.

- A participant advert, i.e., any text (e.g., email) or document (e.g., poster) designed to recruit potential participants.

Included  or

Not required (because no participation adverts will be used)

- A general risk assessment form for research conducted off campus (see section 6).

Included  or

Not required (because the research takes place solely on campus or online)

- A country-specific risk assessment form for research conducted abroad (see section 6).

Included  or

Not required (because the researcher will be based solely in the UK)

- A Disclosure and Barring Service (DBS) certificate (see section 7).

Included  or

Not required (because the research does not involve children aged 16 or under or vulnerable adults)

- Ethical clearance or permission from an external organisation (see section 8).

Included  or

Not required (because no external organisations are involved in the research)

- Original and/or pre-existing questionnaire(s) and test(s) you intend to use.

Included  or

Not required (because you are not using pre-existing questionnaires or tests)



- Interview questions for qualitative studies.  
 Included  or  
 Not required (because you are not conducting qualitative interviews)
- Visual material(s) you intend showing participants.  
 Included  or  
 Not required (because you are not using any visual materials)

## 2. Your details

- 2.1 Your name: [REDACTED]
- 2.2 Your supervisor's name: [REDACTED]
- 2.3 Title of your programme: Professional Doctorate in Clinical Psychology
- 2.4 UEL assignment submission date (stating both the initial date and the resit date):  
 17<sup>th</sup> May 2021

## 3. Your research

*Please give as much detail as necessary for a reviewer to be able to fully understand the nature and details of your proposed research.*

- 3.1 The title of your study: Staff Perspectives of Working with Families of Children and Young People in Paediatric Residential Neurorehabilitation.
- 3.2 Your research question: What is it like for staff to work with families of CYP in a residential paediatric neurorehabilitation?

What are the enablers and barriers to this collaborative work?

- 3.3 Design of the research:

This study proposes to use to online focus groups and interviews with members of staff to learn from their experiences what enables and hinders the development of collaborative working relationships with families of children and young people in residential paediatric neurorehabilitation.

Initially focus groups will be set up. From these focus groups, participants will be invited to interview afterwards. Pragmatically, circumstances may require the

method to change to one to one interviews if recruitment is slow due to staff availability, time or reluctance to join focus groups.

### 3.4 Participants:

People who work with families of children and young people (CYP) at XXXXXXXX. This will include staff who within the residential accommodation as well staff who work the families who come in to provide nursing or therapies. It has been agreed with The XXXXXXXX, to focus recruitment on staff who work with families of CYP in two of their accommodation settings.

### 3.5 Recruitment:

It is proposed that an easy to read advertisement and information sheet be circulated by email to managers and staff as well as physically on staff notice boards to help recruit people to the study. As this provides a top down delivery of information about the study, the language used has to be careful, so that it is not delivered through a frame of co-ercion from a position of power. In addition, the study will be advertised in meetings and I will also be able to liaise with an undergraduate working at the site who will be able to help organise recruiting participants more directly if needed and arrange an appropriate location for video conferences to occur.

### 3.6 Measures, materials or equipment:

The study has been proposed for data collection between October and December 2020. Prior to this, consultations and approvals from stakeholders and ethical boards will need to be concluded. There will also need to be a strong relationship between myself and the proposed undergraduate student who I will be working with to recruit staff, this may require a structured approach to meetings and contact.

There is little requirement in terms of resources, as this study will rely on video conferencing software, Microsoft Teams which has permission of use within the service and the University of East London for confidentiality. The platform has the ability to record on it, this function may need to be enabled by the University.

I will also have a set of scheduled questions to facilitate and direct the focus groups and interviews. I would need to plan some pilots in order to test the technology, ensure my questions are relevant and also practice my role as a moderator; to help avoid common mistakes made in this role.

The possibility of a thank you gift to the service will also be considered, as an acknowledgement for the value of their input.

### 3.7 Data collection:

**Focus Groups:** Focus groups will be held using MS Teams and recorded, both on MS Teams and dictaphone. The discussion will be then transcribed to an MS Word document.

**1:1 Interviews:** Interviews will either be facilitated by MS Teams and recorded using that platform and a dictaphone, or over the phone, which will be just recorded by dictaphone. The discussion will be then transcribed to an MS Word document.

Personal data will be collected on consent forms. Data may also be created by email or phone contact as each participant will have my email address and my supervisor's email address and thus personal data could be found here. Phone calls will be logged with a summary of the contact information on an Excel document.

Once transcribed, recordings will be deleted.

### 3.8 Data analysis:

The method of analysis of the data will be dependent on the nature of the data collected.

It is proposed that an adapted IPA approach be used if the data is derived from focus groups. This method would promote an idiographic story from both individuals and the group, using a double coding approach where we can identify individuals contribution and perspectives within the group setting.

Should the data come from individual interviews then it may be that a reflexive thematic analysis would also be appropriate, allowing for an organic production of themes from individuals which could be brought into a group story.

## 4. Confidentiality and security

*It is vital that data are handled carefully, particularly the details about participants. For information in this area, please see the [UEL guidance on data protection](#), and also the [UK government guide to data protection regulations](#).*

### 4.1 Will participants data be gathered anonymously?

No.

If not (e.g., in qualitative interviews), what steps will you take to ensure their anonymity in the subsequent steps (e.g., data analysis and dissemination)?

Audio recordings will initially be recorded on a dictaphone and then transferred onto a password protected, secured online cloud hosted by the University of East London. This transferring will be done immediately after the data collection. The recording will be deleted from the dictaphone at this point. The dictaphone will be kept in a locked personal drawer. The recordings will then be deleted from the cloud once transcribed anonymously. The files will be stored as the pseudonym and the week of the observation process of the child or young person connected with that family.

Video recordings will be deleted once it is confirmed that the audio recording has been successful.

As to ensure an extra line of security, the list of pseudonyms will be kept in a password protected MS Excel file, kept on a password-protected, personal laptop only. Away from any of the other data storage.

#### 4.2 How will you ensure participants details will be kept confidential?

In addition to anonymising transcripts, deleting original recordings and separately storing pseudonym names. Written consent forms received by email will be printed digitally onto a PDF and uploaded onto the researcher's personal University of East London H: Drive, which is password protected. Copies in the email account will be deleted once uploaded.

Anonymised transcripts and analysis will be saved in separate folders on the University of East London OneDrive for Business. The anonymised data will also be backed up on a personal, encrypted, USB drive. The transcript file names will include the date of the recording and the initials of the pseudonyms.

External confidentiality is more in the control of the researcher, but due to the nature of focus groups, there is the issue of internal confidentiality between participants. Before the start of each focus group, we will prepare for the session by going over ground rules of expectations, this will be laid out in the information sheet and by the moderator at the beginning of the group.

#### 4.3 How will the data be securely stored?

I, the principal researcher will perform all transcriptions and once anonymised, only myself and my supervisor will have access to the full transcripts.

Audio recordings will initially be recorded on a dictaphone and then transferred onto a password protected, secured online cloud hosted by the University of East London. This transferring will be done immediately after the data collection. The recording will be deleted from the dictaphone at this point. The dictaphone will be kept in a locked personal drawer. The recordings will then be deleted from the cloud once transcribed anonymously. The files will be stored as the pseudonym and the week of the observation process of the child or young person connected with that family.

Video recordings will be deleted once it is confirmed that the audio recording has been successful.

#### 4.4 Who will have access to the data?

I will primarily have access to the data. My supervisor for this project will also have some access to the data, but only for the reason of collaborative working with myself.

#### 4.5 How long will data be retained for?

3 years

### 5. Informing participants

*Please confirm that your information letter includes the following details:*

5.1 Your research title:

5.2 Your research question:

5.3 The purpose of the research:

5.4 The exact nature of their participation. This includes location, duration, and the tasks etc. involved:

5.5 That participation is strictly voluntary:

5.6 What are the potential risks to taking part:

5.7 What are the potential advantages to taking part:

- 5.8 Their right to withdraw participation (i.e., to withdraw involvement at any point, no questions asked)
- 5.9 Their right to withdraw data (usually within a three-week window from the time of their participation)
- 5.10 How long their data will be retained for:
- 5.11 How their information will be kept confidential:
- 5.12 How their data will be securely stored:
- 5.13 What will happen to the results/analysis:
- 5.14 Your UEL contact details:
- 5.15 The UEL contact details of your supervisor:

*Please also confirm whether:*

- 5.16 Are you engaging in deception? If so, what will participants be told about the nature of the research, and how will you inform them about its real nature.
- 5.17 Will the data be gathered anonymously? If NO what steps will be taken to ensure confidentiality and protect the identity of participants?
- 5.18 Will participants be paid or reimbursed? If so, this must be in the form of redeemable vouchers, not cash. If yes, why is it necessary and how much will it be worth?

## **6. Risk Assessment**

*Please note: If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible. If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.*

- 6.1 Are there any potential physical or psychological risks to participants related to taking part? If so, what are these, and how can they be minimised?

The risks, in terms of physical harm will be minimal as the research will take place online. However providing a safe environment for participants who are at work will be required, this will be arranged with my liaison with the service. This means a comfortable room with appropriate seating where people will not be

disturbed will be required that is large enough for social distancing measures.

During the focus groups, there may be uncomfortable topics brought up as well as topics that could cause emotional distress such as embarrassment, shame, stigmatization, discrimination or anxiety of over-disclosure. A balance of moderation to assess the situation and the support in the room or if a view needs to be challenged or conversation moved on will be vital for this; the researcher will have time to practice moderating before the study begins to develop these skills. Breaks, pauses and stopping the interview and groups will be an absolute right. In addition, I will signpost participants to resources or organisations I know of to help with distress.

6.2 Are there any potential physical or psychological risks to you as a researcher? If so, what are these, and how can they be minimised?

There may be some uncomfortable moments in the course of the conversation in the focus group, for example: discussing upsetting experiences.

This will be minimised by practicing moderation skills prior to the study and using supervision. I also have my own support network if I need further support.

6.3 Have appropriate support services been identified in the debrief letter? If so, what are these, and why are they relevant?

Yes. For further support for any issues that may come up, the debrief will letter will advice participants to speak to their line managers, occupational health or the people Team (HR).

In addition, participants will be reminded that the Employee Assistance Programme at XXXXXX is a resource they can access. It is for all employees and provides a counselling service in relation to workplace stress.

6.4 Does the research take place outside the UEL campus? If so, where?

The research will take place online. Thus the participants will either be at their normal place of work in a private, comfortable room or at their home.

I will be performing interviews from my home.

