Returning to Mainstream School Following an Acquired Brain Injury: Two Case Studies with Multiple Perspectives on the Barriers and Facilitators to a Sense of School Belonging

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A thesis submitted for the degree of Professional Doctorate in Child, Community and Educational Psychology

Tavistock and Portman NHS Trust
University of Essex
September 2023

Abstract

Existing research emphasises the importance of a sense of school belonging (SoSB) for children's social emotional mental health. Given the importance of a SoSB for typically developing children, it is likely to also contribute to the successful reintegration of children returning to school after an acquired brain injury (ABI). Yet, there is currently a paucity of research in this area. Moreover, despite a recognised need to take a systemic approach when supporting children, research that has focused on the school reintegration process following paediatric ABI has typically only elicited the views of either children, their parents or educational professionals. The current research aimed to address these gaps by using a multiple case study design to explore children's perceptions of factors affecting their SoSB when returning to mainstream school after an ABI, and how these relate to the perceptions of key adults in the systems around them. Semi-structured interviews elicited the views of two 6-year-old children, who sustained an ABI in reception, their parent/s and key school staff. Reflexive Thematic Analysis conducted both across and within cases identified a range of themes including the importance of fitting into the school community, home-school collaboration and ongoing support beyond the reintegration period. Findings showed many of the perceived barriers and facilitators to be highly nuanced and case specific, highlighting the need for schools to take an individualised approach when fostering a SoSB for children with ABI. Findings further emphasised the need for schools to assess the demands being placed on parents during the transition process to support familial adjustment and ensure collaborative working. Implications for both policy and practice are discussed in light of these results. The researcher also proposes a 'framework for thinking' tool for professionals to utilise to foster a SoSB for children with ABI in mainstream schools.

Acknowledgements and Dedication

There are several important people that I need to acknowledge:

> Firstly, the hugest thank you to those that took part in this research, especially both children and their parents. It was a true privilege to listen to your life stories, and I hope that together we will make meaningful and positive change for children with ABI in the future.
>
> Thank you to my research supervisor, Richard Lewis, for his support throughout this journey which at times felt impossible. NHS ethics was no mean feat, and whilst others may have discouraged, you understood the importance of the voice of the child and supported me each step of the way.
>
> Thank you to my placement supervisor, Mark Coates, for going above and beyond to help me. Thank you for taking the time to check in with my thesis progress (however much I disliked this at the time), problem-solving with me and keeping me motivated throughout.
>
> To my parents, my Mum and Dad, who have been by my side no matter what. You have continued to encourage me to dream big, strive for anything I want to achieve and, more than anything, supported me to keep going in the hardest of times.
>
> And to my partner, Lewis, without whom I would never have actually clicked the ‘submit’ button on my doctoral application.

Lastly, I want to dedicate this work to three important people in my life who sadly passed away during the course of the doctoral training, and never got to celebrate its completion. Each of these individuals were talented in their own ways, and taught me some important life lessons:

> My younger brother, Owen Barber (13.07.1999-03.06.2021), who was outgoing and courageous. Owen showed me that stepping out of your comfort zone can lead to greater opportunities. He taught me to grab life with both hands which also means taking time to do the things you enjoy.
>
> My grandad, Stanley Barber (08.12.1928-28.07.2023), a talented musician who always listened and took an interest in my work. Grandad would often cut out psychology related newspapers articles and save them for when I visited.
>
> And my grandma, Margaret Kercher (24.04.1926-22.11.2023), whose stubbornness, fierce determination and sense of justice has definitely rubbed off on me. Grandma lived life for everyone else, and demonstrated how small acts of kindness can make a huge difference in someone else’s life. She was my greatest champion and I hope this work will have made her proud.

> “Never give up! Keep going, always try your best and never give up!”
>
> (Valerie, aged 6, Case Study One)

Confidentiality Statement

The identities of the two children in this research have been pseudo-anonymised to protect their privacy. Considerable thought was taken to choose the two pseudonyms used throughout this research:

> **Valerie** – From the Latin word ‘valere’ meaning brave and strong, encapsulating the fervent determination that Valerie shows in her approach to life! Valerie’s outlook is perfectly captured in the quote above, when she was asked what advice she would give to another child who had an acquired brain injury.
>
> **Leo** – From the Latin word ‘Leo’ meaning lion. Leo shows great strength to voice when he perceives things to be unjust, but hiding underneath the boldness is a child who just wants to belong, like a lion within his Pride.

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CHAPTER 1: Introduction

1.1 Chapter Overview

The present study aims to explore children's experiences of a sense of school belonging (SoSB) when returning to school after an acquired brain injury (ABI). Chapter 1 provides the context of the research, including the definition of ABI, its prevalence, and research on outcomes for children and young people (CYP) with ABI. School belonging is introduced as a key concept for all school children, with additional consideration given to what this may mean for CYP with ABI returning to school. The relevance of the topic to Educational Psychology practice is reflected upon, along with the researcher's own motivation.

1.2 Context of the Research

Childhood ABI is ranked by the World Health Organisation as the leading cause of mortality and disability in children world-wide. Data suggests that each year approximately 1.4 million people attend emergency departments in England and Wales with head injuries (NICE, 2014). Of these, between 33-50% are children below the age of 15. Due to ongoing advances in medicinal technology, more CYP are surviving severe ABIs and returning to mainstream schooling (Leonardi et al., 2012). It is estimated that currently over 2000 children in the United Kingdom (UK) each year return to education after a severe ABI (UK All-Party Parliamentary Group, 2018). For many of these children, they will have lasting physical and physiological difficulties caused by their ABI. In line with the Equality Act (2010), inclusive practice is at the heart of education policy in the UK (Schuelka, 2018). Yet, it is recognised that CYP with Special Educational Needs (SEN) often fail to have their needs met (DfE, 2012; Ofsted, 2022). This is likely to also be the case for CYP with ABI, as effective strategies to support community integration post-ABI are limited (Al Sayegh et al., 2010). Therefore, it is imperative that as professionals we understand how to support CYP with ABI on their return to school and through their ongoing rehabilitation.

At a national level, there is a growing awareness of children's socioemotional development, and the impact of this on both educational and life chances. This follows the introduction of 'social emotional mental health' (SEMH) in the SEN Code of Practice (CoP, 2015) to describe a key area of need. The CoP (2015) places responsibility on schools to engage in preventative practices and early intervention to meet the SEN of all CYP. Given the traumatic experience endured by CYP with ABI and their families, and the complexity of difficulties experienced post-injury, SEMH is an important area of consideration. While the National Institute of Clinical Excellence (NICE, 2022) offers post-ABI guidelines, these are generic and focus on medical procedures; they fail to acknowledge that CYP with ABI have very different needs. Therefore, there is a need for research to explore CYPs experiences to inform how educators can support the social and emotional development of CYP with ABI.

1.3 ABI Definition

ABI is an umbrella term to describe an injury to the brain that occurs post-birth and after a period of typical development. ABIs are of either traumatic or non-traumatic origin. Traumatic brain injuries (TBIs) occur when there is an external impact to the head, such as a road traffic collision, a fall or assault. Non-traumatic brain injuries occur as a consequence of illness or infection, for example stroke, encephalitis, or medical procedures such as surgery for the removal of a brain tumour. The current research uses the definition of ABI, as damage to living brain tissue which causes physiological impairment of normal brain function, to capture all CYP who have sustained a brain injury (Rehab UK, 2002).

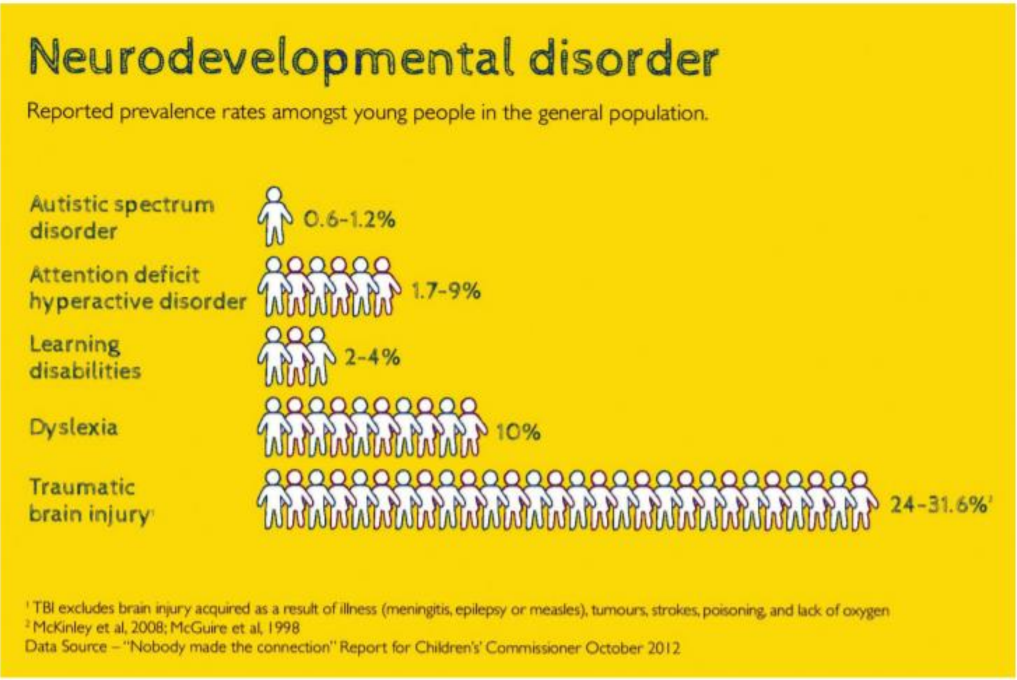
In addition to different origins of ABI, distinction is made between severity of injury (mild, moderate, severe). This is often determined by Glasgow Coma Scale scores on admission to hospital, the levels of intervention required post-injury and the extent of difficulties experienced. Some CYP may return home after a visit to Accident and Emergency (A&E) for a head injury; others may require admission to hospital and/or extensive neurorehabilitation. Frequently CYP will reintegrate straight from hospital back to schools, with no additional specialist support.

1.4 Prevalence

Challenges emerge when ascertaining rates of childhood ABI (McKinlay & Hawley, 2014). Many Local Authorities (LAs) do not have clear pathways from hospital to school or recording systems to capture accurate statistics (Hawley et al., 2002). Data that does exist suggests that every year in the UK approximately 35,000 children are hospitalized as a result of a TBI (Dewan et al., 2016). However, approximately more than 700,000 children attend A&E with a head injury in England and Wales each year (NICE, 2014). Studies in the UK show that the prevalence of traumatic brain injuries (TBIs) in the general population is higher than many widely known neurodevelopmental disorders (Hughes et al., 2012). For example, the reported prevalence of TBI is over 14% higher than dyslexia and over 22.8% higher than autism spectrum disorder (See Figure 1). Although this comparative prevalence data is now over 10 years old, recent data suggests that there is a trend of increasing cases of ABI in the UK. The hidden nature of ABI means it is likely that prevalence is higher in mainstream schools than statistics indicate, making ABI an area of importance for educators.

Figure 1.

TBI Prevalence Compared to Other Neurodevelopmental Disorders as Depicted by CBIT & Nasen (2018)



1.5 Outcomes and Impact

CYP affected by ABI display a range of difficulties, depending on the type of ABI, the severity of brain damage, their age when the injury occurred, and the rehabilitation provided post-injury. Changes can occur to CYPs physical, cognitive, emotional, behavioural and social functioning, many of which are long-lasting (Treble-Barna et al., 2017). The heterogenous nature of injury makes rehabilitation challenging. In addition to identified deficits at the time of ABI acquisition, early injury can compromise the development of neural networks underlying later stages of cognitive development (McClusker, 2005). As such, it is not possible to know the full extent of the ABI until a child reaches maturity or certain developmental points (Dennis & Levin, 2004).

Considerable research has explored the way in which the cognitive needs of CYP with ABI may change over the course of their development (Haarbauer-Krupa et al., 2017). Recent work by Resch et al. (2019) found that CYP who experienced a TBI before the age of 6 had substantial cognitive deficits in their inhibitory control 2 years post-injury that were not seen at 6 months post-injury. This change in cognitive processing over time may relate to the emergence of further challenges as the child develops and starts to utilise different cognitive functions. For example, frontal lobe injuries sustained at the age of 5 may not become apparent until CYP start to use more complex problem-solving skills in their early teens. Given the extensive impact of ABI and its association with a vast array of poorer life outcomes, rehabilitation needs to be a long-term process. For many CYP returning to school after an ABI, their school becomes their main rehabilitation centre. Yet research consistently shows that CYP with ABI are not having their needs met in academic settings (Glang et al., 2008; Haarbauer-Krupa et al., 2017; Kingery et al., 2017). It is therefore imperative that educators and professionals understand the long-term sequelae of paediatric ABI, and can engage in inclusive practices that contribute positively to this ongoing rehabilitation process.

1.6 Socio-emotional Considerations

While the physical and cognitive outcomes of ABI are well researched, fewer research papers have focused on the needs of the CYP and their family post-discharge from a socio-emotional perspective (McKinlay et al., 2016). Research that does exist shows that social impairment is a persistent and debilitating consequence of ABI (Babikian et al., 2015; Ryan et al., 2016). This is highlighted by statistics on youth offending populations, where there is a high prevalence of self-reported TBI (Williams et al., 2010). Social skills difficulties have been associated with a range of cognitive factors including cognitive control deficits (Levin & Hanten, 2009), delayed processing speed (Treble-Barna et al., 2017) and communication impairment (Ferré & Joanette, 2016). In addition, physical limitations and fatigue can also affect social engagement. Research consistently shows that CYP with ABI experience restricted community participation compared to typically developing peers (Law et al., 2011).

Disparity in participation remains evident 7-years post-ABI, demonstrating the pervasive nature of social deficits for CYP with ABI (Câmara-Costa et al., 2015).

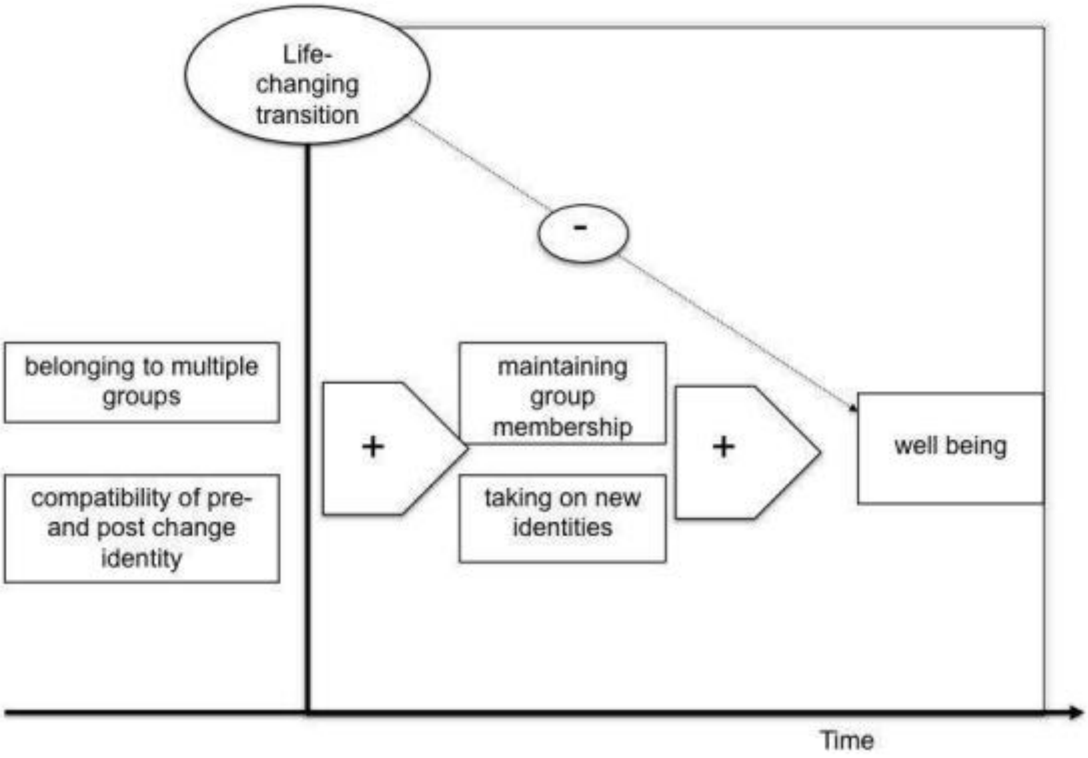
In addition to injury directly affecting social skills and participation, CYP with ABI will have experienced decreased opportunities to interact with peers during their hospitalisation and rehabilitation. In addition, these CYP are exposed to various adults in the health environment and privy to more adult conversations. It is therefore important to also reflect upon the impact of these experiences on later social development, particularly for younger children who experience these disruptions at a critical period for social development.

1.7 Self-identity Following an ABI

Socio-emotional difficulties may also arise from the psychological impact of post-injury adjustment that CYP and their family are faced with. The sudden and unexpected nature of the injury ricochets through the systems around a child and is often accompanied by a grief response (Carroll & Coetzer, 2011; Marwit & Kaye, 2006). CYP with ABI may experience identity loss due to certain deficits (Broks, 2003; Nochi, 1998), as well as taking on the identity of an ABI survivor. Consequently, they must navigate the (re)construction of their sense of self, family identity and social identity (Ownsworth, 2014). The Social Identity Model of Identity Change (SIMIC, Figure 2) proposes that wellbeing after a life changing event is impacted by congruency between pre and post change identity (Jetten & Panchana, 2012). This is supported by recent research that showed adults display poorer emotional wellbeing after experiencing trauma, when the trauma served to destabilise their previous social identities (Muldoon et al., 2019). It is likely that CYP experience a similar adjustment post-ABI, suggesting that rehabilitation should focus on reconstructing a social identity for these CYP.

Figure 2.

The Social Identity Model of Identity Change Taken From Jetten & Panchana (2012)



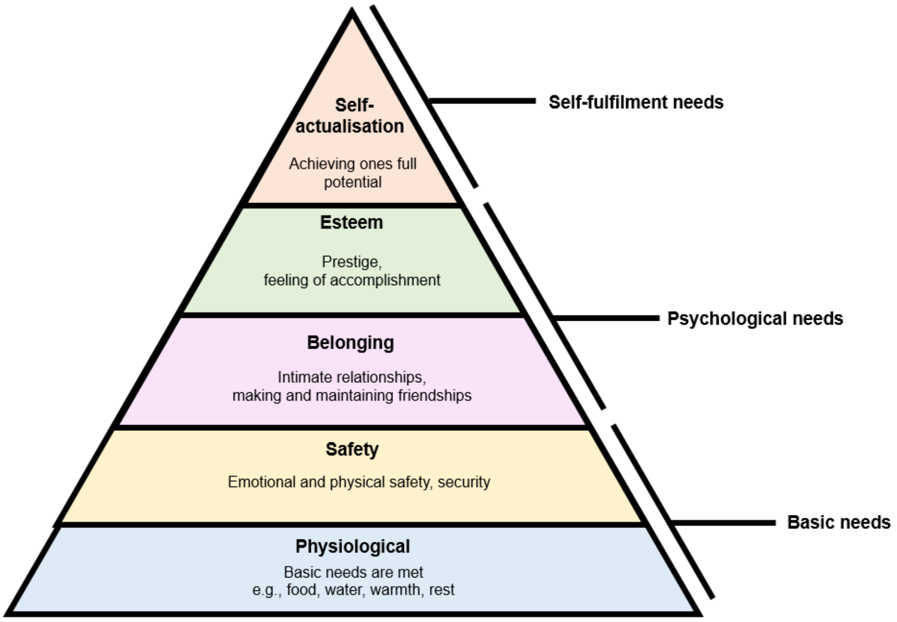
The SIMIC further proposes that social groups prior to the life-change can form a secure base for identity reconstruction (Jetten & Panchana, 2012). In line with the SIMIC, group memberships are found to play a protective role in adjusting to ABI (Muldoon et al., 2019). Muldoon et al. (2019) noted that adults were more resilient to trauma when their valued social identities were maintained or new identities developed. Research focusing on CYP with ABI shows that CYP function better when they have high levels of social support post-injury (Whitnall et al., 2006), suggesting this is a key area of focus within rehabilitation.

1.8 Belongingness

One way in which both social support and group membership may facilitate identity protection or (re)construction, is through the sense of belonging they can foster. According to Maslow (1954), belonging is a basic aspect of psychological functioning that must be satisfied before any learning or self-fulfilment activity can take place (Figure 3). Perceptions of belongingness have been linked to a range of positive outcomes, including increased self-esteem (Leary & Baumeister, 2000) and good mental health (Baskin et al., 2010). Given the possible challenges with social skills and participation, it is likely that CYP with ABI experience a limited sense of belonging after an ABI. Belongingness can be fostered in different social groups across a range of settings, including family, community groups and schools. Given the time that CYP spend in education and the unique structured and unstructured social and participatory opportunities afforded by the setting, schools are well placed to nurture a sense of belonging for these CYP. To do this, there needs to be an understanding of what belongingness at school means for these CYP, and experiences that can facilitate and hinder its manifestation.

Figure 3.

Maslow's (1954) Hierarchy of Needs Depicted by a Graphic Developed by the Author



1.9 Sense of School Belonging

School belonging refers to the ‘extent to which students feel personally accepted, respected, included and supported by others in the school social environment’ (Goodenow & Grady, 1993, p.80). A SoSB has been positively related to academic outcomes, prosocial behaviour and positive MH for typically developing CYP. Research suggests that pupils who have a strong sense of belonging in school tend to be happier, more confident, show better adjustment and display higher academic achievements (Neel & Fuligni, 2013; Pittman & Richmond, 2007). Given the importance of a SoSB for typically developing children, it can be assumed that it is also critical for the successful reintegration of CYP returning to school after an ABI.

Whilst returning to what is familiar is argued to be important to a child’s sense of self following ABI (Sharp et al., 2006), changes are likely to have occurred within the school environment during the child’s absence. Children returning to mainstream provisions are also confronted with peers who may be closer to their pre-ABI identity, highlighting their post-ABI deficits which can be difficult to tolerate. Research highlights that within the school environment, CYP with ABI are at increased risk of bullying and social isolation (Crothers et al., 2007; Ilie et al., 2014), and exclusion (Hawley, 2004). ‘Fitting back in’ is identified by adolescents with ABI as a core component of reintegration to school (Ylvisaker et al., 2005), emphasising the need for inclusive practices to foster a SoSB for these CYP.

1.10 A Role for Educators and Educational Psychologists

As identified by the CoP (2015), schools play a multi-faceted role in child and adolescent development; they offer a meeting place for peer groups, socialisation during unstructured times, and opportunities to learn and develop key social skills during structured activities. Educators are therefore in a unique position to support CYP with ABI within the school system, by promoting an inclusive environment that enables these children to meet their psychological need to belong whilst at school.

Educational Psychologists (EPs) can further use their psychological knowledge of child development, neuropsychology and systems to support schools in this endeavour. In particular, there is a growing awareness of the need to consider the systems around a child when reintegrating back into mainstream school (Brunsden et al., 2015). EPs are well placed to take a systemic approach to understanding the context in which reintegration is occurring, to promote a successful transition back into mainstream education and continuing inclusive practices to aid ongoing rehabilitation.

1.11 Researcher Position

The researcher developed an interest in ABI from working as a Support Assistant at a Paediatric Neurorehabilitation centre. The researcher saw first-hand the trauma endured by these families, and the impact on both the child's self-identity and the family identity. Families often endured things being 'done to' them rather than 'with' them, reinforcing the importance to the researcher of empowering these CYP and their families to have a voice and their priorities heard. Whilst in the neurorehabilitation centre, these CYP and their families existed in a small social bubble with people who had either shared a similar experience or clearly understood the impact of ABI. However, on returning to their home and their school, these families are faced with multiple and changing systems of which they are expected to adjust to, often with minimal ongoing support. After commencing training as an EP, the researcher encountered a lack of systems within the Educational Psychology Service (EPS) and wider SEN services for monitoring these CYPs reintegration to school. Moreover, the researcher noticed a lack of confidence among EPs and other professionals within SEN around ABI. This was identified previously (Bozic & Morris, 2005) and raises concerns as to who is supporting families to make this considerable adjustment when returning home, particularly for CYP who transition home from hospital without further specialist intervention. EPs have extensive knowledge of child development, as well as school systems. Therefore, the researcher believes that EPs are well placed to support schools and educators to understand the ongoing needs of CYP with ABI, and implement changes within school to facilitate positive social and emotional adjustment.

1.12 Rationale

Overall, the aim of this research was to explore CYPs experience of returning to mainstream school after an ABI, specifically focus upon their SoSB. This research was conducted for two reasons. Firstly, there is a paucity of research that examines CYPs sense of belonging as part of their social-emotional development following an ABI. Whilst there is some research on the impact of paediatric ABI on wellbeing and participation, there is comparatively little research focused specifically on a SoSB, a construct identified as key for typically developing children. Exploratory research could support an understanding of some of the barriers and facilitators to a SoSB for these CYP and how educators can actively foster belonging in their schools. Secondly, research in this area has typically only elicited the views of either CYP, their parents or educational professionals. There is a growing recognition within Educational Psychology of the need to consider the systems around CYP and how they interact. This is particularly important for CYP with ABI, where there is likely to be increased dependence on the systems around them to support with their rehabilitation. Given the identified importance of taking a systemic approach to support CYP with ABI (Brunsden et al., 2015), research is needed to bring together these different views. This research sought to gain a greater understanding of the lived experiences of the CYP themselves and the system around them, to enable professionals to offer informed guidance in areas of challenge.

Overall, the current research used a qualitative design to address the following research questions:

1. How do CYP with ABI experience barriers and facilitators to a SoSB when returning to mainstream school after an ABI?
2. To what extent do the perceived factors affecting school belonging differ across the home and school systems around a CYP?

The aim was that by addressing the above research questions, this research will provide insight into how educators and related professionals can effectively nurture a SoSB for CYP returning to school after sustaining an ABI.

CHAPTER 2: Returning to School After an Acquired Brain Injury: What We Already Know-Literature Review

2.1 Chapter Overview

This chapter provides a context for the current research by summarising previous literature relating to the process of CYP returning to school following an ABI. A systematic literature search was conducted, guided by the following questions:

1) What does existing research tell us about how educational professionals currently support CYP returning to school after an ABI, particularly from a socio-emotional perspective?
2) What are the gaps in the research and what would be helpful to add to this field of knowledge?

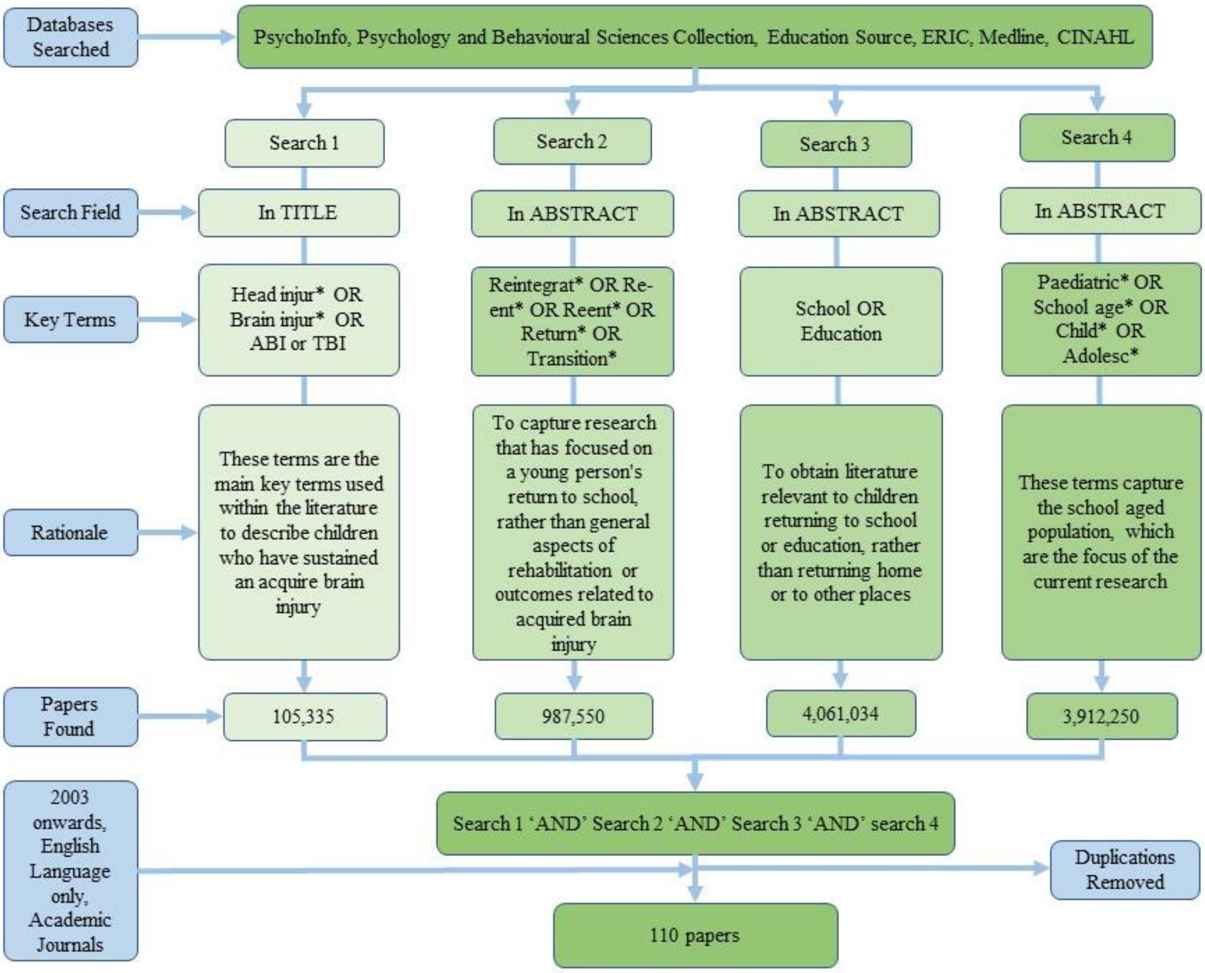
Firstly, the literature search strategy will be outlined, and the empirical research will be described. The literature will be critically appraised, with consideration of how the existing literature has impacted the decision-making process for the current research. Finally, the identified gaps within the field will be discussed, alongside how this research seeks to address them.

2.2 Search Strategy

The following literature search was conducted in January 2023 using the online library database EBSCO. Key search terms were entered into six separate databases to increase efficiency and relevance of results: PsychINFO, Psychology and Behavioural Science, ERIC, Educational Source, CINAHL and MEDLINE. The databases were deemed the most relevant to source the literature as they included academic research covering psychology, medical and educational literature. The search criteria included terms related to ABI, hospital-to-school reintegration/transitions, and school-age children. Search terms were identified by examining key terminology within relevant literature and organisation websites, such as The Children's Trust and Headways. Full search terms and rationales are shown in Figure 4. These were combined with the Boolean 'AND.' Initially, a fifth search was included using terms relating to a sense of belonging as this was the area of focus for the current study (belong* to encompass belonging/belongingness and connect* to encompass connective/connectedness or connection). However, this was met with no relevant results. Therefore, the four searches were re-run with a broadened focus on the general return-to-school process. The search was narrowed to include papers from 2003 onwards, English Language only, and Academic Journals. The researcher recognised that school practices are continually changing in line with societal influences and legislation. Restricting literature to the last 20 years ensured that the identified research papers remained relevant to practices today. In addition, the search was limited to English language only as articles not written in English could not be critiqued by the researcher. The decision to limit based on language rather than country of origin (e.g., UK only) meant that the literature review continued to capture non-UK based research, such as those conducted in the United States of America (USA). The researcher recognised that the legislative backdrop would be different but felt that this would still offer important perspectives on school based practices to support CYP with ABI transitioning back to school.

Figure 4.

Initial Search Criteria for the Literature Review



Once duplicates were removed, this search yielded 110 articles. The title and abstract of these papers were manually scrutinised for relevance, following the inclusion/exclusion criteria outlined in Table 1. This eliminated 74 papers from further scrutiny. The articles with abstracts that did not provide sufficient detail on which to make a clear decision of their inclusion/exclusion status were sourced and read in full. Following this screening procedure, only eleven articles remained. To ensure a thorough search of the literature, additional searches of the reference list and citation searches (via Google Scholar) of retrieved papers took place. These were, again, subject to the inclusion/exclusion criteria below and revealed two additional, pertinent papers that were not captured through the initial literature search.

Table 1

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Paper written in English	Paper not written in English
Paper focused on children and/or youth who had experienced an ABI and/or their parents and/or educational professionals who support them.	ABI acquired in adulthood (>18 years old).
Paper focused on the experiences of the above in relation to the process of returning to school post-ABI	Paper focused only on the impact of ABI and outcomes related to this, or evaluations of specific programmes without explicit focus on experiences of the hospital-school transition.
Paper reported original research only	Secondary review paper or editorial.

The final thirteen articles that remained for extensive appraisal are summarised in Appendix A. The articles were critically evaluated using the Quality in Qualitative Evaluation Framework (Spencer et al., 2003) which focuses on four central principles: research contributions, defensibility in design, rigor in conduct, and credibility in claim. This framework was devised as part of a research programme conducted on behalf of the UK Cabinet Office, to support the critical evaluation of any research that may affect the implementation of social policy, programmes and practice. Ergo, it provided a useful tool for this literature review (see Appendix A for a critical summary of the final thirteen articles). To increase the rigour of the literature review, the author conducted multiple readings of each article. Key data was extracted from each article and used to identify themes.

2.3 Characteristics of Included Studies

The thirteen papers originated from Belgium (n=2), Canada (n=1), UK (n=2), Australia (n=3) and USA (n=5). The two Belgium papers (Vanclooster et al., 2019, 2021) used the same sample of CYP. Therefore, only the participant demographics from Vanclooster et al.,'s (2021) paper, which also included parental and professional experiences, are reported below to prevent duplication. Overall, the studies focused on 188 CYP (43.6% male, 22.9% female and 33.5% unspecified). The CYP with ABI ranged from <5 to 20 years at the time of study participation. Age at the time of injury varied from infancy to 17 years, although seven studies did not report this data. The length of time between their injury and the time of interview ranged from 1 month to 9 years. Across the studies there was also variation in the way that injury severity was classified. Most studies determined severity from Glasgow Coma Scale scores (n=7). Two papers used the Injury Severity Score (Jones et al., 2022) and Abbreviated Severity Score (Jimenez et al., 2020), and in one study, severity was determined by hospitalisation time only (Bate et al., 2021). Three papers did not acknowledge severity; two of these focused solely on CYP with brain tumours (Vanclooster et al., 2019; Vanclooster et al., 2021) and the other reported that the CYP had TBI, but provided no information on severity or the study's inclusion criteria (Crylen, 2015).

Whilst information was reported about the CYP, most studies provided limited information on family circumstances. This is significant given the important role that contextual factors play in shaping experiences. Four studies reported the CYPs family makeup and living situation (Crylen, 2015; Mealings & Douglas, 2010; Robson et al., 2005; Roscigno et al., 2015). Few studies provided statistics on the ethnicity of the CYP and/or families

(Gfroener et al., 2008; Jimenez et al., 2020; Roscigno et al., 2015), the languages spoken and English proficiency (Jimenez et al., 2020), and socioeconomic status (Roscigno et a., 2015).