If so, a 'general risk assessment form' must be completed. This is included below as appendix D. Note: if the research is on campus, or is online only (e.g., a Qualtrix survey), then a risk assessment form is not needed, and this appendix can be deleted. If a general risk assessment form is required for this research, please tick to confirm that this has been completed:

NA
----

6.5 Does the research take place outside the UK? If so, where?

No

If so, in addition to the ‘general risk assessment form’, a ‘country-specific risk assessment form’ must be also completed (available in the [Ethics folder in the Psychology Noticeboard](#)), and included as an appendix. [Please note: a country-specific risk assessment form is not needed if the research is online only (e.g., a Qualtrix survey), regardless of the location of the researcher or the participants.] If a ‘country-specific risk assessment form’ *is* needed, please tick to confirm that this has been included:

NA

However, please also note:

- For assistance in completing the risk assessment, please use the [AIG Travel Guard](#) website to ascertain risk levels. Click on ‘sign in’ and then ‘register here’ using policy # 0015865161. Please also consult the [Foreign Office travel advice website](#) for further guidance.
- For *on campus* students, once the ethics application has been approved by a reviewer, all risk assessments for research abroad must then be signed by the Head of School (who may escalate it up to the Vice Chancellor).
- For *distance learning* students conducting research abroad in the country where they currently reside, a risk assessment must be also carried out. To minimise risk, it is recommended that such students only conduct data collection on-line. If the project is deemed low risk, then it is not necessary for the risk assessments to be signed by the Head of School. However, if not deemed low risk, it must be signed by the Head of School (or potentially the Vice Chancellor).
- Undergraduate and M-level students are not explicitly prohibited from conducting research abroad. However, it is discouraged because of the inexperience of the students and the time constraints they have to complete their degree.

**7. Disclosure and Barring Service (DBS) certificates**

7.1 Does your research involve working with children (aged 16 or under) or vulnerable adults (\*see below for definition)?

NO

7.2 If so, you will need a current DBS certificate (i.e., not older than six months), and to include this as an appendix. Please tick to confirm that you have included this:

NA

Alternatively, if necessary for reasons of confidentiality, you may email a copy directly to the Chair of the School Research Ethics Committee. Please tick if you have done this instead:

NA



Also alternatively, if you have an Enhanced DBS clearance (one you pay a monthly fee to maintain) then the number of your Enhanced DBS clearance will suffice. Please tick if you have included this instead:

NA

7.3 If participants are under 16, you need 2 separate information letters, consent form, and debrief form (one for the participant, and one for their parent/guardian). Please tick to confirm that you have included these:

NA

7.4 If participants are under 16, their information letters consent form, and debrief form need to be written in age-appropriate language. Please tick to confirm that you have done this

NA

\* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, and people who have been involved in the criminal justice system, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children [click here](#).

## 8. Other permissions

9. Is HRA approval (through IRAS) for research involving the NHS required? Note: HRA/IRAS approval is required for research that involves patients or Service Users of the NHS, their relatives or carers as well as those in receipt of services provided under contract to the NHS.

NO

- You DO NOT need to apply to the School of Psychology for ethical clearance if ethical approval is sought via HRA/IRAS (please see [further details here](#)).
- However, the school *strongly discourages* BSc and MSc/MA students from designing research that requires HRA approval for research involving the NHS, as this can be a very demanding and lengthy process.
- If you work for an NHS Trust and plan to recruit colleagues from the Trust, permission from an appropriate manager at the Trust must be sought, and HRA approval will probably be needed (and hence is likewise strongly discouraged). If the manager happens to not require HRA approval, their written letter of approval must be included as an appendix.

- IRAS approval is not required for NHS staff even if they are recruited via the NHS (UEL ethical approval is acceptable). However, an application will still need to be submitted to the HRA in order to obtain R&D approval. This is in addition to a separate approval via the R&D department of the NHS Trust involved in the research.
- IRAS approval is not required for research involving NHS employees when data collection will take place off NHS premises, and when NHS employees are not recruited directly through NHS lines of communication. This means that NHS staff can participate in research without HRA approval when a student recruits via their own social or professional networks or through a professional body like the BPS, for example.

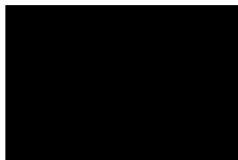
9.1 Will the research involve NHS employees who will not be directly recruited through the NHS, and where data from NHS employees will not be collected on NHS premises?

NO – The research will involve recruiting members of staff of a charity, directly through the charity, that is commissioned for work by the NHS.

9.2 If you work for an NHS Trust and plan to recruit colleagues from the Trust, will permission from an appropriate member of staff at the Trust be sought, and will HRA be sought, and a copy of this permission (e.g., an email from the Trust) attached to this application?

NA

9.3 Does the research involve other organisations (e.g. a school, charity, workplace, local authority, care home etc.)? If so, please give their details here.



Furthermore, written permission is needed from such organisations if they are helping you with recruitment and/or data collection, if you are collecting data on their premises, or if you are using any material owned by the institution/organisation. If that is the case, please tick here  confirm that you have included this written permission as an appendix:

In addition, before the research commences, once your ethics application has been approved, please ensure that you provide the organisation with a copy of the final, approved ethics application. Please then prepare a version of the consent form for the organisation themselves to sign. You can adapt it by replacing words such as

'my' or 'I' with 'our organisation,' or with the title of the organisation. This organisational consent form must be signed before the research can commence.

Finally, please note that even if the organisation has their own ethics committee and review process, a School of Psychology SREC application and approval is still required. Ethics approval from SREC can be gained before approval from another research ethics committee is obtained. However, recruitment and data collection are NOT to commence until your research has been approved by the School and other ethics committee/s as may be necessary.

## 9. Declarations

Declaration by student: I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.

Student's name (typed name acts as a signature):

██████████

Student's number:

██████████

Date: 21 Sept 2020

*As a supervisor, by submitting this application, I confirm that I have reviewed all parts of this application, and I consider it of sufficient quality for submission to the SREC committee.*

## APPENDIX 3: Notice of Ethical Approval

### School of Psychology Research Ethics Committee

## NOTICE OF ETHICS REVIEW DECISION

**For research involving human participants**  
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational  
Psychology

**REVIEWER:** Lucia Berdondini

**SUPERVISOR:** Jenny Jim

**STUDENT:** Benjamin John Peters

**Course:** Professional Doctorate in Clinical Psychology

**Title of proposed study:** Staff Perspectives of Working with Families of Children and Young People in Paediatric Residential Neurorehabilitation

### DECISION OPTIONS:

1. **APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.
2. **APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.
3. **NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

### DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

*(Please indicate the decision according to one of the 3 options above)*

APPROVED

**Minor amendments required (for reviewer):**

**Major amendments required (for reviewer):**

**Confirmation of making the above minor amendments (for students):**

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (*Typed name to act as signature*):

Student number:

Date:

*(Please submit a copy of this decision letter to your supervisor with this box completed, if minor amendments to your ethics application are required)*

**ASSESSMENT OF RISK TO RESEARCHER (for reviewer)**

Has an adequate risk assessment been offered in the application form?

YES / NO

**Please request resubmission with an adequate risk assessment**

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

HIGH

**Please do not approve a high risk application and refer to the Chair of Ethics. Travel to countries/provinces/areas deemed to be high risk should not be permitted and an application not approved on this basis. If unsure please refer to the Chair of Ethics.**

**MEDIUM (Please approve but with appropriate recommendations)**



LOW X

**Reviewer comments in relation to researcher risk (if any).**

**Reviewer** (*Typed name to act as signature*): Lucia Berdondini

**Date:** 26/10/20

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee*

**RESEARCHER PLEASE NOTE:**

For the researcher and participants involved in the above named study to be covered by UEL's Insurance, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

For a copy of UELs Personal Accident & Travel Insurance Policy, please see the Ethics Folder in the Psychology Noticeboard

**APPENDIX 4: Application to Organisation for Research Approval**

**An Outline Proposal for Research at**

[Redacted]

To:

[Redacted]

Date: 24<sup>th</sup> August 2020

Chief Investigator:

[Redacted]

<b>Title of Research Project</b>
Staff Perspectives of Working with Families of Children and Young People in Paediatric Residential Neurorehabilitation.
<b>What is the principal research question?</b>
What is it like for staff to work with families of children and young people (CYP) in a residential paediatric neurorehabilitation?  With a secondary question of asking: What are the enablers and barriers to this collaborative work?
<b>Please explain how your study aligns to our strategic objectives</b>
The Organisation only endorses research projects that support the Research strategy (please see link [Redacted])
This research will help with a number of research objectives that [Redacted] is working towards.
1) Knowing more about staff perspectives of the collaborative working relationship with families of CYP during rehabilitation could allow for a further

development of effective clinical care for children and young people with brain injury and neurodisability.

2) This research could help bring further description to what the active ingredients in rehabilitation are, from the perspective of how staff feel they are able to work successfully with families and what hinders this.

3) This research could provide a platform for further research, having itself has been inspired by Nordic research; allowing for a new voice in the research field about health capital (Guldager et al., 2018, 2019a, 2019b)

4) In line with the University of East London's ethos, there is an ethical duty to disseminate the findings of the research and thus in alignment with the THE ORGANISATION's goal of disseminating findings.

5) This research may have further alignments to the THE ORGANISATION research strategy and goals as it may also highlight the impact of resources and structures that THE ORGANISATION has already developed.

6) It will also allow the possibility of a partnership with the University of East London.

### **Plain English summary (for sharing on THE ORGANISATION website)**

#### **Aim**

A few sentences about what you hope to achieve

The aim of this research is to find out the experiences and perspectives of staff members to see what could be seen as barriers or enablers to working collaboratively with families in a paediatric residential neurorehabilitation setting.

We hope this will bring forward potentially unheard voices in the field of neurorehabilitation which could be used to effect change.

#### **Research outline**

A few sentences about the research and how it will be carried out

This study proposes to use to focus groups and interviews with members of staff to learn from their experiences what enables and hinders the development of collaborative working relationships with families of CYP in residential paediatric neurorehabilitation.



This study will be performed remotely, using video conferencing software (MS Teams) or the phone. Initially online focus groups will be set up. From these focus groups, participants will be invited to interview afterwards if participants would like to elaborate or discuss further points that were felt not possible during the focus group.

Pragmatically, circumstances may require the method to change to one to one interviews if recruitment is slow due to staff availability or reluctance to join focus groups.

#### Outcome or update

What you hope to achieve, what will the research findings be used for and when will it be completed?

I am hoping to be able to have some data about staff experiences of working with families of CYP in a paediatric residential neurorehabilitation service.

The study will be for a thesis project and the final write up will be due for submission in May 2021 at the University of East London. It will be confirmed as of required quality in August 2021 when a viva will be undertaken.

The findings may also be disseminated in future publications, such as literary manuscripts, conference abstracts or presentations. My assumption is this will be negotiated with The Organisation.

#### Investigators

Names of those involved – this could also include their qualifications

[Redacted]

#### Why are you doing it?

(summarise literature findings and why your study fills a gap)

Paediatric Neurorehabilitation services are encouraged to develop a collaborative process with families / carers during their work with CYP. This collaboration is encouraged throughout the rehabilitation process, including psychoeducation, comprehensive assessment, developing goals and negotiating discharge as well as facilitating service user contributions via consultation (NHS England, 2013; Royal College of Paediatrics and Child Health, 2017). This move towards empowering families to work collaboratively with services has been a relatively new shift, taking place over the past two decades (Braga et

al., 2005; Laatsch et al., 2007). This is contrast to a traditional, more compartmentalised approach, where health professionals took a lead in treating and working with the children to improve functional outcomes, whilst parents and carers support integration back into life (Braga, 2009).

The collaborative approach comes from two main drivers; that it makes economic sense, reducing the need for professional intervention, and that it is more effective (Fisher et al., 2019). Integrating the family into neurorehabilitation efforts with children has shown to have cognitive and functional benefits for CYP and reduces the burden that families feel in preparing for changes in their caring roles (Braga et al., 2005; Lawler, Taylor, & Shields, 2013; Lawrence & Kinn, 2013; Novak & Honan, 2019).

Research has highlighted many areas of need for families who have a child with an ABI and often these are unmet; this includes needs for information and emotional and practical support throughout the care pathway and discharge into the community (Bray, 2015; Keetley et al., 2019; Piccenna et al., 2016; Wales et al., 2020). There is also a recognition that needs are not static and change as families adapt to different developmental ages of the CYP, their family and the effect the ABI may have (Lawrence & Kinn, 2013).

Taking this in mind, families have to make many logistical and psychological adjustments in order to participate in care, making accessing services a variable experience (Foster et al., 2012; Olin et al., 2010). There have been some recent studies in Nordic countries about families' experience of participation in rehabilitation. These studies posit that there is a 'cultural health capital' or even more acutely, a 'rehabilitation capital' which can help determine why some families can navigate and get more benefit from neurorehabilitation services (Bourdieu, 1986; Guldager et al., 2018; Shim, 2010). It's suggested that higher rehabilitation capital is curated by larger, concrete, cohesive families that have wider access to supportive networks and potential for time building relationships with professionals (Bystrup & Hindhede, 2019). Additional to this capital, it is also posited that family emotional and strategical responses to a family member acquiring a brain injury and their expectations of rehabilitation can impact collaborative success with professionals (Guldager et al., 2019a; Kelly et al., 2019).

It has also been reported that perhaps health professional's lack of training, understanding, attitude, time or acknowledgement of family member's contribution as an expert resource can also create barriers to family involvement (Guldager et al., 2019b). There have been attempts to support services and practitioners with family collaboration in neurorehabilitation services, with publications on service frameworks and pathways (Brewer et al., 2014; Fisher et al., 2019, 2020; Foster et al., 2012).

So far in my literature search, there is little information of the experience of building working relationships with families in this context.

It is hoped this study could give an insight into the day to day of what staff experience as a 'high rehabilitation capital' or optimal family response in the UK and what creates barriers to this. The conversation could also allow for reflective discussions around the impact of varying levels of systemic difference, such as split-families, being from an ethnic minority, speaking a different language, hegemonic norms or recent immigration; both in navigating the service pathway and making relationships between staff and families (Bystrup & Hindhede, 2019).

This study could help provide a new voice that appears to missing in the field and could be used to develop support or structural changes in the neurorehabilitation services to help attend to inequalities in care. (Keetley et al., 2019)

<b>Will the above differ from normal practice? If so, how?</b>
There will be no difference to normal practice. The discussions may ask participants for up to 90 minutes of their time during a working day but will be discussions around their normal practice with families of CYP.
<b>What are you measuring/recording?</b>
I will be recording conversations in both online focus groups and interviews.
<b>Will children be recruited?</b> If yes, how many? List exclusion and inclusion criteria
No
<b>How will you analyse the data?</b>
My initial thought is to use an adapted interpretative phenomenological analysis (IPA) approach, similar to (Palmer et al., 2010). This approach holds to account that I want to develop an analysis of the data that promotes an idiographic story from both individuals and the group; using a double coding approach where I can identify individuals contribution and perspectives within the group setting.  This approach will be reviewed with the pragmatics of the research method.
<b>What do you hope/expect to demonstrate?</b> (a single sentence – where a specific hypothesis is being tested, please give the hypothesis)
It is hoped that this study could help provide a new voice that appears to missing in the field and could be used to develop support or structural changes in the neurorehabilitation services to help attend to inequalities in care.
<b>Who will benefit and how?</b>

The Organisation will benefit by having more knowledge and information about the working relationships that staff develop with families of the CYP the organisation care for. This could be used to further research or help make changes or resources that encourage aspects that enable better working relationships and change aspects that hinder them. This research could also help attend the inequalities in care.

The respective fields of professionals that are involved in the care and interventions with the additional knowledge that will be brought up in the field.

In turn, it is hoped that the information developed will ultimately help future children and families entering rehabilitation programmes, either receive more effective, informed treatment and feel able to engage with the resources the service is able to offer more fully, or offer staff an awareness of how the working relationships with families work in order to best position them to collaborate as best as they can given certain barriers.

I will also benefit from this research, as it will contribute to the Professional Doctorate in Clinical Psychology that I currently studying at the University of East London

#### **What are the risks?**

The risks, in terms of physical harm will be minimal as communication with mostly be online or via the phone. It is hoped I will have a liaison at The Organisation (an undergraduate student) who I will be able to communicate with to ensure a safe environment is provided for participants I am talking to over the video call.

During the focus groups, there may be uncomfortable topics brought up as well as topics that could cause emotional distress such as embarrassment, shame, stigmatisation, discrimination or anxiety of over-disclosure. A balance of moderation to assess the situation and the support in the room or if a view needs to be challenged or conversation moved on will be vital for this; the researcher will have time to practice moderating before the study to begin to develop these skills. Breaks, pauses and stopping the interview and groups will be an absolute right. In addition, I will signpost participants to any resources or organisations I know of to help with distress.

Transcription and field notes will only be written by me, the principle researcher as to protect confidentiality of participants by anonymisation. In addition, details of participants will be as broad as possible to reduce deductive identification or disclosure.

External confidentiality is more in the control of the researcher, and will be facilitated for by anonymisation once transcribed and original recordings being deleted. However, due to the nature of focus groups, there is the issue of internal confidentiality between participants. Before the start of each focus group, we will prepare for the session by going over ground rules of expectations, this will be laid out in the information sheet and by the moderator at the beginning of the group.

<b>Is ethical approval necessary?</b> if yes give expected submission date if no please state why	
Yes, the study will be applying for ethical approval from the University of East London and will be submitted either late August, or early September 2020.	
<b>Start date and expected duration of the project?</b>	
Date: The start date, depending on ethical approval feedback, is hoped for September 2020, with recruitment and data collection until November 2020.	Duration: 6 – 9 Months
The write up is to be done between January 2021 – May 2021.	

Who else will collaborate?
<p>Myself and my supervisor, xxxxxxxxxxxxxxxx have been grateful for being able to discuss potential research ideas with colleagues from The Organisation.</p> <p>We are also hoping to collaborate with xxxxxxxxxxxxxx and a potential undergraduate student to help make this project as smooth as possible with joining with other professionals and staff members.</p>
Where will it be done
Online
What other resources will be required (e.g. clerical support/statistical advice)
Support in organising focus groups – possibly via undergraduate student on placement.
Date presented to research committee
w/c 24 <sup>th</sup> August 2020

#### 19. Declaration

I, the chief investigator, am taking responsibility for this project and undertake to adhere to ethical and data protection requirements. I understand that the progress of my research will be monitored monthly by the Research Committee

Signature(s) 

**N.B Please note that**

- You can determine if ethical approval is needed by considering this document: <http://www.hra-decisiontools.org.uk/ethics/>.
- Where a study involves prescriptions of drugs, there are particular questions of insurance and confidentiality to be answered. In such cases please take appropriate advice.
- Where ethical approval is required, allow for 2 months for approval and note that the study cannot start until approval has been obtained
- Any amendment to the protocol must be declared to the THE ORGANISATION Research Group and, if appropriate, to the REC
- You will find useful documentation in the Research folder on the Y: drive
- The researchers will be happy to help if you are unsure of some answers

Integrated Research Application System (IRAS) website: <https://www.myresearchproject.org.uk/>

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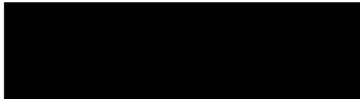


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## APPENDIX 5: Research Approval from Organisation



16 September 2020



Dear



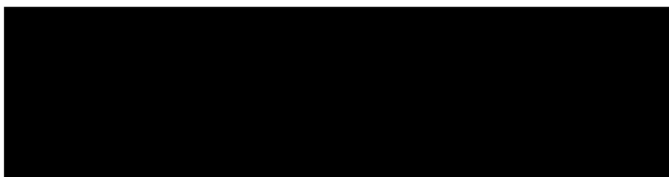
**Staff Perspectives of Working with Families of Children and Young People in Paediatric Residential Neurorehabilitation (0060)**

Thank you so much for sending through your revised research proposal. The research group has reviewed it and is supportive of your project. There were some comments to feedback and perhaps we can discuss them at a future meeting with you. In particular my colleague who has recently conducted qualitative research asked if you had sufficient experience in your supervision team as this method can be particularly challenging.

Otherwise you should proceed to obtaining the appropriate level of ethical approval. Please provide us with a copy of your application and approval letter and then we will support your recruitment.

We would like to encourage you to provide feedback to the staff group at and we would strongly encourage you to publish the results.

Best wishes



## APPENDIX 6: Initial Email After Participant Contact of Interest

Re: Working with families research project

Thu 14/01/2021 09:13

📎 1 attachments (23 KB)

availability Calendar January.docx;

Dear

It's so great to hear from you and thank you for your interest in the study.

A few first steps are detailed below:

### Study Details and Consent:

- I will send you a separate email which has a bit more information about the study and how to consent to participate.

### Arranging the Conversation:

- I know setting up a time can be difficult, so I have attached over a rough guide to my availability over January, if it's helpful to plan.
- Also, have a think if you would prefer a conversation over the phone or through Microsoft Teams. If you need any help getting a private space or access to a phone or ipad, just let me know.