Eight papers focused on the experiences of one group of individuals, either professionals (n=1), the CYP (n=2) or their caregivers (n=5). The remaining papers explored the perceptions of multiple individuals enabling comparison across groups. This included caregivers and school staff (n=1) and caregivers and CYP (n=3). Only one study explored experiences of all three participant groups. Most identified papers collected data via semi-structured or in-depth interviews, consistent with the aims to gather experiences around the return-to-school process. Notably, Roscigno et al. (2015) conducted secondary analysis on a previous dataset, and therefore school reintegration was not the primary focus at the time of data collection. Qualitative interview data was analysed using a range of methods: Grounded Theory (n=3), Thematic Analysis (n=5), Thematic Content Analysis (n=2), Descriptive Phenomenology (n=1) or in-depth case study (n=1). Gfroener et al. (2015) used a questionnaire measure (Back to School Interview, Glang et al., 2006), as part of a broader assessment. Data on parental ratings on school adjustments was subsequent assessed using comparative statistics.

2.4 Themes Emerging From the Literature Review

Sharp et al. (2006) identified two critical phases related to adolescents returning to school: organising the school return and being back at school. These two phases were reflected in the other articles and therefore were used as superordinate themes in this literature review.

2.4.1 Organising the School Return

2.4.1.1 Co-ordination of Care

Of prevalence in the identified literature was the importance of both communication and collaboration between the different systems around the CYP, particularly hospital and school (Bate et al., 2021; Diener et al., 2022; Gagnon et al., 2008; Robson et al., 2005; Sharp et al., 2006). Educators reported greater confidence when they had planning meetings, compared to being given written reports about the child (Bate et al., 2021). This was echoed by parents who described more positive reintegration when there was strong communication (Diener et al. 2022; Robson et al., 2005). Roscigno et al. (2015) found that collaboration between professionals lessened the perceived workload for families. In contrast, poor co-ordination between the health and education systems meant that parents took the position of 'messenger between the hospital and school' (Crylen, 2015, p.169). The shared perception by both parents and professionals that prior co-ordination of care was a critical component of school return, suggests a key area for research in order to inform the development of transition pathways in the future.

Despite the identified importance of co-ordinated care, parents described the level of planning in preparation for the hospital-school transition to vary greatly depending on the length of time a young person spent in hospital and the severity of their injury. For those undergoing intensive rehabilitation, the hospital-to-school transition pathway depended on the care facility. For example, for one young person the hospital had a re-integration programme that involved them arranging meetings with teachers and classmates in the weeks prior to the school return (Crylen, 2015). Families who were discharged directly home from hospital settings were less likely to be provided with service support and had to navigate their own return-to-school (Crylen, 2015; Jimenez et al., 2020). In addition to differences in transition pathways, some caregivers and professionals believed that the laws protecting the privacy of health information created additional barriers to successful co-ordination of care as information was unable to be shared directly from hospital to school (Diener et al., 2022). This further highlights the importance of understanding current transitional experiences and the contexts in which transitions are occurring.

2.4.1.2 Preparing the Young Person

While many caregivers and professionals across studies discussed the importance of a planning phase, only CYP in Sharp et al.,'s (2006) study mentioned this stage. This may reflect the different priorities between CYP and the adults supporting their transition, as CYP may be more focused on the act of returning to school rather than the process underlying it. The CYP in the aforementioned study were all adolescents aged between 14 and 19 years old. Compared to younger children in other studies, they may have been better able to reason about their return process and be included in the decision making around their return. In comparison to caregivers and professionals who focused on the co-ordinated process of planning, the CYP focused on personal preparation (Sharp et al., 2006). Involvement varied for each individual but included activities like completing school work whilst absent, having visits from school peers and/or teaching staff, or going to visit the school beforehand. This is consistent with findings that adolescents showed a greater need for information and to be part of the decision-making around adaptations once back at school (Gagnon et al., 2008; Mealings & Douglas, 2010). This was particularly important for CYP with severe ABI, who had experienced greater perceived loss of control after their injury. Therefore, these findings suggests that the age of a child with ABI affects their level of participation within the organisational process before returning to school.

It is further possible that the research design impacted the experiences that the adolescents shared. Sharp et al. (2006) interviewed families together and therefore the topics that emerged, including the preparation for return, may have been initially facilitated by parents rather than being pertinent to the adolescents themselves.

2.4.2 Being Back at School

2.4.2.1 Returning to 'Normality'

The school return was perceived to be one of the final stages of returning to normality for families (Robson et al., 2005). Families viewed school to be a normal part of life (Mealings & Douglas, 2010), allowing them to focus on things other than their illness/injury (Vanclooster et al., 2021). Returning to normality was linked to a wide range of emotional responses (Mealings & Douglas, 2010; Robson et al., 2005). Whilst families were happy to return to familiar surroundings (Gagnon et al., 2008; Vanclooster et al., 2019), there were concerns about the school demands, particularly for parents of CYP with severe ABI. Parents acknowledged a 'new normal' with changes related to the injury that only become real when the family returned home (Robson et al., 2005). Such changes required significant adjustments at school. Mealings and Douglas (2010) identified these changes to be internal or external. Internal changes included the experience of the traumatic event and adjustment to CYPs sense of identity. External changes included accessibility arrangements, adapted curriculum and restricted school participation. Across the studies, there were individual differences in how these changes were perceived by CYP. Vanclooster et al. (2019) found that younger CYP showed greater motivation to participate at school, but also expressed more negative feelings around their limitations.

In addition, changes over time were reported for younger children with ABI. Vanclooster et al. (2019) found that over time, some children had lower motivation for academic performance as their difficulties persisted. An explanation for this is that older children may be better able to apprehend their limitations. This view was supported by Mealings and Douglas (2010) who found that for some adolescents, their injury provided a novel view of the world, and shifted their thinking towards long-term goals for the future.

While there appears to be individual differences in the response to ABI, the small sample sizes and design of the identified studies prevented these from being explored further. It does, however, emphasise the range of personal losses that CYP with ABI have to adjust to and the significance that families place on the school return as a final stage in the process of returning to ‘normality’.

2.4.2.2 Academic and Practical Support for CYP

To support CYP with ABI to access the school and learning environment, a range of practical support was required depending on the nature of the CYPs injuries. This included reading, note taking, exam consideration, additional breaks, an integration aide and exemption from physical activity due to fatigue (Sharp et al., 2006). CYP who had been hospitalised also required catch-up with the missed curriculum or differentiated work (Jones et al., 2022; Mealings & Douglas, 2010). The level of practical support differed between primary and secondary school due to the additional considerations needed in secondary provision with required movement between classrooms and multi-story buildings (Roscigno et al., 2015). Some secondary-aged students with ABI reported being taught in separate learning spaces, as their typical classroom was physically inaccessible (Jones et al., 2022). Adolescents in secondary schools also reported inconsistencies in the practical and academic support offered by different teachers, a difficulty not observed in primary education where CYP usually have the same class teacher throughout the day. Some adolescents and parents felt a management protocol should be in place regarding the school environment to minimise this (Gagnon et al., 2008).

In contrast to most articles, most parents in one study did not perceive the need for school-based services (Gfroerer et al., 2008). This was the only article that utilised a quantitative measure, and therefore this finding may have reflected the wording of the questions provided. Alternatively, this finding may be related to the research only focusing on the 3 months following school re-entry. Gfroerer et al. (2008) argued that at this stage, parents may be more focused on signs of their child's recovery rather than signs of impairment. Therefore, parents at this stage may be unable to advocate for their child's needs in the school environment, highlighting the need for educators and professionals to do so, to ensure early intervention and preventative working.

2.4.2.3 Socio-emotional Support for CYP

In addition to academic and practical support, families also highlighted the need for socio-emotional support for CYP. Families described an emotional journey when returning to school, with many of the emotions experienced during the initial return phase continuing long term (Robson et al., 2005). Personal adjustments that CYP with ABI had to make post-injury, such as changes to academic performance, became more explicit in the school environment. Such changes put emotional strain on the CYP and their families, leading to feelings of unfairness and sadness (Vanclooster et al., 2019). All studies emphasised the importance of socio-emotional support being provided by people close to the CYP. In particular, personal support from peers aided CYPs readjustment into school (Vanclooster et al., 2019). The reliance on peers was greater for adolescents compared to younger children who typically sought more reassurance from their mothers (Gagnon et al., 2008). When considering peers, some CYP felt that it helped having their peers know what had happened, whilst others did not want their peers to know about their injury (Vanclooster et al., 2019). These findings suggest that while social support from peers at school is an important aspect of the return-to-school, the nature of this support needs to be consistent with what the child with ABI wants.

In addition to support from family and friends, CYP also valued support from healthcare professionals and people involved in their school (Mealings & Douglas, 2010).

Vanclooster et al. (2019) found some CYP valued check-ins and follow-ups with class teachers to talk about their general feelings. However, the age of the CYP typically impacted the support received from school staff. Psychosocial support of this kind was typically only offered to older children, as staff felt that they were able to reflect upon the impact of their experiences/injury. Older children were also more aware of the long-term implications of their injury (Vanclooster et al., 2019), which further suggested a need for emotional support. Notably, whilst there was recognised need for socio-emotional support from key school staff, the research articles offered limited clarity on what this support looked like. This lack of clarity may reflect the difficulty with identifying and managing the socio-emotional needs of CYP with ABI (Robson et al., 2005), a view that was supported by findings from Gfroerer et al. (2008). Gfroerer et al. (2008) found that for parents who sought support, there was a notable distinction between the type of support that was accessible. 93% of parents indicated that it was easy to obtain support of an academic nature. In contrast, only 40% of parents indicated that it was easy to obtain social/behavioural support. As outlined in the CoP (2015), schools hold a key responsibility to recognise the SEMH needs of CYP, and work in both preventative and early interventive ways. This suggests a needs for schools to understand how educators can promote the socio-emotional needs of CYP with ABI attending their school.

2.4.2.4 Fitting Back In

In line with the concept of returning to normality post-ABI, a key theme that emerged for CYP was that of fitting back in at school. Fitting back in was typically regarded as social participation, identified as a core component of school life (Mealings & Douglas, 2010; Gagnon et al., 2008). CYP wanted to return to school primarily because of their pre-existing friendships (Jones et al., 2022; Mealings & Douglas, 2010). Consistent with this, CYP appeared more focused on the social aspects of school compared to parents who typically focused on the academic side (Gagnon et al., 2008). CYP described differences in the reactions they received from peers on return and peer attitudes affected the level of inclusivity that CYP experienced. Some children felt they were treated differently or found it difficult to relate to peers following their absence at school, as peers appeared to have ‘moved on’ during this time (Jones et al., 2022; Vanclooster et al., 2019). Other CYP described being accepted back into their friendship group with no acknowledgement of their injury (Sharp et al., 2006). Some peers took on a protective role which provided important social support to the CYP (Jones et al., 2022). Friendships and participation at school were associated with school identity and a more positive attitude towards school, demonstrating its importance in the return-to-school process (Jones et al., 2022).

Social participation was further challenged by injury-related changes. Physical barriers included limited access to certain parts of the school and reduced mobility affecting participation in activities, particularly physical games, school trips and break times. Adolescents expressed frustration at having to work in classrooms, separate from their peers, that were designated for children with behavioural difficulties (Jones et al., 2022). Adolescents were also no longer able to travel to school independently and relied on parents to transport them (Jones et al., 2022). In addition, the cognitive consequences of ABI meant that some children had difficulties with memory, language and social communication which impacted their social ability (Crylen, 2015). CYP also reported changes to their physical appearance post-ABI that further impacted their confidence to socialise (Jones et al., 2022).

Moreover, the adaptations provided by school to aid physical and academic needs, also impacted their sense of fitting back in. CYP often required support for learning related needs post-ABI, including differentiated work or withdrawal from the classroom for frequent interventions (Mealings & Douglas, 2010). Despite recognising the positive aspects of and/or necessity for some of these adaptations, CYP frequently reported frustrations especially when the adaptations restricted participation with peers (Mealings & Douglas, 2010; Sharp et al., 2006). Overall, injury-related changes and adaptations provided in school all made reintegration more difficult. These changes all impacted the CYPs social participation and their wellbeing around school and peers. When returning to school, CYP and their families have to (re)adjust from the hospital community 'bubble' of other families with similar experiences and staff who understand their needs, to the wider microsystems and mesosystems around them and the school. This therefore suggests that a sense of belonging is important to consider for CYP returning to school.

In addition to peers, the attitude and subsequent response from teachers also impacted CYPs sense of fitting back in. Some adolescents reported that staff were too accommodating, leading to them being singled out from their peers (Mealings & Douglas, 2010; Sharp et al., 2006). In contrast, other CYP reported that educators did not provide adaptations and often did not believe their injuries (Gagnon et al., 2008). CYP described a complex balance for educators to have to manage, to ensure that they are engaging in inclusive practice to meet the CYPs academic and physical needs, whilst also supporting the CYPs socio-emotional needs and desire to fit back into the school community.

2.4.2.5 (Lack of) Educator Knowledge Around ABI

The teacher responses outlined above were frequently associated with their level of knowledge around ABI. CYP, caregivers and professionals across multiple studies reported that school staff lacked sufficient understanding of ABI, and as such, often implemented inappropriate accommodations that made reintegration more challenging (Bate et al., 2021; Diener et al., 2022; Gagnon et al., 2008; Jones et al., 2022; Roscigno et al., 2015; Sharp et al., 2006). In particular, caregivers and CYP felt that there were differences in their treatment depending on whether their difficulties were physical (and visible) or hidden. For CYP who physically ‘appeared normal’, staff who lacked understanding of ABI were less likely to implement support due to beliefs that the young person was recovered (Gagnon et al., 2008; Roscigno et al., 2015; Sharp et al., 2006). Some caregivers related a lack of understanding to teacher’s minimal involvement during the planning phase (Diener et al., 2022), suggesting that teachers may not perceive their involvement to be important. In contrast, others experienced school staff to be receptive to advice but required parents to provide it (Jones et al., 2022). This is significant given that if staff aren’t aware of the implications of ABI, they are unlikely to support these CYP in the most effective way. Notably, most of these studies only focused on perspectives of parents, CYP and other professionals (e.g., health) and were therefore unable to explore further the factors contributing to educator understanding.

Of the two studies that directly captured educators’ experiences, both personal and systemic factors were identified to impact their knowledge of ABI (Bate et al., 2021; Vanclooster et al., 2021). Bate et al. (2021) found that whilst there were lots of similarities described, educators also showed differences in perspective over how the child was managing at school. Staff members who had personal experiences with ABI, reported this to have given them greater insight into its impact (Bate et al., 2021). In addition, staff did not receive direct support and reported challenges with accessing training (Bate et al., 2021; Vanclooster et al., 2021). This was often the case in secondary education, whereby staff were only informed of the CYPs needs once they were allocated to their class. Staff recognised that online resources were limited in their utility because of the variable impact of ABI on CYP, and valued tailored sessions with professionals to understand the unique profile of the CYP they were working with. Staff who relied on written reports also found that they inaccurately portrayed the needs of the CYP in their classroom. They were therefore unsure of the best ways to support these students.

For school staff who received support, they identified the pre-transition planning meetings to be helpful to allow for a collaborative approach with both professionals and caregivers (Bate et al., 2021). However, despite pre-transition planning, teachers reported that the 'true extent and complexity of the child's difficulties' were only discovered after spending time in the school environment (Bate et al., 2021, p.246). Staff described their involvement with CYP with ABI as a continuous problem-solving process. Of particular concern for educators was how to support the emotional needs of CYP with ABI (Bate et al., 2021), consistent with the findings that parents and adolescents perceived emotional and behavioural needs to be largely unmet (Gagnon et al., 2008). Given that for most children their school becomes their main rehabilitation centre, it is imperative that staff have a clear understanding of how to support CYP with all areas of need. Moreover, as parents may not perceive a need in the initial months after a return-to-school, they may be less able to advocate for their child (Gfroerer et al., 2008). This further raises the importance of school staff and educators understanding the impact of ABI, so that they can implement preventative and early interventive support in school during the initial stages of return.

2.4.3 Further Considerations

2.4.3.1 Long-Term Individualised Approaches to Care

A pertinent theme in the literature was the need for ongoing individualised support. The CYP of focus in the articles varied in multiple ways including the way in which their ABI was sustained, the nature and severity of their injuries, the care required and received post-ABI, how they responded and managed the traumatic event and its subsequent impact. Therefore, educators' abilities to flexibly adjust to the CYPs needs was critical for the transitional process.

Findings highlighted the need for care and adjustments to continue longer-term and not be withdrawn immediately following the return-to-school (Bate et al., 2021; Crylen, 2015; Diener et al., 2022; Gagnon et al., 2008; Mealing & Douglas, 2010; Robson et al., 2005; Roscigno et al., 2015; Sharp et al. 2006). For some CYP, their difficulties persisted two years after school re-entry (Vanclooster et al., 2019). Both parents and professionals recognised that children's needs continued to change over time (Diener et al., 2022; Roscigno et al., 2015) with often unpredictable recovery (Bate et al., 2021). Returning to school also often revealed new physical symptoms including fatigue and concentration difficulties (Jones et al., 2022), in addition to CYP requiring more assistance as the expectations at school increased (Vanclooster et al., 2019). Bate et al. (2021) found that all staff who had supported a CYP return to school described ongoing unresolved issues. At the time of interview, this was 6 to 18 months after their transition back to school, suggesting that CYP with ABI experience long-term difficulties that require ongoing adjustment and care within the school environment. Returning to school was also understood to have multiple transition points, including changing year groups and the primary-to-secondary move (Mealings & Douglas, 2010; Roscigno et al., 2015; Vanclooster et al., 2021). Sharp et al. (2006) acknowledged that during both individual changes and transitions, CYP may require a shift back to the organising the school return phase, in line with emerging needs.