I look forward to hearing from you! And again, many thanks for getting in touch

All the best

## APPENDIX 7: Email with Information Sheet and Consent Process

### Research Project: Information Sheet and Consent

Tue 12/01/2021 20:01

1 attachments (24 KB)

Information Sheet - Interview.docx;

Dear

Please find attached an information sheet about the study 'Staff Perspectives of Working with Families of Children and Young People in a Residential Paediatric Neurorehabilitation Service'.

The sheet explains in further detail how the information will be used and confidentiality, if you have any questions, please feel free to email or call me.

If you are happy to participate, please read the paragraphs below and **reply to this email** stating that you give your consent to participate in the study.

- I have read the information sheet relating to the above research study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.
- I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researchers involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.
- I hereby freely and fully consent to participate in the study which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data after analysis of the data has begun.

Kind Regards,



## **STAFF PERSPECTIVES OF WORKING WITH FAMILIES OF CHILDREN AND YOUNG PEOPLE IN A RESIDENTIAL**

### **PARTICIPANT INVITATION LETTER**

#### **What is it like working with families of children and young people in a paediatric residential neurorehabilitation service?**

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

#### **Who am I?**

My name is [REDACTED] and I am a trainee clinical psychologist studying at the University of East London for a professional doctorate in clinical psychology. As part of my studies I am conducting the research you are being invited to participate in.

#### **What is the research?**

Collaboration between health professionals and children and young people (CYP) who have an acquired brain injury (ABI) and their families is an integral part of paediatric residential neurorehabilitation services.

I am conducting research into staff experiences about what it is like to work with families in this setting and what might be barriers or enablers to this collaboration. It is thought that research in this area could help support staff or develop different ways of working.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.

### **Why have you been asked to participate?**

You have been invited to join this because you are currently working within a residential paediatric neurorehabilitation service. It is voluntary if you would like to take part.

### **What will your participation involve?**

If you agree to participate you will be asked to participate in a one to one conversation with me either online or over the phone; according to your preference. Online conversations will use Microsoft Teams. I will endeavour to make the date and time of these conversations convenient, but will be between November 2020 and January 2021.

The conversation will be informal and centre around what it's like to work with families in a neurorehabilitation setting, exploring your experiences and thoughts.

### **What are the possible benefits of taking part?**

The research will hopefully an honest representation of what works and what does not work for you in building working relationships with children, young people and families. It could also give a clear picture of any stresses or strains that develop in this area of work, so that support can be designed with these in mind; this could be direct staff support or thinking about changes in the systems that exist in the workplace.

### **What are the possible disadvantages of taking part?**

The conversation will develop around what you feel is important to you in relation to working collaboratively with families. This may mean that there may be some subject matters that arise that are uncomfortable to discuss. Conversations will be managed actively by myself to ensure that you feel safe and comfortable. Should you want to pause or stop, that is totally fine. Given that we will reflect on what helps and hinders collaborative working it is possible that this might bring up some negative emotions, I will use my skills to manage these times so as to minimise distress.

I will also follow up each conversation with a debrief to check if the conversation brought up anything you would like more support on.

### **Your taking part will be safe and confidential**

Your privacy and safety will be respected at all times.

All conversations from this research will be anonymised, this includes the service name, staff names, family / carer names and children and young people's names.

All digital data (recordings and transcriptions) will be stored on a password protected, secure cloud hosted by the University of East London and deleted once anonymously transcribed. Only myself and my supervisor will have access to this data.

Anonymised transcripts will be kept on the secure cloud for a maximum of 3 years and then deleted.

The transcripts will be analysed as part of the study and this analysis will be published in a thesis and potentially in a journal article and presentation; only segments of the transcription will be published and anonymously.

N.B. If you share any information that is potentially a child safeguarding issue then I may have to share that information with another professional.

### **What if you want to withdraw?**

You are free to withdraw from the study at any time without giving a reason.

The conversation will be transcribed and analysed. Should you want to withdraw all or some elements of the conversation, you can request this. Please note that this will only be possible up to 3 weeks after the interview, before the data has been analysed.

### **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

[REDACTED]

If you have any questions or concerns about how the research has been conducted please contact the research supervisor: [REDACTED]

[REDACTED]

**or**

Chair of the School of Psychology Research Ethics Sub-committee: [REDACTED]

[REDACTED]



## **STAFF PERSPECTIVES OF WORKING WITH FAMILIES OF CHILDREN AND YOUNG PEOPLE IN A RESIDENTIAL**

### **PARTICIPANT INVITATION LETTER**

#### **What is it like working with families of children and young people in a paediatric residential neurorehabilitation service?**

You are being invited to participate in a research study. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

#### **Who am I?**

My name is [REDACTED] I am a trainee clinical psychologist studying at the University of East London for a professional doctorate in clinical psychology. As part of my studies I am conducting the research you are being invited to participate in.

#### **What is the research?**

Collaboration between health professionals and children and young people (CYP) who have an acquired brain injury (ABI) and their families is an integral part of paediatric residential neurorehabilitation services.

I am conducting research into staff experiences about what it is like to work with families in this setting and what might be barriers or enablers to this collaboration. It is thought that research in this area could help support staff or develop different ways of working.

My research has been approved by the School of Psychology Research Ethics Committee. This means that the Committee's evaluation of this ethics application has been guided by the standards of research ethics set by the British Psychological Society.



### **Why have you been asked to participate?**

You have been invited to join this because you are currently working within a residential paediatric neurorehabilitation service. It is voluntary if you would like to take part.

### **What will your participation involve?**

If you agree to participate you will be asked to participate in either an online focus group / joint interview or a one to one conversation, either online or over the phone; according to your preference. Online conversations will use Microsoft Teams. I will endeavour to make the date and time of these conversations convenient, but will be between November 2020 and January 2021.

Joint interviews will be constructed with no more than three of your colleagues and take no longer than 90 minutes. The conversation will be informal and centre around what it's like to work with families in a neurorehabilitation setting, exploring your experiences and thoughts. After the conversation, there is an opportunity to have a follow up conversation, one to one, should you want to add further thoughts to those raised.

If you agree to participate in a one to one conversation, you will have a conversation with me either online or over the phone; according to your preference. Online conversations will use Microsoft Teams. I will endeavour to make the date and time of these conversations convenient, but will be between November 2020 and January 2021. The conversation will be informal and centre around what it's like to work with families in a neurorehabilitation setting, exploring your experiences and thoughts.

### **What are the possible benefits of taking part?**

The research will hopefully an honest representation of what works and what does not work for you in building working relationships with children, young people and families. It could also give a clear picture of any stresses or strains that develop in this area of work, so that support can be designed with these in mind; this could be direct staff support or thinking about changes in the systems that exist in the workplace.

It also provides a chance to benefit from shared ideas of positive practice with peers to take forward in own practice etc.

### **What are the possible disadvantages of taking part?**

The conversation will develop around what you feel is important to you in relation to working collaboratively with families. This may mean that there may be some subject matters that arise that are uncomfortable to discuss. Prior to the conversation starting, we will spend some time, as a group, preparing and laying some ground rules to help keep it

as comfortable as possible and to agree confidentiality measures between us and what we'd like to do if someone would like to or needs to leave.

There may be issues that you don't feel able to talk about; follow up conversations could be arranged, one to one, if you would like to add further information that is important to you.

Conversations in both joint and one to one interviews will be managed actively by myself to ensure that everyone feels safe and comfortable. Should you want to pause or stop, that is totally fine. Given that we will reflect on what helps and hinders collaborative working it is possible that this might bring up some negative emotions, I will use my skills to manage these times so as to minimise distress.

I will also follow up each conversation with a debrief and provide support if the conversation brought up anything you would like more support on.

### **Your taking part will be safe and confidential**

Your privacy and safety will be respected at all times.

All conversations from this research will be anonymised, this includes the service name, staff names, family / carer names and children and young people's names.

During the conversation briefing, we will discuss the boundaries of confidentiality within the group and how anonymity will be ensured with the data, as a collective.

All digital data (recordings and transcriptions) will be stored on a password protected, secure cloud hosted by the University of East London and deleted once anonymously transcribed. Only myself and my supervisor will have access to this data.

Anonymised transcripts will be kept in the secure cloud for a maximum of 3 years and then deleted.

The transcripts will be analysed as part of the study and this analysis will be published in a thesis and potentially in a journal article, only segments of the transcription will be published and anonymously.

N.B. If you share any information that is potentially a child safeguarding issue then I may have to share that information with another professional.

### **What if you want to withdraw?**

You are free to withdraw from the study at any time without giving a reason.

It can be difficult to withdraw from an ongoing conversation in a group; during our briefing at the beginning, we will discuss how participants can leave the group if they like to or need to due to unforeseen circumstances.

The conversation will be transcribed and analysed. Should you want to withdraw from the group, we can discuss whether you are still happy for your data to be used or not. This can be discussed within 3 weeks of the conversation, before the analysis begins.

With one to one interviews, you can request all your data to be withdrawn up to 3 weeks after the interview.

### **Contact Details**

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

[REDACTED]

If you have any questions or concerns about how the research has been conducted please contact the research supervisor: [REDACTED]


[REDACTED]


**or**


Chair of the School of Psychology Research Ethics Sub-committee: [REDACTED]

[REDACTED]



## APPENDIX 8: Example Participant Interview Invites

 Phone Conversation [REDACTED]


 [REDACTED]

 Calendar

---

 Remind me: Never 

---

 Dear [REDACTED]

Thank you for agreeing to participate in the study 'Staff Perspectives of Working with Families of Children and Young People in a Residential Paediatric Neurorehabilitation Service'.

This calendar invite contains the date and time we have agreed to have a conversation.

Below are just some questions for your reference, if you have any further questions, please feel free to contact me.

All the best

[REDACTED]

**What should I expect?**

Thank you for providing your phone number. I will call you at the agreed time using the phone number 07708510906.

For recording purposes, I will have my phone on speaker during the main part of the call as to allow recording using a dictaphone.

The conversation will last no more than an hour.

**What if the phone cuts out?**

If you drop out of the call, I will call you back.

**What if I need to re-arrange?**

Please just feel free to suggest an amend time via this invite or give me a separate email or call and we can re-arrange.

● Conversation [REDACTED]



[REDACTED]



Calendar



Remind me: Never ▾



Dear [REDACTED]

Thank you for agreeing to participate in the study 'Staff Perspectives of Working with Families of Children and Young People in a Residential Paediatric Neurorehabilitation Service'.

This calendar invite contains the date, time and Microsoft Teams link for our agreed time to have a conversation.

Below are just some questions for your reference, if you have any further questions, please feel free to contact me.

All the best

[REDACTED]

**What should I expect?**

When you enter the link, you will go into a Teams video call and will be met by myself. I will be in the room a few minutes before the meeting as to welcome you.

The conversation will last no more than an hour and will be recorded using the Teams recording option as well as a separate audio device as a back-up.

**What if I have internet connection issues?**

If you drop out of the call you may try and re-enter. Please feel free to email me or call me if this does not work and we can try and resolve any issues together.

**What if I need to re-arrange?**

Please just feel free to suggest an amend time via this invite or give me a separate email or call and we can re-arrange

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## Microsoft Teams meeting

**Join on your computer or mobile app**

[Click here to join the meeting](#)



**University of  
East London**

For assistance on joining and information on supported clients click the 'Help' link above

[Learn More](#) | [Help](#) | [Meeting options](#) | [Legal](#)

## APPENDIX 9: Data Management Plan

### UEL Data Management Plan: Full

Completed plans **must** be sent to [researchdata@uel.ac.uk](mailto:researchdata@uel.ac.uk) for review

*If you are bidding for funding from an external body, complete the Data Management Plan required by the funder (if specified).*

Research data is defined as information or material captured or created during the course of research, and which underpins, tests, or validates the content of the final research output. The nature of it can vary greatly according to discipline. It is often empirical or statistical, but also includes material such as drafts, prototypes, and multimedia objects that underpin creative or 'non-traditional' outputs. Research data is often digital, but includes a wide range of paper-based and other physical objects.

<b>Administrative Data</b>	
PI/Researcher	[REDACTED]
PI/Researcher ID (e.g. ORCID)	[REDACTED]
PI/Researcher email	[REDACTED]
Research Title	<b>STAFF PERSPECTIVES OF WORKING WITH FAMILIES OF CHILDREN AND YOUNG PEOPLE IN PAEDIATRIC RESIDENTIAL NEUROREHABILITATION</b>
Project ID	
Research Duration	To be completed and written up by May 2021. Data collection likely to begin Sept 2020 and completed by December 2020.

Research Description	<p>This study proposes to use to focus groups and interviews with members of staff to learn from their experiences what enables and hinders the development of collaborative working relationships with families of children and young people in residential paediatric neurorehabilitation.</p> <p>Initially focus groups will be set up. From these focus groups, participants will be invited to interview afterwards. Pragmatically, circumstances may require the method to change to one to one interviews if recruitment is slow due to staff availability or reluctance to join focus groups.</p>
Funder	N/A – part of professional doctorate at University of East London
Grant Reference Number (Post-award)	N/A
Date of first version (of DMP)	15 <sup>th</sup> June 2020
Date of last update (of DMP)	24 <sup>th</sup> September 2020 updated with change of data collection methodology due to Covid-19 v.2
Related Policies	<a href="#">Research Data Management Policy</a>
Does this research follow on from previous research? If so, provide details	No, although inspired by previous research, there will be no data used from previous research

<b>Data Collection</b>	
<p>What data will you collect or create?</p>	<p>Focus Groups: Focus groups will held using MS Teams and recorded on this online platform. In addition, as a backup the conversation will be recorded on a Dictaphone. The discussion will be then transcribed to an MS Word document.</p> <p>1:1 Interviews: Similarly, interviews will be facilitated by MS Teams and recorded using that platform and Dictaphone as a backup. There is also an option to have interviews over the phone, which will be recorded by Dictaphone alone. Conversations will be then transcribed to an MS Word document.</p> <p>Personal data will be collected on consent forms. Data may also be created by email or phone contact as each participant will have my email address and my supervisors email address and thus personal data could be found here. Phone calls will be logged with a summary of the contact information on an Excel document.</p> <p>Each participant will be given a pseudonym for anonymisation. Pseudonyms will be chosen by participants in private conversations. A password protected excel sheet will have the list of participants and their pseudonyms. Only first names of the participants will be on this list.</p>
<p>How will the data be collected or created?</p>	<p>1:1 Interviews: Interviews will either be facilitated by MS Teams and recorded using that platform and a Dictaphone as backup, or over the phone, which will be recorded by a Dictaphone alone.</p> <p>Conversations from focus groups or interviews will be transcribed into an MS word document.</p> <p>Once transcribed the original recording will be deleted.</p>
<b>Documentation and Metadata</b>	
<p>What documentation and metadata will accompany the data?</p>	<p>Documents accompanying the data will include consent forms and information sheets for the agreement to participate in the study for parents/guardians, children and young people.</p> <p>Metadata for logging the information will include:</p>



	<p>Focus Groups:</p> <p>Date Participants (Anonymised with a pseudonym) The coding process for analysis</p> <p>Interviews:</p> <p>Date Participants (Anonymised with a pseudonym) The coding process for analysis</p> <p>Although the focus groups will have an emergent framework, which will lead onto questions for the interview: a current guideline of the kind of questions asked include:</p> <p><b>Briefing (for focus groups):</b></p> <p>Consideration of ground rules</p> <p><b>Part 1:</b></p> <p>Who is in the room? Experience and demographics of staff present (perhaps via short survey before the work).</p> <p><b>Part 2:</b></p> <p>What's your opinion on the importance of staff-family relationship in outcomes for CYP?</p> <ul style="list-style-type: none"> <li>- What does a good staff – family relationship look like?</li> <li>- Experience of building relationships</li> <li>-</li> </ul> <p>Thinking about your roles in xxxx, What is it like making relationships with families in that context? (different levels to consider - trauma, emotional impact, weight of expectation etc)</p> <ul style="list-style-type: none"> <li>- What do you have to do to help build those relationships? (given trauma, emotion, logistics)</li> <li>- Do you find yourself doing more for some families to build that relationship more than others? Why?</li> </ul> <p>Who in the family do you tend to make relationships with? Why do you think that is?</p> <ul style="list-style-type: none"> <li>- Is this due to their availability?</li> <li>- Do you feel more comfortable with them?</li> </ul>
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	<p>Can you think of a time when staff-family relationships have made a very positive impact?</p> <ul style="list-style-type: none"> <li>- What facilitated this? (different levels to consider - e.g. personal connection, team factors, service factors etc)</li> </ul> <p>Can you think of a time when the staff-family relationship wasn't what you had hoped it be?</p> <ul style="list-style-type: none"> <li>- What made the relationship difficult?</li> <li>- Did you feel it impacted the outcome of treatment?</li> </ul> <p>Are there any other aspects of making relationships with families that I didn't ask about or that want to share</p> <p>Anything to re-visit now or in individual follow-up...</p>
<p><b>Ethics and Intellectual Property</b></p>	
<p>How will you manage any ethical issues?</p>	<p>I will provide information sheets and debrief letters for participants</p> <p>I will seek written consent from participants by email and also require verbal consent prior the beginning of each conversation.</p> <p>I will advise participants of their right to withdraw from the study and I will be taking an active role in checking in on continued consent as the study is active.</p> <p>If a participant would like to withdraw from the study completely, they will have the right to withdraw data from the study, however if they have already contributed to the focus group, data withdrawal is more difficult as their contribution to the focus group is in synergy with that of others. In this case the data prior to analysis is not revocable but a conversation on the elements of the conversation that are of concern can be had and themes no added to the report.</p> <p>The risks, in terms of physical harm will be minimal; although it is with communication with my liaison at the service that a safe environment is provided for participants I am talking to over the video call. For example a room that is private and allows social distancing.</p> <p>During the focus groups, there may be uncomfortable topics brought up as well as topics that could cause emotional distress</p>

	<p>such as embarrassment, shame, stigmatization, discrimination or anxiety of over-disclosure. A balance of moderation to assess the situation and the support in the room or if a view needs to be challenged or conversation moved on will be vital for this; the researcher will have time to practice moderating before the study begins to develop these skills. Breaks, pauses and stopping the interview and groups will be an absolute right. In addition, I will signpost them to any resources or organisations I know of to help with distress.</p> <p>Transcription and field notes will only be written by me, the principle researcher as to protect confidentiality of participants by anonymisation. In addition, details of participants will be as broad as possible to reduce deductive identification or disclosure.</p> <p>External confidentiality is more in the control of the researcher, but due to the nature of focus groups, there is the issue of internal confidentiality between participants. Before the start of each focus group, we will prepare for the session by going over ground rules of expectations, this will be laid out in the information sheet and by the moderator at the beginning of the group.</p>
<p>How will you manage copyright and Intellectual Property Rights issues?</p>	<p>N/A</p>
<p><b>Storage and Backup</b></p>	
<p>How will the data be stored and backed up during the research?</p>	<p>Audio recordings will be recorded on a Dictaphone and then transferred onto a password protected, secured online cloud hosted by the University of East London: UEL's OneDrive for Business and encrypted. It will then be deleted once transcribed anonymously. The folder these will be stored in will be password protected.</p> <p>Video recordings: will be automatically saved on Microsoft Stream, part of the password protected, secured online cloud hosted by the University of East London. It will then be deleted once transcribed anonymously.</p> <p>Written consent forms received by email will be printed digitally onto a PDF and uploaded onto separate password</p>

	<p>protected folders on the secured online cloud hosted by the University of East London: UEL's OneDrive for Business. Copies in the email account will be deleted once uploaded and local copies of the PDF print will also be deleted.</p> <p>Anonymised transcripts and analysis will be saved in separate, password protected, folders on the University of East London OneDrive for Business. The anonymised data will also be backed up on a personal, encrypted, USB drive. Each participant will be given a pseudonym.</p> <p>As to ensure an extra line of security, the list of pseudonyms will be kept in a password protected MS Excel file, kept on a password-protected, personal laptop only. Away from any of the other data storage.</p> <p>Anonymised data may be analysed using NViVo or MS Excel</p>
<p>How will you manage access and security?</p>	<p>I, the principal researcher will perform all transcriptions and once anonymised, only myself and my supervisor will have access to the full transcripts.</p> <p>Audio recordings which will initially be recorded on a dictaphone and then transferred onto a password protected, secured online cloud hosted by the University of East London. This transferring will be done immediately after the data collection. The recording will be deleted from the dictaphone at this point. The dictaphone will be kept in a locked personal drawer. The recordings will then deleted from the cloud once transcribed anonymously.</p> <p>Video recordings will be automatically saved on Microsoft Stream, part of secured online cloud hosted by the University of East London. It will then be deleted once transcribed anonymously.</p>
<p><b>Data Sharing</b></p>	
<p>How will you share the data?</p>	<p>Anonymised transcripts may be shared with the research supervisor via UEL email for analysis support.</p> <p>The initial analysis of the research will be shared with individuals who took part in the process to have their input to what I came up with. This will only be possible if all participants in each group consented to this.</p> <p>Extracts of transcripts and field notes will be quoted in the final report of the research and possibly subsequent publications.</p>