2.4.3.2 Experiences of Support Across the System

Whilst participants in ten articles identified the need for long-term individualised care in school for CYP with ABI, fewer participants considered support for the wider system. Although it is recognised that the focus of the studies was on the process of school return, this is surprising given both the vast impact that ABI can have on the systems around a child, and the recognised importance of these systems in supporting the child's development

(Bronfrenner, 1994). A clear theme in parental interviews was the long-term challenges and emotional impact of a child's ABI on the whole family system. On returning home, families left the community they had formed during their rehabilitation/hospital stay, which included key professionals and other families enduring similar experiences (Crylen, 2015). Despite supportive social networks, some caregivers described feelings of social isolation during this time as many family members and friends did not understand the impact of their experiences. After returning home, families also often faced new stressors and life events that required additional management (Robson et al., 2005). Caregivers took on the 'burden of advocacy', reported by both Robson et al. (2005) and Crylen (2015). Caregivers became the expert of their child's emerging needs and had to learn to advocate for them, something that was exacerbated by poor coordination across hospital-school systems after return (Diener et al., 2022; Jones et al., 2022; Vanclooster et al., 2021). Despite this high level of need, caregivers perceived care to be withdrawn following the crisis phase (Diener et al., 2022). Caregivers identified that a step-down-care plan would be helpful to support them emotionally following discharge (Diener et al., 2022). Caregivers who received a follow-up phone call felt this 'met their need for support post-hospitalisation' (Gagnon et al., 2008, p.167). Given the position of school as a source of community (Sharp et al., 2006), there may be a role for school staff or related professionals in providing family-centred processes of care, as well increasing communication and coordination to reduce their burden of advocacy.

In addition, only participants in two studies discussed the need for school staff to have ongoing support and advice to meet the changing needs of the CYP with ABI (Sharp et al., 2006; Bate et al., 2021). This is significant given the identified complexity of issues that educators face when supporting a child with ABI in mainstream education. Many aspects of supporting CYP with ABI were emotionally demanding, including encounters with both CYP and their caregivers. Educators also often took responsibility for supporting the child to fit back in, further impacting their own wellbeing. Therefore, school staff may also require ongoing practical and emotional support when working with families. Given the importance of taking a systemic approach to supporting CYP, further consideration is required to identify the specific needs of the different systems around CYP with ABI and how best to support them.

2.4.3.3 Impact of Legislation on School Return

Despite national legislative frameworks providing an important context, only participants within four papers discussed the way legislation shaped the school return. Within the UK, only Bate et al. (2021) explored perceptions of the SEND CoP (2015) during this transition. SENCo's in this study reported that the statutory Education Health Care Plan (EHCP) process was unsuitable for CYP with ABI returning to school due to the pace at which their needs changed during this time. In addition, due to the 20-week statutory process, schools were often unable to implement the required support at the point of re-entry, and this affected the appropriateness of school placements. Parents in three studies conducted in the USA referenced the Individualised Education Plans (IEPs), which are similar to EHCPs in the UK, and issued in line with the USAs Individuals with Disabilities Education Act (IDEA, 2004). Similar to Bate et al.,'s (2021) findings, caregivers in both Roscigno et al. (2015) and Diener et al.,'s (2022) studies reported challenges with school provision due to CYP not immediately being identified as eligible for an IEP by school staff. For CYP with IEPs, challenges were also raised with the plans not always being communicated with key staff, implemented or revised. This experience was similar for three of the four parents in Crylen's (2015) study who were not communicated with regarding their child's individualised plan. For the one parent whose child's IEP was co-collaborated, they reported subsequent difficulties with staff not monitoring the plan's implementation. These findings are all in line with a recent

UK bill proposed in the House of Commons, which sought to prioritise long-term care pathways for people with ABI and increase the connectedness between the systems supporting ABI survivors (Acquired Brain Injury Bill, 2021). This suggests that consideration of the legislative context in which research is conducted is required, as this is likely to (at least in part) impact a child's return-to-school.

2.5 Additional Limitations of the Identified Research

2.5.1 Social & Contextual Factors

All studies reported in this literature review were small qualitative designs. Therefore, their findings may not represent the experiences of other CYP with ABI, their caregivers or school staff. Only two of the studies were conducted in the UK, and therefore transferability is also challenged for the other studies where the health and school systems and legislative context, as previously mentioned, are different.

Another limitation of this review is the reduced acknowledgement of a range of social factors within the systems around the CYP that may also shape their experience of returning to school. Less than a third of studies reported the child's family composition and living situation (Crylen, 2015; Mealings & Douglas, 2010; Robson et al., 2005; Roscigno et al., 2015). In addition, only two studies reported families social living status (Jimenez et al., 2020; Roscigno et al., 2015) and only one study captured family socio-economic status (Roscigno et al., 2015). Contextual factors related to the wider system were also not reported, such as the economic availability of the health and school services involved in the child's care. These wider systemic factors are likely to contribute to things such as the level of social support available to the CYP and their primary caregivers, and their access to resources. Therefore, it is important to understand their influence on the readjustment process.

2.5.2 Potential Sampling Bias and Attrition

The articles used a diverse range of participants in regards to their social role/positioning, including the CYP with ABI, parents, other family members, school professionals and health professionals. However, as outlined previously, very few studies reported information about participant and/or family ethnicity, language or socio-economic status. In addition, with the exception of Jimenez et al. (2020) whose study focused explicitly on Hispanic families, of those that did report this information, the participants lacked diversity in regard to both ethnicity and social status. Whilst this was recognised by multiple authors, it limits the transferability of the research to other ethnic groups. Jimenez et al. (2020) demonstrated the additional complexities that can occur for families of ethnic minorities, whereby language posed a significant barrier to effective communication post-injury. This highlights there are a range of other factors that may also impact the return-to-school process, that haven't been acknowledged with a non-diverse participant sample.

Consideration should also be given to the participant sample and their motivations behind participation. In many cases, caregiver views were only represented by mothers. Robson et al. (2005) observed differing reactions between mothers and fathers to their CYPs ABI, suggesting that a sample of predominantly mothers is likely to impact the type of experiences being reported. Individuals may also be more likely to partake if they have had a problematic experience with the return-to-school, a view supported by the attrition rates within some studies. Both Gfroener et al. (2008) and Roscigno et al. (2015) reported that families withdrew from their research as they no longer felt their child required support at school. It is further possible that families who experienced dissatisfaction with the return were more likely to agree to participate. This likely resulted in a skewed sample of CYP with ABI, reducing the scope for capturing the positive experiences/transitions that are also occurring. Positive experiences of returning to school are also important to investigate, as they provide insight into the facilitators of successful transitions. It is therefore important that future studies seek to capture this cohort of CYP and their families.

2.5.3 Researcher Reflexivity

All studies utilised qualitative designs and reported procedures to increase the trustworthiness of data analysis, such as multiple coders (Bate et al., 2021; Diener et al., 2022; Gagnon et al., 2008; Jimenez et al., 2020; Mealings & Douglas, 2010; Robson, 2005; Roscigno et al., 2015). However, very few studies acknowledged the reflexivity of the authors, and the impact of this on the research findings. Only one article explicitly stated their ontological position (Bate et al., 2021), and Gagnon et al. (2008) reported that the authors were of various epistemological positions that may have impacted their interpretations. The researchers of two articles kept a reflective journal (Sharp et al., 2006; Vanclooster et al., 2019). However, the way in which the reflections were utilised was not discussed further. The position of the researcher is important for understanding the context around the research and the interpretations of data. Therefore, this limits the ability to assess the rigour of the conclusions that were drawn (see Appendix A for the critical summary of the papers).

2.6 Literature Review Implication and Summary

2.6.1 Implications for the Current Research

The current literature demonstrates the complexity of elements that should be considered for CYP returning to school after an ABI. The literature identified two main phases of school return: organising the school return and being back at school. Emphasis was placed on the need for co-ordination between the systems around a child with ABI in order to support the transition process. This included educator training to allow them to understand the possible sequalae of ABI and work in a flexible way to support the individual needs of CYP with ABI.

In line with existing literature on ABI which has predominantly focused on the cognitive impacts, CYP with ABI experienced a range of academic and physical difficulties that required adaptations within the classroom. The research also drew attention to the socio-emotional needs of CYP with ABI, which appeared to be less understood and therefore less supported at school. Of significance in the literature, when considering socio-emotional needs, was the importance of social participation to CYP with ABI. In contrast to caregivers who predominately focused on the academic implications of ABI, CYP themselves focused on the social aspect of school. CYP described positive aspects of school return related to an increased SoSB, including supportive peer groups and school participation. However, for many CYP social participation was hindered by post-ABI difficulties, as well as the adaptations that school provided to support academic demands. Notably, an initial scope of the literature identified a paucity of studies that examined CYPs sense of belonging as part of their social-emotional development when returning to school following an ABI. However, while the current articles focused on general experiences of re-entry, the emerging themes of social support and social participation demonstrated that school belonging is a key area of focus during the transition back to school for children with ABI. Given the importance of belonging in Maslow's hierarchy of needs, it is crucial that educators are aware of these factors so that they can implement strategies and interventions to promote this in mainstream schools. The current research aims to explore factors that facilitate and hinder the development of school belonging for children with ABI.

In addition, the research demonstrated the value of exploring experiences from a range of individuals involved in the school return. Less than half of the research identified sought to explore the views of CYP themselves. The research that did capture the views of CYP showed that they hold valuable insight into their own needs (Mealings & Douglas, 2010); it demonstrated the importance of hearing these voices, particularly as the priorities of CYP may be different to the adults supporting them. Moreover, the identified research tended to focus on either eliciting the views of the CYP themselves, their caregivers or professionals. Given the identified importance of taking a systemic approach to support CYP with ABI, research is needed to bring together these different views. Few studies sought the views of multiple participant groups, allowing themes to be drawn across the participant groups. However, this research design prevented exploration of the ways in which the home and school systems around a CYP, including social contextual factors, interact to impact the return-to-school. Given that the decision making around how best to support a CYP is likely to occur between individuals in different groups, it is important to triangulate data with other relevant individuals within a shared system, such as school staff, EPs or families. The current research seeks to gain the collective voices of the CYP with ABI, caregivers and school staff about a shared experience, in order to better understand this process.

2.7 Chapter Summary

The purpose of this chapter was to review the literature on the process of CYP returning to school after an ABI, and to identify a focus for the current research that will help develop the understanding in this area. Thirteen articles were identified that sought the views of a range of individuals, including CYP with ABI, their parents and related health/education professionals. The research highlighted the importance of taking a holistic approach to reintegration. In addition to support for academic and physical needs, the need for socio-emotional support was also recognised. CYP raised the importance of fitting back in at school. This was typically associated with participation at school and social support, both of which are linked to a SoSB. However, despite a growing understanding of the importance of a SoSB for all CYP, the literature review found that current research has paid limited attention specifically to a SoSB for CYP with ABI. The current study will therefore bring together the experiences of different individuals within the key systems around a CYP with ABI, to better understand how to support CYPs SoSB after returning to school.

CHAPTER 3: Methodology

3.1 Introduction

As outlined in the introductory chapter, the aim of this research was to explore children's experience of returning to mainstream school after an ABI, specifically focused upon their SoSB. This chapter outlines how the research was undertaken and relevant considerations. Firstly, the ontological and epistemological perspectives, which informed both the adoption of a constructivist paradigm and the methodological decisions throughout this study, are outlined. The rationale for a multiple case study design is presented, with consideration given to the boundaries of this methodology. The research design and procedure are outlined, including participants, recruitment and data collection. The rationale for using reflexive thematic analysis (RTA) to analyse the data is provided, alongside a description of the analysis process. Finally, the ways in which rigour is established, and the ethical implications of conducting the research are addressed.

3.2 Purpose

This research has an exploratory purpose as the literature review demonstrated that limited attention has been given to the socio-emotional effects of ABI and the impact on children's sense of belonging at school during and after the school reintegration process. In addition, few studies considered the contextual influences on children, families and schools during the re-integration process. This research takes a systemic approach to understanding how specific contextual factors as well as different views of the members within a system can interact and influence the return-to-school process. By doing this, the research hopes to give a space for children with ABI to have their voices heard, in comparison to the previously marginalised position that is widely seen in the literature (Armstrong et al., 2016).

3.3 Researcher Stance

3.3.1 Ontology

This research was underpinned by the ontological belief (world view) that there are multiple realities, informed by our interactions and engagement with the world. This view contrasts with the realist position that research is in pursuit of the scientific 'truth' (Gergen, 1999). Based on a relativist world view, it is assumed that "individuals seek understanding of the world in which they live and work... [through]...subjective meanings of their experiences" (Creswell, 2007, p.8). By taking a relativist ontology, the researcher recognises that individuals will hold different perspectives of reality. It is therefore important that the experiences of different individuals within the systems that support school return for children with ABI (home and school) are explored.

3.3.2 Epistemology

Whilst ontology is concerned with the question of 'What is reality?', epistemology considers what knowledge is and how it can be acquired (Guba & Lincoln, 1994; Ormston, et al., 2014). A constructivist stance informed this research (Guba & Lincoln, 1994), accepting the view that individuals construct their own sense of meaning from their interactions with their environment and with other people. Therefore, it is important to understand individual lived experiences. However, the researcher also accepts that individual meaning-making is not devoid of systemic influence and therefore it is also important to understand the contextual landscape in which experiences are located (Pilgrim, 2020). When considering the return-to-school for children with ABI, this includes contextual factors at micro-level (family context), meso-level (school context), and macro-level (e.g., educational policy, statutory processes for EHCPs and funding pathways).

3.3.3 Reflexivity

Researchers are shaped by social, cultural and political contexts and previous experiences, all of which can contribute to assumptions and biases. Reflexivity is considered a core component of quality qualitative research (Finlay & Gough, 2008, Braun & Clarke, 2013). The researcher was aware of self-in-role during the process of data collection, analysis and interpretation (Mauthner & Doucet, 2003). As mentioned in the introductory chapter, the researcher's previous work in a neurorehabilitation centre and current EP training influenced the direction of this research. In addition to professional experiences, it is also important to consider the impact that personal experiences also have on values and beliefs. The researcher's experiences, beliefs and personal values that likely impacted on this research study are outlined below:

- The researcher has a chronic pain condition and associated fatigue, as the result of a road traffic collision over 10 years ago. The researcher is therefore directly aware of the substantial long-term impact that on-going injury can have, both physically and psychologically. This has likely heightened the researcher's attention towards the socio-emotional impact of ABI.
- Two years ago, the researcher directly experienced bereavement following the death of her sibling from a sustained ABI. Whilst bereavement by ABI is recognisably different to long-term injury by ABI, families often report feelings of grief related to multiple non-finite loss experiences (e.g., loss of the child they knew, altered hopes and potential future pathways for the child). This bereavement undoubtably increased the researcher's focus on the importance of considering the socio-emotional impact of

trauma on the systems around the child, particularly the family system, in addition to the way in which long-term support is provided.

- Tying the above points with those outlined in the introductory 'researcher position' section, is the belief that a child's development is influenced by wider systemic factors, and not solely biological factors. In line with Bronfenbrenner's (1992) ecological systems theory, this research endeavoured to explore and acknowledge the wider systems that exist within the lives of children who are returning to school following an ABI. In line with this, is the belief that returning to school needs to involve both the home and school system around the child.

In line with Korstjens and Moser's (2018) suggestions, the researcher kept reflexive notes that included subjective experiences, to raise awareness of potential biases. A journal was maintained throughout the study as reflexivity is argued to involve continual self-awareness regarding one's subjectivity (Finlay & Gough, 2008).

3.4 The Research Design

This research utilised a qualitative approach, informed by the ontological and epistemological positions outlined above. As the aims of the research were centred on exploring individual experiences, a case study research strategy was utilised. Previous research identified in the literature review had drawn themes from the experiences of groups of individuals (e.g., parent or child). However, there is concern that by doing this, that unique and contextual information is lost. Given the importance of both home and school systems, it would limit the research to study individual cases devoid of their context. This research therefore adopted a multiple-case design, focusing on two children and the home and school systems around them. Grounded in Bronfenbrenner's ecological systems theory (1992), a case study approach allowed for the child's return to school following an ABI (phenomenon) to be explored in-depth within the home and school context (Robson & McCartan, 2016). A multiple case study design enabled similarities and differences between and within the cases to be explored. This allowed the researcher to learn about the phenomenon of school return post-ABI, whilst still capturing the unique contextual factors that impacted those individual children, their families and schools.

Individuals within each case (child with ABI, parent/s and school staff) were interviewed to gain their views and experiences. The data was subsequently analysed using Reflexive Thematic Analysis (RTA) to extract themes related to the school return, ways that a SoSB was facilitated and ways that it was challenged (Braun & Clarke, 2006). Analysis sought to draw themes between individuals within a system (child-home-school) as well as across cases. In addition, RTA acknowledges that researchers play an active role throughout the research process and therefore this process is relational (Finlay, 2006). This again was coherent with the relativist ontology adopted by this research.

Alternative methodological approaches were considered including Grounded Theory (GT) and Interpretative Phenomenological Analysis (IPA). GT is focused on using the data to develop a theoretical framework (Glaser & Strauss, 1967). The literature review showed that there is currently limited research on the process of returning to school after an ABI. Therefore, further exploratory research is required prior to explanatory investigations offered through GT. This research aimed to start to bridge this gap. In addition, IPA has an ideographic focus. Whilst IPA would have offered a route to delve into the experiences of children with ABI, this research aimed to take a systemic approach by also understanding the perceptions of their parents and teaching staff.

3.4.1 Sample Size

Braun and Clarke (2022) suggest that 6 to 10 participants are acceptable for a ‘small’ qualitative project to provide enough data to observe patterns without becoming unmanageable. The research sought to explore two children’s transition back to school following an ABI, gaining information from the child themselves, parents and school staff. The concern was that the more case studies included, the more diluted the experiences of those become. Two case studies allowed for a multiple case comparison, whilst still providing rich in-depth data. A small sample size was decided upon to allow for rich, in-depth data.