	<p>These will not include identifiable information. The full transcripts will not be put in the final report appendix. The final report will be publicly available via the UEL open access publication site ROAR. The full raw data will not be deposited in a data repository, that will only be shared between the principle researcher and supervisor.</p>
<p>Are any restrictions on data sharing required?</p>	<p>Full raw data will not be shared beyond the research team.</p>
<p><b>Selection and Preservation</b></p>	
<p>Which data are of long-term value and should be retained, shared, and/or preserved?</p>	<p>This data could be used as a platform for further research and development in the area, thus it could be useful to have elements of the research available for further analysis.</p> <p>The anonymised transcripts, field notes and analysis will be kept for a maximum of 3 years after the thesis has been examined and passed. This is to provide opportunity for publication and re-examination of the text. No-one else, other than principle researcher and supervisor will have access to the raw transcripts or observation data.</p> <p>The list of pseudonyms will be deleted once the thesis has been written up.</p> <p>As I will have left UEL before the end of the three years, the data on the UEL OneDrive for Business will be deleted before I leave and the backup data on the encrypted USB stick will be the only source of data left.</p>
<p>What is the long-term preservation plan for the data?</p>	<p>After the 3 year period, the raw data will be deleted completely, leaving only the analysis data that is included in the final written thesis report and any subsequent peer-reviewed publication.</p> <p>As I will have left UEL before the end of the three years, the data on the UEL OneDrive for Business will be deleted before I</p>

	leave and the backup data on the encrypted USB stick will be the only source of data left.
<b>Responsibilities and Resources</b>	
Who will be responsible for data management?	I will, the principle researcher.
What resources will you require to deliver your plan?	Dictaphone, double verification files on One Drive, UEL secure online service, MS Excel, MS Word, NVivo.  Access to arranging meetings on MS Teams.
<b>Review</b>	
	<b>Please send your plan to <a href="mailto:researchdata@uel.ac.uk">researchdata@uel.ac.uk</a></b>  <b>We will review within 5 working days and request further information or amendments as required before signing</b>
Date: 24/09/2020	Reviewer name: <span style="background-color: black; color: black;">[REDACTED]</span> Research Data Management Officer

## Guidance

Brief information to help answer each section is below. Aim to be specific and concise.

For assistance in writing your data management plan, or with research data management more generally, please contact: [researchdata@uel.ac.uk](mailto:researchdata@uel.ac.uk)

## **Administrative Data**

### **Related Policies**

List any other relevant funder, institutional, departmental or group policies on data management, data sharing and data security. Some of the information you give in the remainder of the DMP will be determined by the content of other policies. If so, point/link to them here.

### **Data collection**

Describe the data aspects of your research, how you will capture/generate them, the file formats you are using and why. Mention your reasons for choosing particular data standards and approaches. Note the likely volume of data to be created.

### **Documentation and Metadata**

What metadata will be created to describe the data? Consider what other documentation is needed to enable reuse. This may include information on the methodology used to collect the data, analytical and procedural information, definitions of variables, the format and file type of the data and software used to collect and/or process the data. How will this be captured and recorded?

### **Ethics and Intellectual Property**

Detail any ethical and privacy issues, including the consent of participants. Explain the copyright/IPR and whether there are any data licensing issues – either for data you are reusing, or your data which you will make available to others.

### **Storage and Backup**

Give a rough idea of data volume. Say where and on what media you will store data, and how they will be backed-up. Mention security measures to protect data which are sensitive or valuable. Who will have access to the data during the project and how will this be controlled?

### **Data Sharing**

Note who would be interested in your data, and describe how you will make them available (with any restrictions). Detail any reasons not to share, as well as embargo periods or if you want time to exploit your data for publishing.

### **Selection and Preservation**

Consider what data are worth selecting for long-term access and preservation. Say where you intend to deposit the data, such as in UEL's data repository ([data.uel.ac.uk](http://data.uel.ac.uk)) or a subject repository. How long should data be retained?

## APPENDIX 10: Example Debrief Email and Letter

A thank you, a debrief and a voucher

Mon 14/12/2020 16:35

3 attachments (118 KB)

Amazon Voucher 1.pdf; Participant Voucher Claim Form 2020-21 (1).docx; Study Debrief Letter.docx;

Dear

Thank you for participating in the study 'Staff Perspectives of Working with Families of Children and Young People in a Residential Paediatric Neurorehabilitation Service'.

Please find attached:

- A £5 amazon voucher as a thank you
- A Voucher Claim Form
- A study debrief letter which contains some information about the study and some contact details if there are any questions or if you would like to reach out about anything we spoke about.

If you could please confirm receipt of the voucher by filling in and returning the voucher claim form, that would be very helpful for my bookkeeping for the project.

Again, many thanks for your help and support of the project.

All the best



## STAFF PERSPECTIVES OF WORKING WITH FAMILIES OF CHILDREN AND YOUNG PEOPLE IN A RESIDENTIAL

### **PARTICIPANT DEBRIEF LETTER**

Thank you for participating in this study. This letter offers information that may be relevant in light of you having now taken part.

#### **What will happen to the information that you have provided?**

All digital data (recordings and transcriptions) will be stored on a password protected, secure cloud hosted by the University of East London and deleted once anonymously transcribed. This is to ensure the confidentiality and integrity of the data you have provided.

Anonymised transcripts will be kept in the secure cloud for a maximum of 3 years and then deleted. Transcripts will be analysed and written up in a report for a doctoral thesis at the University of East London.

██████████ kept up to date about the conclusions of the study but there will be no identifiable information attached to the contributions from yourself or other participants. Anonymised information from the project may be published in a professional journal and presented at a conference to share knowledge with others who have an interest in acquired brain injury.

#### **What if you have been adversely affected by taking part?**

It is possible that your participation – or its after-effects – may have been challenging, distressing or uncomfortable in some way. If you have been affected, you may find the following resources/services helpful in relation to obtaining information and support:

Speaking to your line manager, occupational health or the people team (HR).

The Employee Assistance Programme at ██████████. This is a resource that all employees can access and provides a counselling service in relation to workplace stress.

In addition, there are public services that can be of help for mental wellbeing such as the Samaritans, or local NHS services which your GP can advise you about local resources.

You are also very welcome to contact me or my supervisor if you have specific questions or concerns.

**Contact Details**



If you have any questions or concerns about how the research has been conducted please contact the research supervisor:



Chair of the School of Psychology Research Ethics Sub-committee:



## APPENDIX 11: Example from Research Log

The screenshot shows an Excel spreadsheet titled "Log of Events and Ideas - Excel". The ribbon is set to "Home". The spreadsheet contains the following data:

	A	B	C	D	E
60	18-Dec-20	Interviews	One more interview		
61	07-Jan-21	Submission	Submitted draft Methods section. This methods section was still open to the idea that focus groups could be used, although unlikely. Thus it was quite long Had research meeting with supervisor. Discussed the need to pick up the recruitment drive. Agreed to do another round of emails.  Discussed the interviews that have been so far. Discussed ways in which I could perhaps contain difficult subject matters whilst also being containing and open. 'Can you tell me a bit more about that?', 'What do you think would help support you in those moments', 'What helped / did not help during those times?'.  Also discussed some elements to think about for biopsychosocial formulations: SPECS presentations were then sent to me to mull over. Good for thinking about the construction of introduction		
62	08-Jan-21	Supervision	Also discussed some elements to think about for biopsychosocial formulations: SPECS presentations were then sent to me to mull over. Good for thinking about the construction of introduction		
63	08-Jan-21	Interviews	2 more interviews		
64	13-Jan-21	Interviews	1 more interview		
65	15-Jan-21	Interviews	2 more interviews  Morgan et al 1997 was used to think about whether the conversation I was having with 2 people would be classed as a joint interview or a focus group. Identified that I could class it as a focus group as it held together 3 requirements from Morgan : 1) , it clearly states that focus groups are a research method devoted to data collection. 2), it locates the interaction in a group discussion as the source of the data. 3)It acknowledges the researcher's active role in creating the group discussion for data collection purposes. Also holds true to that frey and Fontana defining group interviews are something other than focus groups if they: (i) are conducted in informal settings; (ii) use nondirective interviewing; or (iii) use unstructured question formats.  I am reticent to use the term joint interview as there is not much information around this type of interview for guidance and seems to focus on an joint event, where the participants will be talking about ideas and experiences that may not be joint in experience and therefore will not be constructing a fixed idea on one thing <a href="https://sru.soc.surrey.ac.uk/SRU15.html">https://sru.soc.surrey.ac.uk/SRU15.html</a> Arskye 1996  However, perhaps focus groups is so well defined throughout literature that it will describe a specific process and it will very much depend also how I am analysing the data.		
66	18-Jan-21	Reading	To discuss in supervision		
67	19-Jan-21	Interviews	1 more interview		
68	21-Jan-21	Interviews	1 more interview		
69	21-Jan-21	Submission	Methods section returned: Main key points -		
70	25-Jan-21	Submission	Introduction section sent to Jenny		

## APPENDIX 12: List of Initial Codes

Theme	Code
1	Interacting with the family; formally and informally
2	Working with family is integral, particularly for more severe injury or counterintuitive measures
3	Working differently with different members
4	Timing of a conversation and intervention
5	Time to explain things to parents
6	Balancing the different pressures of the role and what families need at a given time
7	Trusting intuition, body language for timing and need of a conversations
8	No formal training in navigating positioning and timing of conversations and picking up needs of families
9	Expectations from family
10	Collaborative knowledges – how to co-create to focus on safe care, so many new members of staff (Role of education)
11	Hearing the family
12	Expectations /intentions from the team
13	Tapering expectations for preparation of life beyond the service
14	Personality of families
15	Personality marriage between staff and family
16	Misunderstandings / one bad conversation as a barrier; awareness of avoidance
17	Honest feedback is a good sign (Being questioned / being shown dissatisfaction)
18	Family being receptive to ideas
19	Respect from staff – who earns this or not?
20	Formality of relationship
21	Space, time and acknowledgement to build relationship
22	Where the family are at dictates how you work
23	Flexibility of communication
24	Going through medical language
25	Take in mind confidentiality when speaking in open spaces
26	Changing accent to help communication
27	Perception of your profession
28	Preparation for a relationship on referral
29	Difference between staff intention and what was received
30	Experiences leading up to admission have an impact on expectations
31	Previous experience leading up to will impact family confidence
32	Extra things families are managing: becoming a care coordinator, family splits, basic needs not met
33	Single point of contact
34	MDT sharing of information and joint working
35	Parent speaking about staff behind backs
36	Personality that works well together to build relationship
37	Parents sharing or not sharing can dictate work
38	Language barriers
39	Interpreters going well, continual relationship
40	Being curious about culture is important – understanding rehab goals
41	Experiences of racism affect relationship
42	Sometimes you can't build a good relationship with young children
43	Becoming a middle person between family conflicts
44	Culture in expectation of how much involved in rehabilitation
45	Difficulties navigating expectations: team, family and child
46	Navigating parents wanting to do as much as possible
47	Understanding the different knowledges informing expectations
48	Ruptures and repairs with staff and families
49	Being honest from where you are coming from