3.4.2 Research Strategy

3.4.2.1 Participant Criteria

This study sought to interview children who had returned to mainstream school following an ABI, their parent/s, and one or two key school staff. To be included in this study, children had an identified moderate/severe ABI. This demographic was chosen because the majority of CYP with mild TBI or concussion recover within 1-3 months (Lumba-Brown et al., 2018) compared to children with moderate/severe ABI who typically experience life-long challenges (Jantz & Bigler, 2014). Children needed to be of school-age, have attended a mainstream provision prior to the ABI, and returned to school in the last two years. The two-year time scale was chosen to ensure that the research was not reliant on retrospective accounts, which can often be skewed by memory biases and the hindsight effect. CYP with moderate/severe developmental disability prior to the ABI were excluded as this may have confounded the findings. Data collection aimed at primary school children (5–11-year-olds), because it was acknowledged that experiences of school return are likely to be different in primary and secondary education. Please see Table 2 for full inclusion and exclusion criteria.

Table 2.

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria	Rationale
Sustained a moderate/severe ABI	Sustained a mild brain injury or concussion	The impact of a moderate/severe ABI is long-term, and therefore the support required will likely be more significant.
Currently in primary education (aged 5-11)	Currently in secondary education	It was acknowledged that experiences of school return are likely to be different in primary and secondary education.
Returned to the same mainstream school	Returned to a different school	If children did not return to the same school, staff will not have an understanding of the child's development pre-injury.
Returned to school in the last two years	Returned to school >2 years ago.	To prevent the research being reliant on retrospective accounts, which can introduce more bias.
	Children with identified developmental disability prior to sustaining an ABI	A pre-existing disability prior to their ABI may impact how a child perceives a SoSB.

3.4.2.2 Recruitment

Participants consisted of a purposive sample of children, their families and school staff from England. Due to the small cohort of possible participants, the research information was distributed in multiple ways via an advert (See Appendix B). The researcher contacted hospitals with neurorehabilitation centre beds and paediatric neurorehabilitation centres, and asked them to share the research poster with families. The researcher was aware that recruitment via neurorehabilitation facilities would only access a group of children who received intensive rehabilitation care. However, there are many children who are discharged home straight from hospital and it was recognised that their return to school may look different. The advert was therefore also posted on forums for families of children with ABI, and professionals (e.g., EPNet), and distributed to schools in England via an email to the Head Teachers.

The research advert provided contact details for families and/or schools to contact the researcher directly to express their interest in participating. At this stage of recruitment, the researcher received interest from a range of parents and school staff who wanted to share their experiences, but where the children had returned to school at least three years prior and therefore did not meet the inclusion criteria. For families/staff where the child met the inclusion criteria, they were offered a remote consultation to find out more about the research and arrangements were made for the researcher to visit the school to complete the interviews. Details of the final participant groups can be seen in Table 3. All names have been pseudo-anonymised.

Table 3.

Participant Information

Interview	**Case Study 1: Valerie's return to school**		**Case Study 2: Leo's return to school**	
Child	*Valerie*	Aged 6, Year 1 White British Female Non-traumatic brain injury in Reception: Brain tumour diagnosed and surgically removed Returned to same school in Reception Year	*Leo*	Aged 6, Year 1 White British Male Traumatic brain injury in Reception from a fall at school Returned to same school in Reception Year
Parent(s)	*Mother & Father*	White British Family of seven	*Mother*	White British Family of six
School Staff	*SENCo* *Class Teacher*	Both White British Females Church of England Primary School, in England	*Class Teacher*	White British Female Academy Primary School, in England

	One form entry school. Approximately 250 students across Reception to Year 6	Two form entry school Approximately 420 students across Nursery to Year 6
	Rated ‘good’ at last OFSTED (2017)	Rated ‘good’ at last OFSTED (2023)

3.5 Data Collection

3.5.1 Interview Data

Narrative interviews were used to enable a dialogue and allow for detailed, in-depth exploration of personal experiences (Ritchie et al., 2013). Interviews were semi-structured to ensure that key areas of interest in relation to the research question were covered, whilst providing space for participants to share the experiences pertinent to them (Coolican, 2014). In preparation, the researcher designed key interview prompts with main areas of focus and possible questioning (see Appendix C). However, given the narrative nature of the interviews, these prompts were used to greater and lesser extent depending on the interviewee and their direction of focus in the interviews.

3.5.2 Interview Procedure

Interviews took place in June and July 2023. Face-to-face interviews were conducted with the parent/s in a private room at the child’s school, followed by the child interview. One staff interview was also conducted face-to-face at school. However, the remaining adult interviews took place online due to school timetabling constraints. This was not deemed to be problematic, as the video calls still allowed for non-verbal communication (e.g., body language, facial expressions, gestures). All adults participating in the research were provided with the information sheet and consent form prior to the interview (See Appendix D). However, to ensure full informed consent, at the start of all interviews, the researcher checked the participants understanding of the research, provided opportunity for questions or clarification, and obtained verbal consent. Interviews lasted approximately one hour with staff, and one and a half hours with parent/s. Adults also received a debrief sheet which signposted to various websites and charities they could seek additional support from post-interview if they felt they required it (Appendix E).

3.5.3 Eliciting Child Views

Parents provided consent for their child to participate in the research (see Appendix F). At the start of the interview, the children were also shown an age-appropriate information sheet with visuals (Appendix G) and provided assent to participate. Interviews were conducted in a private room at the child's school. Both children declined an offer of a familiar adult to stay in the room with them during the interviews. The interview lasted approximately one hour. It was posited that the interviews may need to take place over multiple days rather than in one session, as fatigue is a commonly reported sequela following an ABI (Wilkinson et al., 2018). However, both children completed the interview in one sitting with a short break halfway through. The initial stage of the interview focused on rapport building. During the interview, the children were provided with pens and paper, and given the option of talking and/or drawing. Given the children's ages, the 'bear feeling cards' (Qcards, 2010) were used as a stimulus for identifying feelings and emotions when relevant during the interview, for example, when the child was unable to articulate a feeling. A selection of 'bear feeling cards' were laid out on the table, and the researcher invited the children to select a bear that represented how they were feeling.

3.5.4 Reflexive Journal

The researcher recorded initial thoughts and reflections following the interviews. This continued throughout the transcription phase, in keeping with researcher reflexivity (Nowell et al., 2017). By documenting emerging thoughts, ideas and interpretations, the researcher remained aware of their perceptions and beliefs throughout the analysis process.

3.5.5 Transcription

Interviews were recorded using Microsoft Teams inbuilt recording and a Dictaphone for later transcription. Only audio recording was retained to minimise participant identification. This was deemed important given the vulnerability of the children in this study. The audio recordings were transcribed verbatim and checked multiple times against the original audio. A clean verbatim technique was used so that filler words such as ‘ums’ and ‘erms’ were removed, and only significant pauses remained. Participants were encouraged to use a pseudo-name or initials during the interviews. However, this proved challenging, particularly during emotive conversations. Therefore, the researcher removed all identifying names/information from the written transcript. All data received was destroyed following analysis.

3.6 Data Analysis using RTA

Transcripts from all interviews were analysed using RTA following the six phases outlined by Braun & Clarke (2021). Whilst presented in linear phases below, it should be noted that the process was in fact iterative, reflexive and recursive.

3.6.1 Phase 1: Familiarisation

Following transcription, the researcher familiarised themselves with the data through repeated listening of the interview audio and re-reading of the transcriptions. Active reading was utilised, whereby initial perceptions and salient thoughts were noted so they could be reviewed during subsequent phases.

3.6.2 Phase 2: Data Coding

For each case, interviews were coded in the order of child, parent, school staff. To ensure that any disparity or differences between individual accounts were not disregarded (Braun & Clarke, 2013), data was coded separately for each participant. To familiarise themselves with the data, the researcher initially completed line-by-line coding by hand using printed transcripts. Codes were then collated and organised using the data analysis software MAXQDA (see Appendix H).

Data coding followed an inductive approach, allowing the participants narrative to emerge from the raw data. One could argue that data coding cannot truly be inductive due to the researcher's prior knowledge and experiences. Braun & Clarke (2021) emphasised the importance of reflexive practices at this stage so that the researcher is aware of the influences on their sense-making. In addition, to reduce the level of interpretation at this stage, semantic codes were initially developed utilising the participants language. Latent coding was subsequently used to identify underlying meaning from the quotes (Boyatzis, 1998).

3.6.3 Phase 3: Generating Initial Themes

Phase 3 involved generating candidate themes. Cross-case synthesis of the children's interviews was conducted first. Codes from the children's interviews were collated, reviewed and grouped in MAXQDA. Based on patterns of meaning between the codes, central organising concepts were identified. Within-case analysis was subsequently conducted with codes from the parent and staff interviews in each case study collated separately, reviewed and again grouped in MAXQDA.

3.6.4 Phase 4: Reviewing and Developing Themes

The candidate themes were reviewed to check their viability. This involved re-engagement with the data set and coded extracts to examine the coherence of the themes and pattern development. Once this was done, the review was expanded to the entire data set to explore participant-theme correspondence. Once themes were established, a cross-case synthesis (Yin, 2014) thematic map was created for the children's experiences, and within-case thematic maps were developed for each case study.

3.6.5 Phase 5: Refining, Defining and Naming Themes

Theme definitions were written for each theme, addressing the four questions set out by Braun and Clarke (2022):

- What is the theme is about (central organising concept)?
- What is the boundary of the theme?
- What is unique and specific to each theme?
- What does each theme contribute to the overall analysis?

Theme names were established and quotations from transcripts that supported each theme's definition were collated for use within the thesis.

3.7 Rigour of the Research

While quantitative research uses reliability and validity measures to establish the rigor of research, qualitative research examines trustworthiness. Trustworthiness is considered in terms of credibility, dependability, transferability and confirmability. According to Sandelowski (1993), researchers conducting qualitative research must make their practices visible and auditable in order to meet these quality criteria. Korstjens and Moser (2018) further suggest that reflexivity is an important component of qualitative research. These key concepts are considered below in relation to the proposed research.

3.7.1 Credibility and Confirmability

Credibility refers to the degree to which the research findings provide a correct interpretation of the data (Korstjens & Moser, 2018). This research employed methods of triangulation as suggested by Gunawan (2015) to gain a holistic view of the system around the child. It triangulated data by also interviewing the parents of the child with ABI and school staff involved with these children, not observed in the previous studies identified by the literature review. Both Guba and Lincoln (1989) and Gunawan (2015) advocate for the use of member checks as a way of establishing credibility. Whilst member checks were not carried out post-interview, the researcher utilised summarising and clarification techniques throughout the interviews to check understanding and meaning. Moreover, to ensure that the analysis was grounded in the participants experiences, direct quotes from the participants interviews were used to demonstrate the themes.

Confirmability is degree to which research findings are also confirmed by other researchers. This research did not utilise inter-researcher reliability checks during RTA, as this counters the relativist stance taken. However, measures were taken to increase the confirmability. Interviews were recorded to ensure that transcription was accurate. The researcher used clear coding schemes in MAXQDA which allowed for the research to be repeatable and the process of RTA was iterative, meaning that the data was checked and rechecked during analysis.

3.7.2 Dependability

Dependability refers to the extent that the research could be repeated by other researchers and consistent findings will be obtained. One way in which dependability is created is through transparency. According to Sandelowski (1993), researchers conducting qualitative research must make their practices visible and auditable in order to meet these quality criteria. The interviews were recorded so that transcripts were verbatim, providing scope for the data to be checked. The researcher documented their decision making throughout the analysis process. They used MAXQDA to label and code their data, which allowed the codes to be re-checked with the interview transcripts, further offering transparency.

Korstjens and Moser (2018) further suggests that reflexivity is an important component of qualitative research. Intrinsically linked to transparency, reflexivity refers to the researcher's transparent recognition of their own biases in role. These were reflected upon in both the introduction and at the beginning of the methodology section. Both personal and professional experiences, values and beliefs will have inevitably influenced the research process and outcomes. Reflexivity was used throughout the research process to attempt to mitigate these (Jootun et al., 2009).

3.7.3 Transferability

Case studies are critiqued for their inability to generalise to wider contexts, as is often the goal with quantitative 'positivist' research. However, generalisation is not the aim of the case study design nor coherent with the researcher positioning. Stake (2006) argued that "the power of case study is its attention to the local situation, not in how it represents other cases in general" (p. 8). Therefore, there are no claims about the replication of this research. Instead, it is more helpful to consider the transferability of the research. Transferability refers to the way in which the study findings apply to similar settings or individuals. Stake (2006) argued that multiple case study approaches offer transferability as they allow for comparison across different contexts. Notably, Korstjens and Moser, (2018) argued that it is not the researchers position to assess transferability. Instead, it is the researcher's role to provide detailed, clear descriptions of both the participants experiences and the research process, in order for the reader to make judgements as to transferability.

The researcher also recognised the limitations of this research design, such as the sample size and contextual inferences only being made in relation to the settings explored in the original research. Therefore, the findings from this research will not transfer to other educational institutions such as higher education settings, where different mechanisms may be at play.

3.8 Ethical Considerations

As professionals, Educational Psychologists must also adhere to the HCPC 'Standards of Conduct, Performance and Ethics' (2016) and the BPS's 'Code of Ethics and Conduct' (2021). In addition, according to the BPS (2021) Code of Human Research Ethics, psychology researchers must actively identify, analyse and address any ethics issues that may arise in their research. The researcher encountered challenges gaining ethical approval due to the vulnerability of children with ABI, and experienced time delays in conducting the research as a result. Ethical approval for this research was obtained from the NHS Health Research Authority (HRA) and the following measures were taken to ensure the research was ethical. See Appendix I for confirmation of ethical approval from the HRA.

3.8.1 Involving Vulnerable Children in Research

It has been argued that researchers should consider the necessity of involving children to answer the research questions (Greig & Taylor, 1999). This is especially the case with children with ABI, who are likely to have medical and learning needs that increase their vulnerability. The focus of this research was examining the experiences of returning to school. To not involve children in exploring a situation that surrounds them, are we saying that they have nothing meaningful to contribute? Previous research suggests that children have awareness of what is helpful and unhelpful to them (Mealings & Douglas, 2010) and can share their views. Therefore, it was important to include children with ABI in the research design. As such, careful consideration was given to the ethics of involving CYP in the research.

Whilst it has been noted that it is difficult to gain informed consent from children, the researcher ensured that the children understood the purpose of their involvement. As mentioned previously, the research was explained in age-appropriate terms, alongside visuals to support understanding (Appendix G). In addition to informed parental consent, the researcher sought informed assent from the children (Robson, 2002). If children had refused assent, then the interview would have been discontinued.

3.8.2 Emotive Interview Content

The research was designed and undertaken on principle of "avoiding potential risks to psychological well-being, mental health, personal values, or dignity" (BPS, 2021, p9). The researcher acknowledged the psychological impact associated with the discussion of emotive experiences. All participants were in a private room at the child's school (both remote or in person) for the duration of the interviews. This meant there was a trusted adult nearby, who could offer support if required. Children were also invited to have a trusted adult with them in the interview. As a trainee Educational Psychologist, the researcher was well positioned to recognise discomfort or distress and to ensure that if this was the case the interview was terminated. This was, however, not required. All adults received clear signposting to various charitable organisations, support websites and forums that they could utilise after the research period, if they felt they needed additional emotional or psychological support.

3.8.3 Power Imbalance

In all research, there is a power imbalance between the researcher and participants. Compared to quantitative research, qualitative inquiry is argued to redistribute power differences by encouraging authenticity between researcher and participant (Karnieli-Miller et al., 2009), and focusing on marginalized understandings and experiences (O'Connor & O'Neill, 2004). However, the researcher believes this to be paradoxical as 'giving voice' to individuals and 'allowing' their story to be heard through research constitutes a power imbalance itself. The researcher grappled with this throughout this research, and considered ways that the power could be shifted. Firstly, at recruitment, participants were not sought directly; instead, they were invited via the advert to contact the researcher if they were interested in participating. Additionally, the chosen case study approach is argued to minimises the distance between the participant and the researcher (Creswell, 2007). The researcher remained conscious to the fact that the contribution of both researcher and participant is necessary for research to occur. During data collection, the researcher also utilised a true listening ethos throughout the interviews, to ensure that participants were heard effectively (Armstrong, 1995; Gersch, 1996). Moreover, an inductive approach to the data analysis was adopted to ensure that the participants voices remained central to the research (Azungah, 2018). Finally, critical reflexivity increased the researcher's awareness of how their actions may impact the participants throughout the research process and ongoing consideration of the power dynamics between the researcher and participants.

3.8.4 Confidentiality

In line with the Data Protection Act (2018), all data obtained through the research was stored on a password protected laptop and de-identified. All interview recordings were transcribed, pseudo-anonymised and deleted following completion of the analysis process. This ensured that no identifiable data was retained for longer than necessary.

CHAPTER 4: Findings

4.1 Chapter Overview

The current chapter outlines the findings following the data analysis process. Firstly, contextual information is presented for the two children of focus in the case studies. The themes emerging from the interviews with the children are then presented to address the initial research question on how children with ABI experience barriers and facilitators to a SoSB when returning to mainstream school after an ABI. Thematic maps from the two case studies are subsequently presented separately, to examine how children's perceptions of a SoSB interact with the perceptions of key adults within the home and school systems. It is notable that whilst presented separately, the themes identified through the research were not mutually exclusive and instead appeared to be highly related.

4.2 The Children Involved in This Research

This section provides information about the two young people at the centre of each case study, Valerie and Leo. Context is provided regarding the background to their ABI, and medical treatment prior to returning to school.