50	1 <sup>st</sup> impressions are important; setting up the relationship
51	Physical environment of rehab centre
52	Language: non definitive, dual planning
53	Scaling back
54	Family availability is a key factor in relationship building: mums more available than dads?
55	Not being around and change in roles for HCPs
56	Empathy as a core skill to help positioning
57	Being prepped
58	Importance of debrief and reflective practice / supervision
59	Showing extra time, care and responsiveness
60	Families coping and support of each could impact interactions with staff
61	Enabling fun is important
62	Parents different way of coping
63	Families creating network of support within the service
64	Noticing where family are at
65	How you care and work with child can impact the relationship
66	Factors that affecting time to explain things properly
67	Families responsive / engaging on coming to rehab
68	Seeing positive change can positively affect relationship. Going beyond where thought it would go
69	Focus on the child to keep professional resilience
70	Acknowledging and controlling your emotions is important
71	Suggestions to help team joining; so many new people
72	Bringing energy when beginning work with families
73	Bringing elements of yourself into the room
74	Adapting approach to not burst the bubble of hope but still being honest
75	Always leave room for doubt
76	Managing not knowing why a parent acts in a way that affects you
77	Power in making judgements with parenting - safeguarding
78	Curiosity with histories
79	Challenges in covid
80	Noticing and praising strengths in the family helps build rapport
81	Gradually supporting rehabilitation engagement through exposure
82	Making sure you allow permission for families to challenge and engage
83	Goal setting as a good icebreaker for relationship and understanding family
84	Using humour culture of family as a joining process (language ability of YP)
85	Affecting outcomes if not able to connect with parent
86	Ensuring the basic information has come across; not assuming it has
87	Delivery of information rather than content: Who does it where?
88	Keeping a professional boundary whilst being empathetic
89	Prioritising what you are going to work on with a family
90	Short time frame supports difficult conversations
91	Short time frame is a pressure to provide interventions
92	Family reactions are not personal to you
93	Ensuring you address when the work does hit you personally
94	Managing safeguarding concerns whilst trying to maintain relationship
95	Supporting MH of a parent
96	Frustration when nothing is being done
97	Being someone comfortable to talk to
98	Being at service: like being under spotlight
99	Doing what you said you would
100	Being clear and definitive about your role and what your able to do
101	Supporting parents to take respite and making that okay to meet their own needs
102	Using your own strengths and character as a practitioner and being flexible with it
103	Considering siblings
104	Wanting to make people louder and advocate for themselves more

105	Seeking out families on the house can be good or invasive
106	Preparation for large meetings
107	Coping strategies getting in the way of collaborative working: Threatening legal action. protection
108	Nursing team – trying to keep family in mind around duties on child focus
109	Nursing contact with families dictate ability to build relationship and understand what families need
110	Nursing being a profession that doesn't need as much rapport form parents
111	Rapport with grandparents
112	Good rapport with dads
113	Continuity of nursing care is good
114	Being attuned to family's needs
115	Non-judgemental to outburst of emotion
116	Managing different roles of the team and goals as a nurse: Sometimes a go between of HCPs and family
117	Noticing things that show a lack of trust or perhaps the lack of control
118	Interventions are a small moment in time
119	Bringing older children into decision making
120	Professional Boundary of what is helpful and not; signposting
121	Gradual readiness for life after admission
122	Using relationship with family as a bridge to external HCP relationships
123	Making sure people understand your role helps relationship
124	Encouraging absent parent to be involved
125	Focus on child to help navigate difficult conversations
126	Being in conversations that people are avoiding
127	Different social graces
128	Different Social grace being used (or not) as a joining aspect
129	Accepting what the family want to do
130	Safeguarding actions that affect family makeups with parents not together
131	Supporting young people who want independence to go home
132	Changing in roles again for families, supporting that comes with practice
133	Joining with people's language
134	Balancing needs and wants of children with family in difficult system; including capacity
135	An opportunity to have a good relationship with professionals after discharge
136	Professionals naming difficulties
137	Societal expectations of profession
138	Meetings not effortful is good sign
139	Good previous experience allows a good relationship and easier for HCP
140	Gender roles impacting how people engage with HCP
141	Families' ability with technology
142	Meeting family before online calls
143	Funding priorities are for children, not families
144	Comparison with other CYP and families
145	Reduced contact in pandemic
146	Where interactions happen
147	Keeping the relational link live in the pandemic
148	How this service acted in pandemic compared to others was positive for relationships
149	Everything should be documented
150	I need to show confidence in my role to build relationship
151	I need to be myself and warm to build relationship
152	Families have to feel heard
153	Need resilience and confidence in own practice to manage difficult situations
154	Guarded parents harder to work with
155	Always giving your best
156	Easier to build relationship with family members with reciprocal acceptance of roles
157	Role of psychology
158	Role of nursing

159	Part time workers
160	Relationship is key in lubricating process for discharge (e.g., with schools)
161	Relationship with parents is key for relationship with YP
162	Reciprocal respect is important
163	Age of child will affect how much you work with family
164	Learning family relationship; getting to know them
165	Initial assessments and checks helps to ground information
166	Being key worker helps in building relationship
167	Endings are difficult; no idea what happens next
168	The need for managers and authority to come in
169	More regular chats between team to help keeping informed of knowledge around family; focus is on children in handovers
170	Need courage to speak up that having difficulty
171	Brain injury education
172	Type of injury impacts readiness

## APPENDIX 13: Example of Codes and Quotes

5	Time to explain things to parents	<p>And it's really important to spend that time, giving the explanations around why you're doing a particular thing. Otherwise, it's not going to be done. P3: 80</p> <p>Yeah, and my availability to and me making that time. Actually, scheduling it in and insuring that it happens. P3: 152</p>
6	Balancing the different pressures of the role and what families need at a given time	<p>And like having a conversation where the parent goes 'I don't know why you're asking me these questions?' or like 'I can't think about that at the moment because I'm not there' like yeah. Sort of like 'stop talking to me about this'. Or the parent just being incredibly stressed by, understandably, very stressful things and not really knowing how to negotiate that and how do you sort of move forward with what needs to happen in terms of discharge planning or. You know, my role, whatever I'm working on with them like balancing that P2: 251</p>
7	Trusting intuition, body language for timing and need of a conversations	<p>I basically had planned to have this conversation and had thought about like how to make it constructive and positive and hopefully, you know, a good conversation and I actually at the start of the session with the parent clocked that she wasn't really in the right space for ...She basically said. Um, 'just get on with it like I don't really care.,' like. Not very engaging but also not shutting it down. So I guess my judgment was saying leave this for another time but then, because the parents said just get on with it I was like, 'OK, well we'll try it'. And it, yeah, it basically was just: a really challenging conversation. And I ended up kind of, I guess I also then got a bit flustered by that, and then was trying to like pad around the conversation rather than being direct and I think we kind of got somewhere in the conversation, but then also just parked it and I was like m revisit that another day. P2: 265</p> <p>I think the fact that I managed to pick up, probably from the family and how they presented, I could just tell that they were really defensive of their son, rightly so. And they've clearly been through the mill and had to defend him a lot. And I just, just really endeavoured to actually make sure that my communication approach and style with them was just as open, just as honest and to make them understand that we weren't focused on his behaviour, were focusing on his brain injury and we understood how that related to how we may present with his behaviour, but that actually were here to get them the support that they needed as a family, that obviously including the child I think once I won her over made her realize that I wasn't judging them. It was plain sailing there an absolute joy to work with. P6: 430</p>



8	No formal training in navigating positioning and timing of conversations and picking up needs of families	<p>I can't recall any particular training, just like a kind of reading the person. And how they, you know, if they come into the room and like it's like your body language, like if they come in and like slumped down in the chair and like 'Sigh' and reading all of those nonverbal cue. P2: 298</p> <p>There was a counselling element and also in my first job did some like more counselling style training- And then. Yeah, it's kind of being developed throughout experience as well, but yeah, I've always been that it is just part of the role. Very lucky here as well to have a psychology team. So it's much easier to go and get support around how to approach these conversations and what to do with bits of information that you might have been told. P3: 187</p> <p>I guess I just sensed that's what they needed, don't think there was any there was no more, sort of, in it other than I knew that they wanted to be engaged, but I could totally see that they weren't able to and therefore I thought, 'well, I'll just keep you up to date, I'll send you an if. And I knew they'd appreciate photos, so I just used to print off some photos, put them an envelope with a little note, leave them on his board, and then you to collect that there. P5: 121</p> <p>[in dealing with emotive moments] – I'm so used to it, and I used to work in the hospital setting where the emotions, if anything were actually more heightened. Um, so in some ways it's actually easier here for me, but it's just time and experience. I genuinely... I'm not convinced anyone can teach it. I think it's just what, what comes. Um... with time and experience and an obviously to some people more slightly more naturally than others. P6: 340</p>
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## APPENDIX 14: Example of Grouping Codes to Initial Themes