4.2.1 Valerie

Valerie was six at the time of interview, and in Year One. She lived at home with her parents and siblings. Valerie started at her current school at the start of the reception school year, following a recent family relocation into the area. Valerie began displaying neurological symptoms eight days after starting reception. She was subsequently diagnosed with a brain tumour near her brain stem, requiring invasive surgery to remove it. Valerie was four at the time. Following surgery, Valerie remained in the hospital for five days before being discharged home. She returned to her previous reception class after the October half-term on a graduated timetable, starting with approximately 20 minutes a day. Her mother accompanied her at all times. At the time of interview, Valerie had increased her hours to independently attending school for two mornings and two afternoons a week.

4.2.2 Leo

Leo was six at the time of interview, and in Year One. He lived at home with his parents and siblings. Leo started at his current school at the beginning of the reception school year. In the spring term of reception, at the age of five, Leo fell and hit his head at school during free play. Leo suffered an extradural haematoma and underwent an emergency craniotomy. Following surgery, Leo remained in the hospital for a week before being discharged home. Leo returned to school approximately seven-eight weeks later, on a graduated timetable. His attendance increased back to full-time towards the end of the summer term of reception.

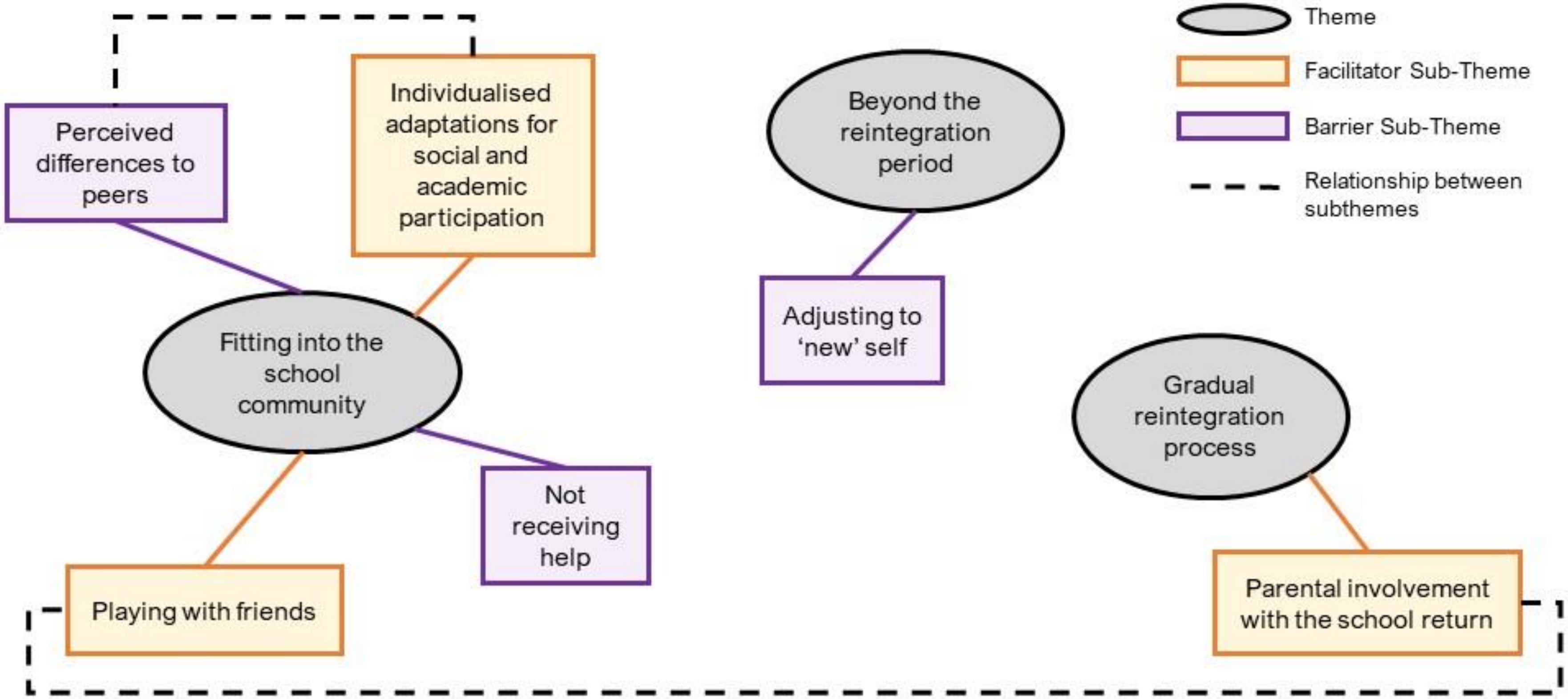
4.3 RQ1: Experiences of Children Returning to School Following an ABI

How do children experience barriers and facilitators to a SoSB when returning to mainstream school after an ABI?

Cross-case synthesis of the children's interviews was conducted, to gain an understanding of how Valerie and Leo experienced a SoSB when returning to mainstream school after an ABI. In line with Personal Construct Psychology, cross-case synthesis analysis of the children’s interviews amplified the voices of the children, who are often the quietest in the system. This direction of analysis was also consistent with current legislation (CoP, 2015) and HCPC Standards (2016), which emphasise the importance of keeping CYPs views central to decision-making. From the analysis of the children’s interviews, three themes were identified in the data (See Figure 5). These were: the Gradual Reintegration Process; Fitting into the School Community and Beyond the Reintegration Process. The themes were comprised of various sub-themes, created to understand the data more clearly. Direct quotations from the participants’ transcripts are included to demonstrate the themes, alongside any ‘Bear feeling cards’ (Qcards, 2010) selected by the children to help identify their feelings.

Figure 5.

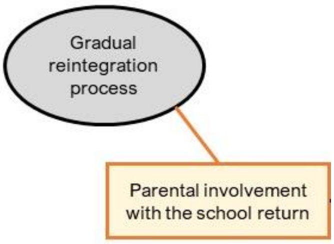
Thematic Map Depicting Valerie and Leo's Experiences When Returning to School Post-ABI



4.3.1 Theme 1: Gradual Reintegration Process

Figure 6.

Visual Depiction of Theme 1 and Subtheme



4.3.1.1 Subtheme: Parental Involvement With the School Return

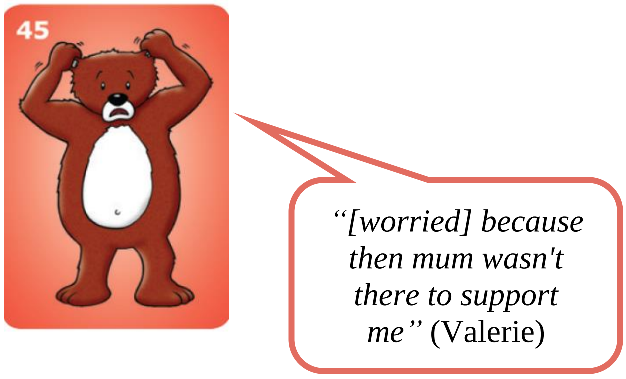
Both children highlighted the importance of their mothers staying with them in school when they first returned. This allowed the children to leave when they were starting to feel tired or unwell.

> *"I only stayed like there for a little bit. But when I said I wanna go home. I just like go to my mum and like say 'I wanna go home.'"* (Leo)

Valerie also described the importance of having her mother with her when she first returned to school, as she was relearning to walk during this time. Her mother helped her to participate at school ("my mummy had to help me. We have stuff in reception, like climbing. I couldn't actually do things. My mum had to carry me around and I couldn't speak") but also to keep her physically safe ("Mum was there to catch me if I fell"). Valerie identified that she would have felt more worried about returning to school in reception if her mother hadn't attended with her (Figure 7).

Figure 7.

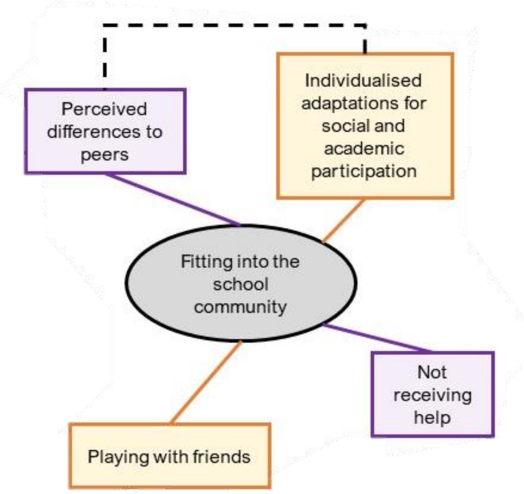
Valerie's Feelings if Her Mum Hadn't Been Part of the Transition



4.3.2 Theme 2: Fitting Into the School Community

Figure 8.

Visual Depiction of Theme 2 and Subthemes

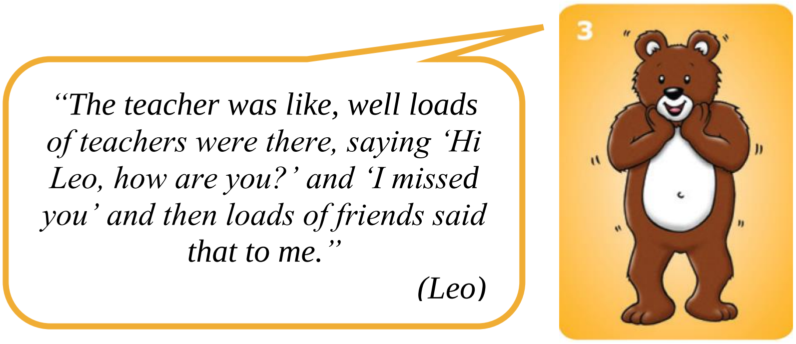


4.3.2.1 Subtheme: Playing With Friends

Being able to play was the most dominant narrative throughout the child interviews. Both children reported feeling sad when they were at home and wanting to return to school to play. Leo was glad to be back because he missed his friends and wanted to play with them. He described how members of the school community acknowledged his return, which also made him feel happier (Figure 9).

Figure 9.

School Acknowledged Leo's Return

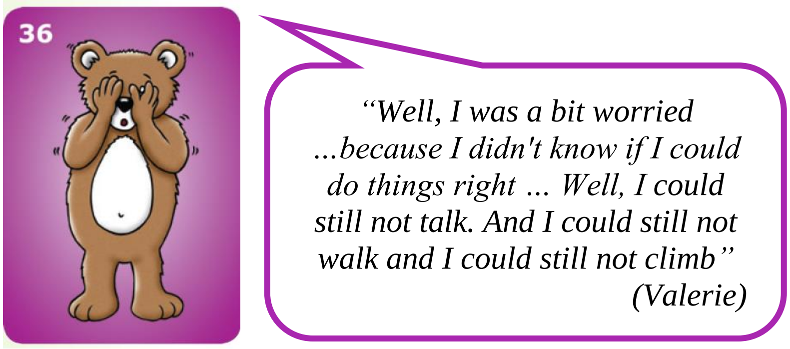


"The teacher was like, well loads of teachers were there, saying 'Hi Leo, how are you?' and 'I missed you' and then loads of friends said that to me."
(Leo)

Whilst Valerie was also keen to return to school, she identified feeling nervous about the return (Figure 10). Her worries related to her limitations post-ABI, and the impact on her ability to participate in school activities including playing.

Figure 10.

Valerie's Worries About Returning to School



"Well, I was a bit worried …because I didn't know if I could do things right … Well, I could still not talk. And I could still not walk and I could still not climb"
(Valerie)

Similar to Leo, “playing with my friends” helped Valerie to feel happy at school. Valerie reported that the other children helped her by playing the games that she wanted to play. This meant that despite having some mobility difficulties, she was included in the play.

4.3.2.2 Subtheme: Perceived Differences to Peers

Following the reintegration process, Leo outlined things that made him feel different to his peers. Many of these centred around procedures that were implemented to maintain his safety post-ABI. Firstly, whilst both children initially described the graduated return as helpful, Leo expressed his frustration at not being able to stay at school full-time. He reported that his peers had noticed his absence and this made them upset:

> *“But my friend was crying because he thought I was staying at school but it was only like for a short hour.”* (Leo)

In addition, whilst Leo felt physically able, he was restricted from participating in physical activities at school due to risk of further head injury. Leo recalled his peers playing when he couldn’t: “The children were already playing and I was like ‘where’s my play?” Leo was unable to join his peers outside at break and lunch times, which made him “not very happy” because he was by himself. His friends also noticed that he wasn’t joining them outside for playtime and kept saying “why [are] you in there?” Mid-way through Year One, Leo was able to join his peers in the playground. However, Leo recalled having to wear a “yellow bib” (hi-visibility jacket) which he hated. He reported that yellow bibs were worn by the children in reception, and so he was mistaken for being in a younger year group.

> *“Not very good because everyone was saying ‘you are supposed to be in foundation’ and I keep saying ‘no, I'm in year one’ .... I always looked like foundation”* (Leo)

Notably, Leo focused on perceived differences to peers to a greater degree than Valerie who focused more on her personal differences post-ABI (see Adjusting to 'New' Self subtheme). As such, she seemed more accepting of individualised adaptations if it meant she could engage better with the learning in the classroom (see below Subtheme: Individualised Adaptations for Social and Academic Participation).

4.3.2.3 Subtheme: Individualised Adaptations for Social and Academic Participation

Both children spoke of individualised adaptations at school that helped them to feel a greater SoSB. These included adaptations to support participation with peers (e.g., facilitated break out spaces with one or two peers at break and/or lunch time), in the school environment (e.g., eating lunch in a quieter environment) and with learning (e.g., differentiated work). Valerie also found it helpful to go back to reception for phonics sessions.

Specific adult support was identified to be a key facilitator to both children's participation at school and engagement with learning. At the time of interview, Leo had a one-to-one throughout the day. Leo showed conflicting feelings around having a one-to-one which he found challenging to articulate. He identified that it made him feel like the image in Figure 11, suggesting that whilst having a one-to-one increased the visibility of his ABI, Leo recognised their importance for maintaining his safety.

Figure 11.

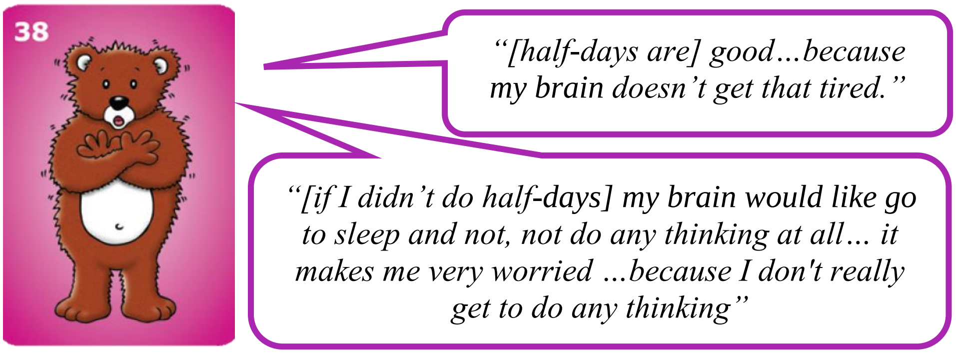
Leo's Perceptions Around Having a One-To-One

Leo spoke about how having a one-to-one meant that some of the provision that made him feel different to his peers (see subtheme: Perceived differences to peers) was no longer required. For example, as his key adult accompanied him during unstructured times, "every teacher said 'you can take off your bib now'" and this made him feel happy. Therefore, for Leo, the benefits of having a key adult for his social participation, outweighed the perceived differences that came with having a one-to-one.

While Leo discussed how adult support positively impacted his social participation, Valerie focused more on how adult support enabled her to participate with the learning activities. She spoke positively about having a helper when she was in reception for academic support and recalled a recent maths lesson in which she felt happy because an adult worked with her and read her the questions. Valerie also highlighted the importance of individualised adaptations to promote the quality of her time in school. At the time of interview, Valerie was still on a reduced timetable, attending school four half-days a week. In contrast to Leo who wanted to return to school full time like his peers, Valerie spoke positively of the reduced timetable, and its necessity due to her fatigue (Figure 12).

Figure 12.

Valerie's Perceptions of Her Reduced Timetable



By building in structured breaks throughout the week, it meant that when Valerie was in school, she could fully engage with her peers and participate in the learning. Therefore, it ensured that her time in school was most meaningful.

4.3.2.4 Subtheme: Not Receiving Help in Class

Valerie also identified a range of things she found difficult post-ABI that she didn't feel she had received help for in school. She identified aspects of the school environment that made learning more challenging to her following her ABI, including the noisy classroom, which affected her participation with learning activities. Valerie also compared learning at school to learning at home. At home, Valerie got to have "lots of breaks" when she needed it. She identified that at school it would help to have a break in a quiet location to do "some quiet colouring or have a little walk ... or look at a book." Valerie reported not getting these breaks at school, and was unsure why teachers weren't providing them. In addition, at home Valerie was taught one-to-one with her mother. In comparison, Valerie found it difficult to obtain help in the classroom and perceived the adults to be unresponsive to her needs.

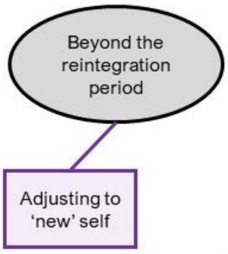
> "*Yeah, I've tried to put my hand up. But they don't want to look at it. They don't really see it at all.*" (Valerie)

This subtheme centred around the availability of key adult support in school, accounting for why it emerged in Valerie's interviews and not Leo's. As Leo had one-to-one adult support at the time of the interview, many of the barriers noted by Valerie were ameliorated by the flexibility that a key adult provided. Consistent with this, when asked if there was anything she would change to make school better, Valerie identified that she would want to "make a helper appear." She believed an adult helper would be good as they could explain things to her when she didn't understand and repeat things when she couldn't hear the teacher.

4.3.3 Theme 3: Beyond the Reintegration Period

Figure 13.

Visual Depiction of Theme 3 and Subthemes



4.3.3.1 Subtheme: Adjusting to 'New' Self

Another subtheme throughout the interviews was the impact of the ABI on the children's sense of self, and their need to adjust to their post-ABI identity. Although Valerie showed a greater awareness of her ABI compared to Leo, both children showed awareness of the difficulties they were experiencing. They identified a range of negative emotions linked to their ABI including feeling sad, worried and nervous. In addition, both children reported feeling angry by things they were finding difficult post-ABI (See Figure 14). For Leo this was his memory and forgetting. He recalled that “when I didn’t have that [ABI] I could like remember stuff.” For Valerie, she felt angry about her processing speed as she couldn’t complete her work in the allocated time.

Figure 14.

Both Children Reported Feeling Angry by Things They Were Finding Difficult Post-ABI

“If I normally can't finish my work in time … someone comes to collect it and the teacher checks that it’s right … she just puts a red dot or line in my book. And we have to start all over again.” (Valerie)

“I just don't know cause my like, my mum says like ‘stop forgetting’ and I was like ‘I can’t’ cause I use all my head, and my body keep forgetting stuff. And it’s tricky.” (Leo)

In addition, both children expressed worries about their ABI and future implications. Valerie wished she didn’t have her brain tumour because it was making lots of things difficult. She spoke of her worries about “having another big injury” and how she tried to think about “mermaids and princesses” to distract from these worries. Leo was worried about secondary school because people wouldn’t know he had a bump on his head. When asked if they had a magic wand and could change anything, what they would change? Valerie identified the following three things: to have a fish tank in the classroom with mermaids in to look at when feeling worried, to have a helper and to not have a brain injury at all. Leo identified that if he had a magic wand, he would change the following: the writing to be easier by getting rid of the hard words, and getting rid of peas when he had sausage and mash. Whilst some of these ‘wishes’ demonstrate the difficulties these children had with adjusting to their ABI, they also demonstrate a key message: children with ABI are children who are adjusting to a whole new world, whilst still navigating the existing complexities of childhood self-discovery.

4.4 RQ2. Perceived Factors Affecting SoSB Across the Wider System

To what extent do the perceived factors affecting school belonging differ across the home and school systems around a child with ABI?

To explore how the perceived factors affecting school belonging differ across the systems around a child with ABI, within-case analysis was also conducted. Themes were identified for each case study, and two thematic maps were produced. These are presented in turn below for Valerie (Case 1) and Leo (Case 2). Pertinent subthemes from the children’s interviews are shown faded in each thematic maps, to demonstrate their relationship with the wider systems.

4.4.1 Case 1: Valerie

The total number of interviews for Valerie’s case study is summarised in Figure 15. Please see Section 3.4.2.2 (Methodology Chapter) for further details about the participants.

Figure 15.

A Visual Representation of the Participants in Case Study One

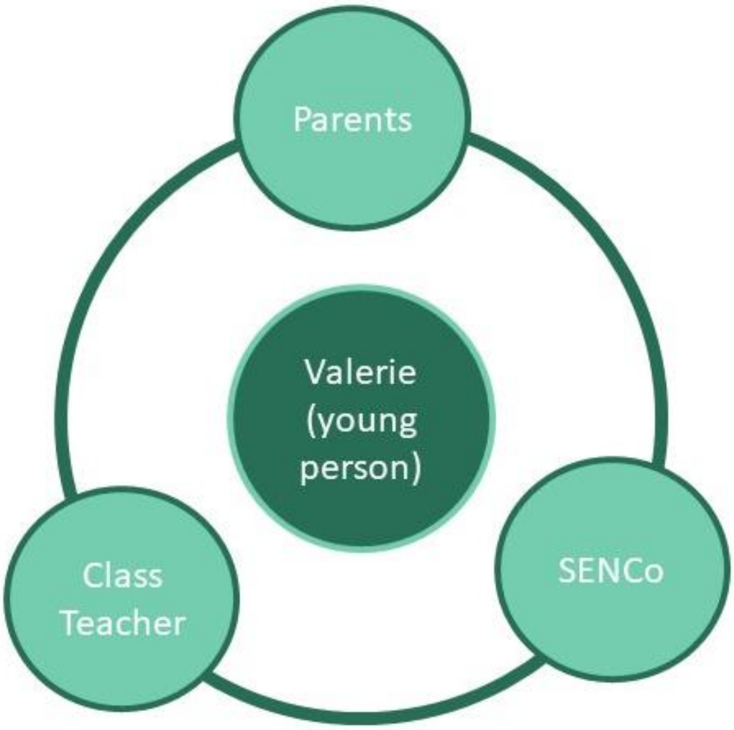
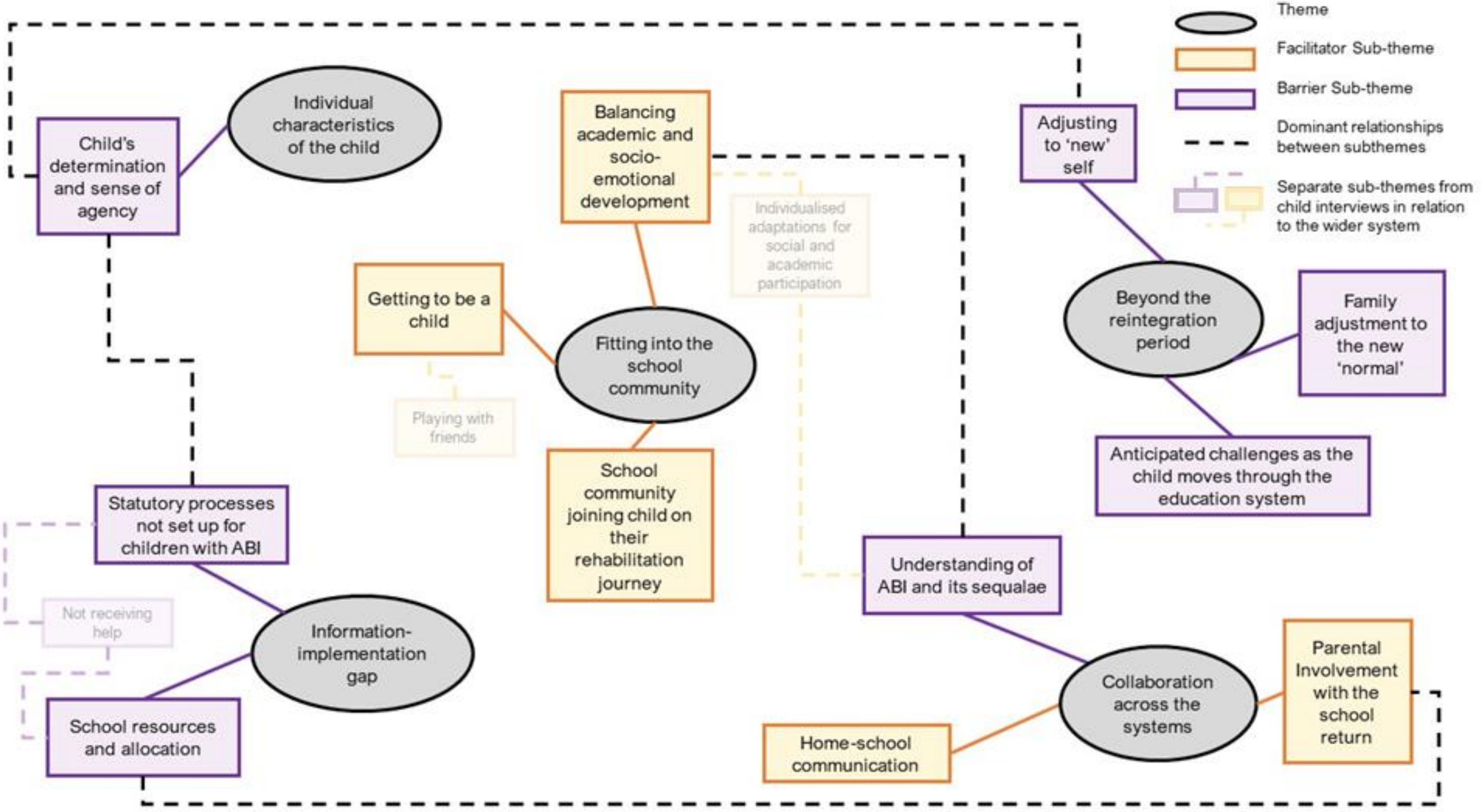


Figure 16.

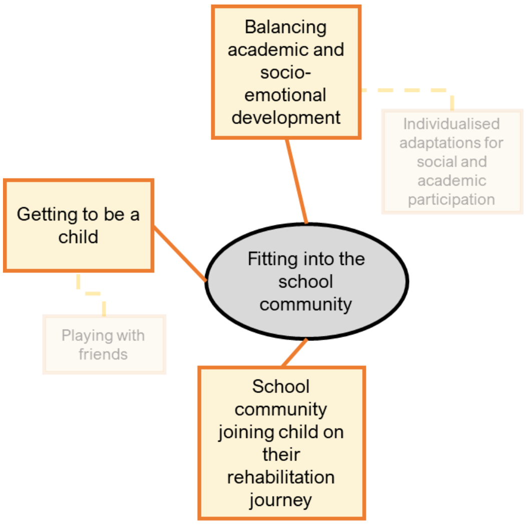
Thematic Map for Case Study One



4.4.1.1 Theme 1: Fitting Into the School Community

Figure 17.

Visual Depiction of Theme 1 and Subthemes



4.4.1.1.1 Subtheme: Getting to be a Child

When returning to school, Valerie's parents expressed their concerns that Valerie had only attended school for eight days prior to her illness, and hadn't had time to establish friendships. She therefore "had to like make friends and fit in amongst that group of kids who've then had a term [together]." However, they found that returning to school provided a sense of normality for Valerie, allowing her to experience the typical things a child experiences such as peer interaction. This fit with the subtheme that emerged from the children's interviews of 'Playing with Friends' whereby the social aspect of school and playing with peers was important. Valerie was "absorbed" by the class which supported her SoSB, and gave her the motivation to want to get stronger to participate in school alongside her peers.

> *"She's surrounded by physios and OTs and oncologists and neurosurgeons and grownups who are helping her, which is all fine, but she's a kid and she just needed to*

> *be a kid and she got distracted from how difficult things were by the fact that the class just absorbed her back in again.*
>
> *And they just passed her a doll or a pen or whatever, and she'd just take it rather than seeing it as like a physio task, or something's going to be difficult. She just wanted the pen, so she took the pen. She just wanted to wash her own hands. So she washed her own hands. She just stopped thinking about it in a medical sense. She just existed and it made so much difference to how quickly she improved. She just flew when she was back at school, and bearing in mind she was only in school like for a maximum half an hour, four days a week. It wasn't much at all. It just gave her being a child back."* (Valerie's mother)

In line with this, both the SENCo and class teacher spoke of lunchtime provision to ensure that Valerie had quality peer interaction during unstructured times. Valerie initially came into school after lunch on Thursdays and Fridays, but this was extended to coming in before lunch. The class teacher explained how Valerie found the lunch hall to be too noisy, "so to help with that, she then chooses a friend and she goes to an area outside the hall where she sits quietly and eats with a friend." The class teacher noticed that this provision at lunchtime "made it a lot happier for her". The SENCo also reflected on the positive impact this provision had on Valerie's social development and SoSB.

> *"I often pass the little group there, and they're having a chat and a giggle and they're just sitting eating their lunch really quietly and I think that's been a good opportunity for building up those positive social relationships with peers."* (Valerie's SENCo)

4.4.1.1.2 Subtheme: School Community Joining Child on Their Rehabilitation Journey

Another strong theme during the parent interviews was the way in which the school community was supported to be part of Valerie's rehabilitation journey. Valerie's parents were "very open with the other children in the class." When Valerie was reintroduced to the class, her peers were told "in an age-appropriate way what had happened" to her and the support that she needed. Valerie's parents felt that the early return and the honesty with peers about

Valerie’s ABI helped remove any stigma around her injury and allowed her peers to become part of her recovery journey.

> *“As it was, I think her starting so early actually really helped because they saw how incredibly unwell and fragile she was. They could see the scar, like it was still like healing, like it was gross, but it meant they could see how bad it was. And it meant that they were part of her recovery.”* (Valerie’s mother)

Children took on the responsibility of looking out for Valerie and ensuring that she was safe. Valerie’s mother recalled a “swarm of really enthusiastic boys” who took on the role of “Valerie protectors.” Valerie’s mother also noticed how children instinctively helped Valerie with little things such as taking the snack bowl to her, which helped her to feel supported and part of the class.

> *“I think bringing them along from very early really helped them to understand what she needs and what she benefits from. It just [her ABI] never became a big deal.”* (Valerie’s mother)

In addition, Valerie’s parents described how the wider school community was informed and parents were both encouraged and facilitated to discuss the topic of ABI with their children.

> *“We published on [school web app] a thing saying basically for the parents if they heard about it, or if their children came home and had questions, that they'd be able to support their child in answering those. So we went into details about, first of all what the symptoms were, just because I would hate for another parent to miss the symptoms. And then we went through what she'd been through, how she was coming back, what we'd explained to her and we told them that we were keen for them if they wanted to, to talk to their children about it, because the more everyone knows about it, the less she has to explain to them, which is a good thing. But it also means that it's just everyone's on board. I don't, I don't, I didn't want to hide it away like it was something to be ashamed of. And I think that's that worked really well.”* (Valerie’s mother)

By encouraging members of the entire school system to understand Valerie’s needs, parents felt that it supported her SoSB.

4.4.1.1.3 Subtheme: Balancing Academic and Socio-emotional Development

A strong narrative throughout all the adult interviews was the balance of academic and socio-emotional considerations, especially given Valerie’s time in school had not increased as anticipated. However, perspectives differed across the adults in the systems, based on the priorities tied to their role. Valerie’s class teacher felt that Valerie was socially competent and growing in confidence at school. As such her social development was not an area of priority. Instead, she was most concerned with Valerie’s academic progress, given that Valerie was missing chunks of her schooling. Her priority as class teacher was directed towards addressing those gaps and giving Valerie the skills to progress academically. She spoke about how Valerie’s absence at school was the main barrier to her SoSB, as it was increasing the gaps in her learning. She felt that Valerie should attend “four mornings because then she wouldn't miss out on lots of literacy and maths” and would receive the necessary learning interventions to make progress in these areas. Without the foundational skills such as reading and writing, Valerie’s class teacher felt that she would be unable to participate in afternoon lessons.

Similarly, the SENCo acknowledged the demands placed on schools to meet specific academic criteria. However, she also spoke about how school plays a pivotal role in the holistic development of a child and therefore the provision in school needed to reflect that.

> *“Schools are busy, we're really busy. We've got to meet our, you know, everybody's got to achieve this by the end of foundation stage and that in the phonics at year one, and they've got to do that in SATS at year two …. But actually, school is about a lot more than that.”* (Valerie’s SENCo)

The SENCo reflected on the need to strike a balance between the child’s academic and socio-emotional development when at school. She agreed with parents for Valerie to complete two mornings and two afternoons a week so that she was experiencing “a variety of subjects” and opportunities for collaborative working with peers. In addition to a range of subjects, the

SENCo felt that it was important for Valerie's SoSB for her to attend school consistently, even if it wasn't full-time.

> *"And I think [her fatigue] that's one of the biggest, the biggest things we have to be mindful of because if she becomes too fatigued too quickly, she then has a period of a week, say a week off … but she hasn't missed any school. So this [reduced timetable] has actually kept her in school on a regular basis. And she's got that regular contact with school. If she were to become really fatigued, a week off school wouldn't be helpful. Again, its striking that balance."* (Valerie's SENCo)

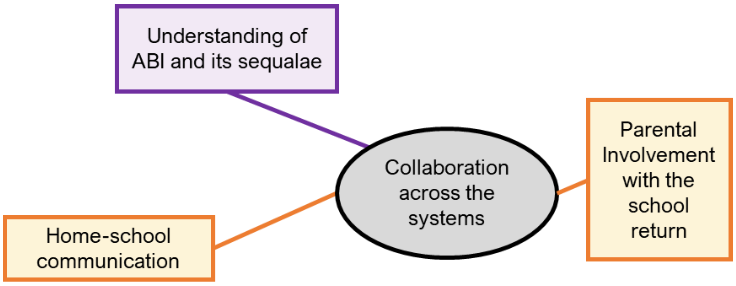
The SENCo also spoke of the importance of taking into account Valerie's wellbeing and SoSB when making decisions around interventions.

> *"[It helped Valerie] to go down to foundation stage to access the phonics sessions. Because the child had a really positive experience with that class teacher, and that style of, the foundation stage style of learning worked, worked really well for her. So I think that was a two-fold. I think that was actually about the learning but it was also about her social and emotional well-being because she really enjoyed, mum described her as being really happy to go there and happy and enjoying learning in that setting."*
> (Valerie's SENCo)

4.4.1.2 Theme 2: Collaboration Across the Systems

Figure 18.

Visual Depiction of Theme 2 and Subthemes



4.4.1.2.1 Subtheme: Parental Involvement With the School Return

All adults highlighted the importance of parental involvement at all stages of the return. Valerie's parents were described as being instrumental in preparing for the return, and planning with school what the reintegration process looked like. Consistent with the theme in the child interviews, there was a focus on Valerie’s mother initially attending school with her as she had to be “careful about her knocking her head for the first year after surgery.” Valerie’s mother described taking up the role of “a human shield” to allow Valerie to return to school, whilst maintaining her safety. Valerie also disliked being in the wheelchair so her mother would carry her where she needed to go. Parents highlighted that their involvement in the school return was only possible due to the accommodation of Valerie’s father’s workplace. At the time, Valerie’s mother was a stay-at-home parent as her youngest children were only 18-months-old. Valerie’s father had just started a new job but was given leave and “paid in full” during this period, meaning that the family were not worrying about finances at this time. This allowed him to stay at home with their youngest children whilst Valerie’s mother accompanied her into school each day.