Analysis EXCEL - Excel

Ben Peters

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Key

	A	B	C	D
	No.	Code	Potential Themes	Sub - themes / Belong in other themes
2	1	Interacting with the family: Formally and informally	Positioning / Organisation	Flexibility where you meet the family
3	1			
4	2	Working with family is integral, particularly for more severe injury or counterintuitive measures; Law; For each of the different roles	Work needs and focus	Working with families integral for work
5	2			
6	3	Working differently with different members	Work needs and focus	Working with families integral for work
7	3			
8	4	Timing of a conversation; When to talk w / child there; With regards to thinking when best to have what conversation; Timing of intervention	Positioning	When and how to hold a conversation
9	4			
10	5	Time to explain things to parents	Empathic planning and responding to family needs	To plan time to have conversations
11	5			
12	6	Balancing the different pressures of the role and what families need at a given time	Positioning	Working out what a parent needs at that moment
13	6			
14	7	Trusting intuition, body language for timing and need of a conversations	Positioning	Using intuition and experience to work out where family are at and manage situations
15	7			
16	8	No formal training in navigating positioning and timing of conversations and picking up needs of families	Positioning	Using intuition and experience to work out where family are at and manage situations
17	8			Is supported implicitly in organisation - but explicit training would helpful
18	10	Collaborative knowledges - how to co-create; Focus on safe care; Co-therpists; Can help facilitate joining when so many new members of staff; What model of collaboration are staff implicitly saying?; Role of education	Work needs and focus	Collaborative working helps enable useful strategies from joining knowledges.
19	10		Joining	Collaborative working helps ensure safe practice for discharge - for family independence
20	10			Collaborative working - helps with assessing more in full and relevant goals
21	11	Hearing the family	Positioning	Collaborative working - seeing the families knowledge helps joining relationship
22	11		Joining	Collaborative working allows an easier joining to introduce staff expertise
23	12	Expectations / intentions from the team: Independence, holistic needs, honesty, hope, becoming care co-ordinator		Collaborative working - seeing the families knowledge helps joining relationship
24	12		Work needs and focus	Belief in promoting independence and care co-ordinator development in parents as awareness of the real world res outside organisation - concern in being set up to fail
25	13	Tapering expectations for preparation of life beyond the service		Honesty from the family about their thoughts on the rehab
26	13		Work needs and focus	Belief in promoting independence and care co-ordinator development in parents as awareness of the real world res outside organisation - concern in being set up to fail

Sheet1 Sheet2 Sheet4

Analysis EXCEL - Excel

Ben Peters

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Wrap Text

General

Conditional Formatting Format as Table Cell Styles

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N11

	A	B	C	D	E
1	No.	Theme	Sub themes		
2	17	Communication	If families are able to ask for their needs, it's an indicator their job is going well - helps position and rehab		
3	22	Communication	Flexibility in communicating for families not ready can be very helpful - emails - gradual exposure		
4	23	Communication	Flexibility in communication style - not the news - it's how it's delivered - how this is different when advocating		
5	26	Communication	Ensuring you are understood - accent		
6	45	Communication	Scaling back		
7	52	Communication	Dual Planning; tentative prognosis language - managing expectations whilst working		
8	56	Communication	Showing care and empathy is way you communicate - important - GP example / where family at / being honest and balanced		
9	87	Communication	Showing care and empathy is way you communicate - important - GP example / where family at / being honest and balanced		
10	34	Communication	ensure consistency and not repetitive		
11	49	Communication	Being open and honest from where you are coming from and hearing where the family are coming from.		
12	28	Communication	Getting co-ordinated to parents style of communication for positioning - facts		
13	53	Communication (Therapy goal setting)	Scaling Back; Solution Focused - managing expectations whilst working		
14	24	Communication / Positioning	happens		
15	29	Communication / Positioning	Ensure you are active listening - intentions aren't enough, what is perceived is important		
16	22	family needs	Managing dual planning of what staff feel may be needed and realistic timelines (ordering equipment) and fam not ready		
17	5	family needs	To plan time to have conversations		
18	21	Empathic planning and responding to family needs	Space to allow people to express emotion / catch up		
19	114	family needs / Organisation / Joining	Continuity of care supports a rel'ship and ensures smooth knowledge base to continue care - not disrupted		
20	169	Empathic planning and responding to family needs / Organisation / Joining	Being key worker with continuity of care supports a rel'ship and ensures smooth knowledge base to continue care - not disrupted		
21	106	Empathic planning and responding to family needs / Positioning	Preparation for large meetings with families can help them prepare for them and ensure that what they want gets adressed		
		Empathic planning and responding to			

Sheet1 Sheet2 Sheet4

70%

Analysis EXCEL - Excel

Ben Peters

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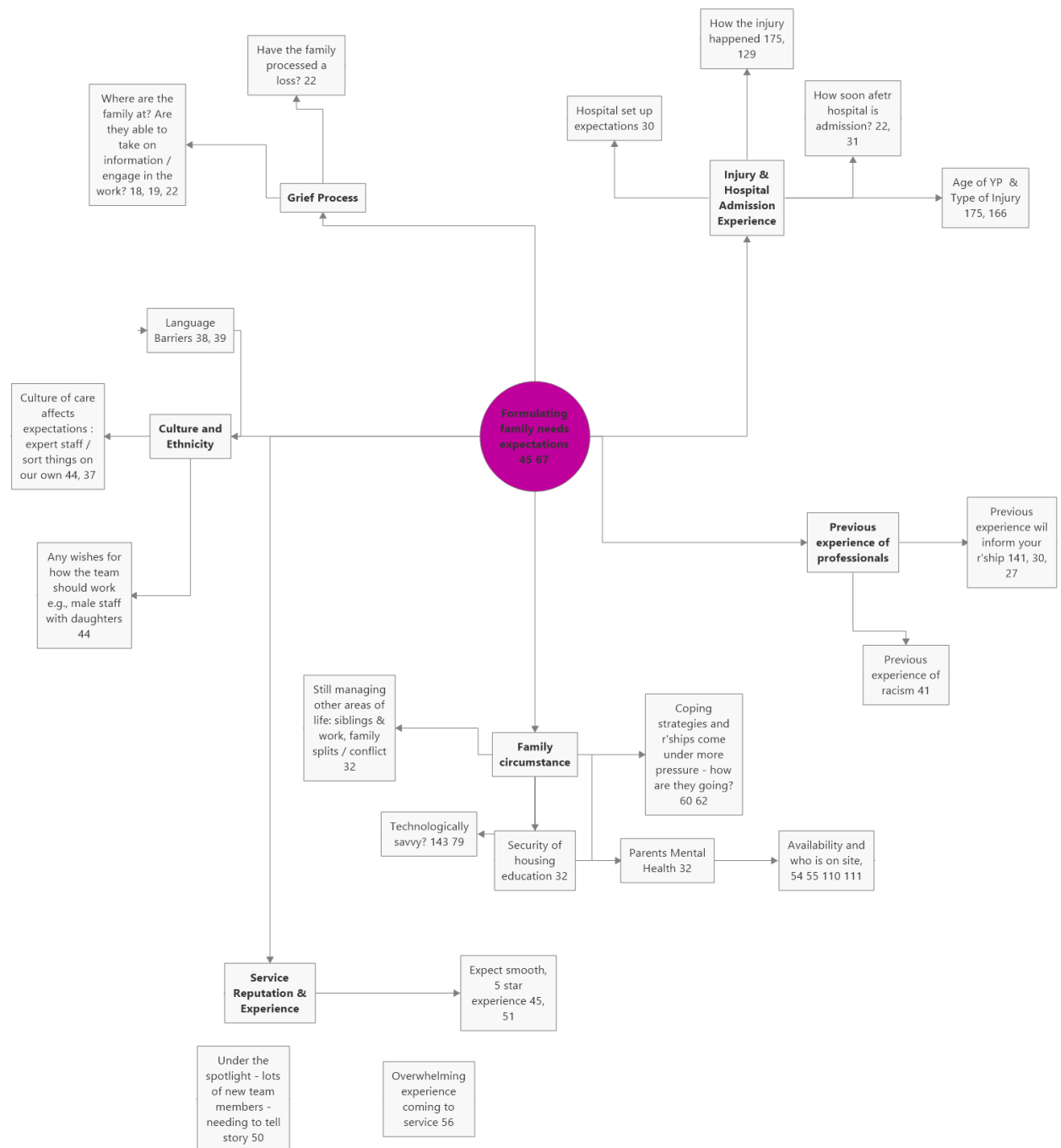
AD1

	A	B	C	D	E	F	G	H
1	<b>Draft Themes</b>	<b>Can be included together in another theme</b>						
2	Communication		1					
3	Communication (Therapy goal setting)		1					
4	Communication / MDT considerations / Personal Impact		1					
5	Communication / Positioning		1					
6	Dads		2					
7	Empathic planning and responding to family needs		3					
8	Empathic planning and responding to family needs / Joining		3					
9	Empathic planning and responding to family needs / Organisation		3					
10	Empathic planning and responding to family needs / Organisation / Joining		3					
11	Empathic planning and responding to family needs / Positioning		3					
12	Expectations		4					
13	Family Circumstance and Coping		5					
14	Family Circumstance and Coping / Organisation		5					
15	Family Circumstance and Coping / Communication		5					
16	Gender		6					

Sheet1 Sheet2 **Sheet4**

100%

## APPENDIX 15: Example of Mapping Themes and Subthemes



1. **Formulating family needs expectations 45 67** ..... **Error! Bookmark not defined.**
2. **Grief Process**..... **Error! Bookmark not defined.**
3. **Injury & Hospital Admission Experience**..... **Error! Bookmark not defined.**
4. **Previous experience of professionals** ..... **Error! Bookmark not defined.**
5. **Family circumstance** ..... **Error! Bookmark not defined.**
6. **Culture and Ethnicity**..... **Error! Bookmark not defined.**
7. **Service Reputation & Experience**..... **Error! Bookmark not defined.**
8. **How the injury happened 175, 129** ..... **Error! Bookmark not defined.**

9. Age of YP & Type of Injury 175, 166..... **Error! Bookmark not defined.**
10. Hospital set up expectations 30..... **Error! Bookmark not defined.**
11. Culture of care affects expectations : expert staff / sort things on our own 44, 37  
**Error! Bookmark not defined.**
12. Expect smooth, 5 star experience 45, 51..... **Error! Bookmark not defined.**
13. Have the family processed a loss? 22 ..... **Error! Bookmark not defined.**
14. Where are the family at? Are they able to take on information / engage in the work? 18, 19, 22..... **Error! Bookmark not defined.**
15. Coping strategies and r'ships come under more pressure - how are they going? 60 62 **Error! Bookmark not defined.**
16. Previous experience wil inform your r'ship 141, 30, 27 ..... **Error! Bookmark not defined.**
17. How soon afetr hospital is admission? 22, 31..... **Error! Bookmark not defined.**
18. Still managing other areas of life: siblings & work, family splits / conflict 32 ... **Error! Bookmark not defined.**
19. Security of housing education 32..... **Error! Bookmark not defined.**
20. Parents Mental Health 32 ..... **Error! Bookmark not defined.**
21. Previous experience of racism 41 ..... **Error! Bookmark not defined.**
22. Any wishes for how the team should work e.g., male staff with daughters 44. **Error! Bookmark not defined.**
23. Availability and who is on site, 54 55 110 111 ..... **Error! Bookmark not defined.**
24. Technologically savvy? 143 79..... **Error! Bookmark not defined.**
25. Language Barriers 38, 39..... **Error! Bookmark not defined.**
26. Under the spotlight - lots of new team members - needing to tell story 50 .... **Error! Bookmark not defined.**
27. Overwhelming experience coming to service 56..... **Error! Bookmark not defined.**