> *“The introduction very early on in recovery was really instrumental. But I would like to point out, we were only able to do that because Valerie’s Dad’s work were unbelievably accommodating, Valerie’s* Dad *had only just started a new job. They basically said ‘your kid has a brain tumour take whatever time you need. We don't care. The bottom line doesn't matter right now your kid could die, just take time off.’”* (Valerie’s mother)

Valerie’s parents highlighted that without these unique circumstances, Valerie wouldn’t have returned to school early on in her recovery journey, deemed to be an importance facilitator to her SoSB (See subtheme: Subtheme: Getting to be a Child).

> *“If it hadn't been for that really unique set of circumstances, there’s not a chance she would have been able to go back to .. I mean she’d have returned to school maybe March or April would have been safe enough for her injury wise. Because school haven’t been able to get any funding.”* (Valerie’s mother)

Parental involvement was not limited to the reintegration period. Due to her ongoing part-time timetable, Valerie’s mother had to be available to drop and collect Valerie during the school day. In addition, whilst the family had sourced a tutor through the council to deliver a weekly session, Valerie’s mother was teaching Valerie at home where possible to catch-up missed learning. Valerie’s father felt that at present Valeries mother was “teaching more than school.” They noted the importance of Valerie’s mother taking on this dual teacher-parent role, to prevent her from falling even further behind academically, as this would affect her ability to work alongside her peers at school. Since Valerie’s siblings had started nursery in the summer term of Year One and there had been increased communication regarding curriculum content (see subtheme below), Valerie’s mother noticed a positive impact on Valerie’s learning:

> *“I’ve had more time one on one with her which makes a massive difference how much I can get to teach her as there’s not distractions. Plus, school’s got a bit more organised with what they're teaching her but also what they're sending home for us so that it joins up with what she’s learning at school ... they only started doing that in the last half term and in the last half term, we've had reports back that she's catching up ... so bearing in mind that she's still massively lower hours than other children, she's already catching up.”* (Valerie’s mother)

Parents felt that a key adult to support Valerie with her learning when needed throughout the school day would support her learning and enable Valerie’s mother to step away from the teacher role.

4.4.1.2.2 Subtheme: Home-School Communication

All adults reflected upon the importance of ongoing communication between home and school due to a need to engage in continuous problem-solving. The SENCo identified that children are more likely to speak to their parents about things they are finding hard at school. She emphasised the importance of “listening to parents, taking on board what they are reporting back and what Valerie was reporting to them reported back to us and just acting on those things”. Once they were aware of the things that Valerie was finding difficult, they were able to “modify” what they were doing and “put some support in place to address those things.” The

SENCo also felt it was important for there to be “really honest conversations” between home and school, so that multiple options could be discussed and an informed decision made.

Despite the recognised importance of home-school communication, all adults identified factors within the school structure that posed a barrier to this. Due to moving classes for various learning interventions, Valerie had multiple teachers which made communication more complex.

> *“So that's been a challenge in school to ensure that everybody in the team is aware of, you know, all information and class teacher has taken that on ... the class teacher that sees the least of the child has taken that on as the person that, that, that coordinates that and ensures that people, and myself really, you know, several times we get some new information or some changes, making sure that the whole team are aware of that”.*
> *(Valerie’s SENCo)*

While the class teacher had been allocated the role of co-ordinator, she had limited contact with Valerie due to staff job shares, Valerie’s reduced timetable and interventions throughout the day. She noted the importance of having an allocated key adult, but that careful consideration is needed to determine who is best placed for this role. The class teacher also discussed the importance of the key adult communicating with parents when extra-curricular class activities (e.g., sports day) were taking place so that the child was included in those. The class teacher gave an example of a class assembly on a day that Valerie was usually absent, whereby she arrived but hadn’t been allocated a role. Parents also identified the importance of the class teacher informing them of the curriculum content across the week, to provide continuity between the teaching at home and school.

> *“We have been incredibly clear since day one: ‘I'm a stay-at-home parent. I'm gonna throw everything I can into this kid because she deserves it. And you can't currently do that as a school. So I will do it, but you [school] have to provide me with the content.’”*
> (Valerie’s mother)

Valerie’s mother felt that, given her attendance at school remained reduced, it was important to take every opportunity when Valerie was feeling well to focus on her learning: “it's really valuable that 10 minutes when she's only at school three hours a day, four days a week, it’s so valuable, 10 minutes.” Home-school communication regarding curriculum topics was therefore deemed a priority.

4.4.1.2.3 Subtheme: Understanding of ABI and its Sequalae

Both Valerie’s parents had educational backgrounds in psychology, and they felt that this put them in better stead to understand Valerie’s diagnosis, prognosis as well as advocate for her needs in school.

> *“I've been able to ask quite a lot of questions in the right way to the right care providers. So they've been able to speak to me more on a level than some other parents.”*
> (Valerie’s mother)

Valerie’s father reflected on the additional strain placed on families who were not privy to existing knowledge as even if they had “the will and ability to take on the information, they’d have to do that in addition to looking after their kid.” Despite the parental understanding of ABI, further strain was placed on parents due to the limited understanding of ABI among school staff. Parents felt that some staff took a perspective of “‘Oh yeah, it's a shame that she doesn't learn much at school.’ And that's kind of the end of it.” They expressed frustration that “people are giving up on her.” Parents spoke about the onus being on them to educate school staff about ABI. Valerie’s mother “sat [staff] down at the beginning of the year and was like … ‘I haven’t had a chance to talk to you about this, and I really think that we should be having a conversation about this’”. Parents also provided school staff with the neuropsychology report which outlined Valerie’s cognitive profile post-ABI.

In addition to this, there were multiple multi-disciplinary (MD) meetings over the transition period between home, school and healthcare professionals. The SENCo felt that whilst it was helpful to have the MD meetings to gain an understanding of Valerie's learning needs, the school would have benefitted from an external professional with knowledge of ABI to deliver more holistic training to the wider staff team:

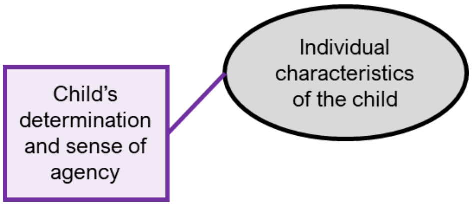
> *"I think one of the other things in terms of in an ideal world is if there was a person, like yourself, or somebody somewhere that has expertise and experience of supporting children with ABI that could come in ... could have come into school and done a [training session] and then being appointed contact if you like, in terms of what it means."* (Valerie's SENCo)

The SENCo expressed that training was needed to put "that whole picture forward," including a focus on the socio-emotional impact of ABI.

4.4.1.3 Theme 3: Individual Characteristics of the Child

Figure 19.

Visual Depiction of Theme 3 and Subtheme



4.4.1.3.1 Subtheme: Child's Determination and Sense of Agency

Valerie was described as having determination, which impacted how she coped through her diagnosis and medical treatment. Her parents shared that "she was known in hospital as the giggler because she just was constantly laughing." Whilst Valerie's parents felt that in some ways her determination and unrelenting optimism had "put her in better stead for dealing with this," they felt that "in other ways it means it's been really, really hard on her in a way that other children perhaps wouldn't have had the same effect on them." Valerie was reported to mask many of her difficulties in school, particularly around her fatigue. Parents related this to Valerie's personality; they felt there was "still this like 'I can do it' about her" which meant that she was persevering through the school day and reaching burnout in the afternoons at home. This narrative was consistent with Valerie's interview; when asked what advice she would give to other children with a brain injury, Valerie said "never give up! Keep going, always try your best and never give up!" Masking behaviours made it difficult to extend Valerie's time in school, as she was unlikely to tell an adult if she was fatiguing and needing to go home. The class teacher thought "she'd want to keep going" and in a classroom of thirty children, it was challenging to be attentive to subtle signals of fatigue. She thought that it would be helpful to have an adult at school "to be with her, to go around with her, to be able to see those telltale signs."

In addition, parents spoke about the potential impact of the brain tumour on Valerie's sense of agency. They spoke about their decision to include Valerie as much as possible in the discussion prior to her operation, in order to provide this:

> "*I think the way that we raised our children is to try and make them feel as consulted as possible because we want them to be active participants in their own lives. I feel like that's a natural extension of that. And that for 'Valerie', it was out of her hands. She couldn't make decisions about it but the next best thing we could do is inform her about what was happening and why and that nothing was a surprise and she'd then be best placed to understand what had happened, why..."* (Valerie's father)

By including Valerie in the conversations, she could ask questions from a child's perspective. As such, Valerie was better able to comprehend what had happened to her as reflected in her level of self-awareness. However, despite parental efforts to encourage a sense of agency, they remained concerned with the impact of the ongoing challenges obtaining support in school on her motivation.

> *"It's so frustrating. Everything else has been in her control. She has been able to absolutely blast all the expectations. With this one she is falling further and further and further behind."* (Valerie's mother)

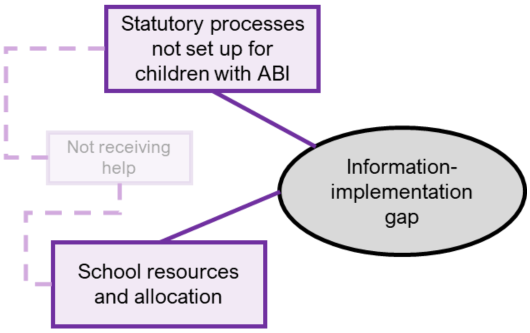
This subtheme linked to challenges accessing funding and necessary support for Valerie in school. Her parents expressed frustration that external factors were hindering Valerie's progress with her learning when "the hard stuff was the brain surgery and the re-learning to walk and talk." Her father reflected upon the impact on Valerie's own wellbeing and perceptions of school if she felt she was not supported: "It's a really shit lesson to learn as a kid that if you try hard, nothing happens, things don't get better." Both parents were fearful that Valerie would lose her motivation in school, without school support in place.

> *"She loves learning new stuff, she wants to learn new stuff. She's curious. She picks it up fast. She's, like, she's really rewarding to teach new stuff to. I just … my biggest fear is that she doesn't get the support she needs to before she loses that."* (Valerie's mother)

4.4.1.4 Theme 4: Information-Implementation Gap

Figure 20.

Visual Depiction of Theme 4 and Subthemes



4.4.1.4.1 Subtheme: School Resources and Allocation

Both Valerie and her parents spoke about not getting the adaptations she needed in school. However, whilst Valerie typically spoke about this in relation to the teachers not helping her, her parents discussed this within a wider theme of limited school resources.

> *"She just she gets so tired so quickly, and school just isn't set up to be able to give her the breaks that she needs. Like she needs regular brain breaks. It's been something that was clinically advised last March, so like a year and a bit ago, and school can't do it because they can't allow her to sit in the cloakroom on her own because it's not supervised they don't have the staff just to let her sit for five minutes.*" (Valerie's mother)

The SENCo highlighted that whilst information from a range of professionals and parents gave school "a far better understanding of the child", limited school resources prevented them from putting many of the interventions/strategies in place. School described the challenges of obtaining resources due to the child not being in school for more than 15 hours a week, affecting their access to alternative funding streams. In addition, the SENCo reported difficulties sourcing resources midway through the year and "the capacity within school because staff are already allocated". Valerie's class teacher raised additional concerns with staff recruitment; she felt this would have been a problem even if funding resources had been available.

Whilst the SENCo attributed funding to be the greatest barrier at present for Valerie getting the support she needed to participate in school, she spoke about this being a "national picture" and not unique to their situation. The SENCo identified that "in an ideal world, we'd like a lot more SEND funding but we're not living in an ideal world. We have to work with what we've got." Parents expressed their ongoing frustration that resource allocation and similar "arbitrary blockers" within school were preventing Valerie from getting the tailored support she needed and impacting her academic progress.

> *"It's just so frustrating to see her have to go through this. And for this to be the stumbling block of all the things that she has ... like she learnt to walk when we were told she was never going to. Like she cried standing next to the pushchair because her legs wouldn't work and she just couldn't do it, and she walked two days later, because she was so obsessed with 'I'm going to walk' like ... it's so frustrating. Everything else*

> *has been in her control. She has been able to absolutely blast all the expectations. With this one she is falling further and further and further behind."* (Valerie's mother)

4.4.1.4.2 Subtheme: Statutory Process Not Set Up for Children With ABI

Both parents and school staff also felt that the statutory EHCP process did not work for children with ABI. Statutory barriers consumed parents time and focus, when they "should have been able to just cope with the awful situation." Parents described the short time frame from Valerie's diagnosis to discharge to school return, and how this contrasted with the time it takes to apply for and obtain statutory funding. Parents spoke about how there wasn't "any consideration given to future implications" within the current system:

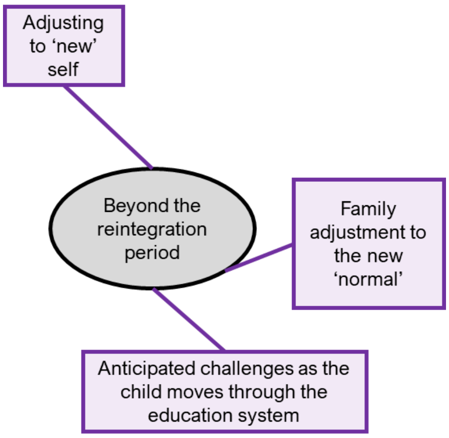
> *"It just really winds me up that the whole system is always rigged against someone who wants to have an education and wants to work hard and does her absolute best. Why is that? Why is this something where it's literally some paperwork somewhere? This kind of thing makes me think that in terms of school because it's so important you miss time, like this is a huge .. it's is a third of her life she's missed now. Right? That's huge. That's like me being 20 something and lost the last 10 years like this is huge, it's massive. And why is it that you have to go through the bureaucracy of who's going to pay for blab la bla. No, if an educational psychologist says this person needs this many additional hours a week, it should .. the funding should go through. They can argue about who's going to pay for it behind closed doors. It shouldn't affect the child in the meantime, because we've had two years now of running around while Valerie has no education. While other people are like .. well I'm not funding it."* (Valerie's mother)

Notably, these systemic barriers were not unique to the education system. Similar difficulties were reported with the disability living allowance and blue badge scheme which required evidence of the child's difficulties over a period of time. Both parents and SENCo felt that children with ABI require interim funding or a "bridging grant" to better support the initial reintegration process.

4.4.1.5 Theme 5: Beyond the Reintegration Period

Figure 21.

Visual Depiction of Theme 5 and Subthemes



4.4.1.5.1 Subtheme: Anticipated Challenges as the Child Progresses Through the Education System

During the interview, future challenges were foreseen. Valerie’s parents were concerned that the narrative around her ABI would get lost, reducing the support she received in future. They felt there had already been a shift from reception to Year One in terms of the support that Valerie has received. In part, this was attributed to staff members not knowing Valerie during her initial recovery and most of her disability was now hidden or masked. Moreover, whilst there were some staff members who actively problem-solved to help Valerie, her mother felt that not all school staff shared this attitude: “But I feel like that that like, impetus doesn’t exist in the rest of the staff that she's coming to contact with. I mean, it just makes me so frustrated that people are giving up on her.” She was concerned that this was impacting, and would continue to impact, the support that Valerie received in school.

In addition, there were concerns that challenges would emerge as Valerie progressed through the education system and into secondary school. Both parents and school staff spoke of the changes that occur in terms of the learning environment, and level of demands placed on children. This was already observed with the reception to Year One transition, with the increased child to adult ratio reducing the level of direct adult support Valerie received in class. Moreover, Valerie's parents also spoke about the impact of "having a brain tumour so young" as difficulties are likely to emerge as the child gets older, as well as the uncertainty of what the future would look like for Valerie "because her recovery has been so difficult."

4.4.1.5.2 Subtheme: Adjusting to 'New' Self

Valerie was described as high-achieving prior to her ABI. Valerie's parents felt that, compared to other children, she had been advanced in most respects and as such, her ABI has "massively changed her sense of what she can achieve."

> *"I mean, she learnt at the age of four, that there was a good chance she was going to die. You know that's a big thing to learn when you're an adult. It's huge to learn aged four, particularly for a kid who up until that point genuinely believed anything was possible. So it really has ... she's much more fearful now."* *(*Valerie's mother*)*

Consistent with themes emerging from Valerie's interview, both home and school spoke about Valerie's high levels of self-awareness which meant that she was knew she was struggling post-ABI.

> *"I think she's a very sensitive little girl and she's got a really good level of self-awareness. And I suspect, I don't know for sure, but she knows that she is finding learning far more challenging than it was, and she knows that. Perhaps she, she seems, she thinks that if she tries and tries and tries to get it, she'll ... I don't know, I don't, I don't know whether she thinks that if she tries and tries and tries, she'll reach those same levels as she .. as prior to surgery, or whether she sees that if she tries and tries and tries she'll be better than or as good as some peers that she sees around her."*
> *(Valerie's SENCo)*

Both Valerie's parents and the SENCo spoke of the psychological impact of the diagnosis, treatment and ABI on Valerie's sense of identity. They identified that Valerie "can be quite tough on herself." Parents felt that that Valerie needed mental health support "before the operation, post the operation … and then continued for as long as needed." Both parents recognised that ongoing nature of the adjustment process. As such, they felt that Valerie required psychological support "probably for life to be honest. But absolutely for a few years whilst she is adapting to her new self." This sentiment was also shared by the SENCo: "it's a person and it's the rest of that person's life."

> *"If she's aspiring to be somewhere and she's putting every bit of her soul into that and is falling short by her own standards, then I suppose that's when you see those difficulties with self-esteem and reduced confidence over time".* (Valerie's SENCo)

In addition, Valerie's father raised concern that whilst Valerie currently showed a strong SoSB, difficulties may emerge in the future. He was worried that as she gets older, Valerie may feel "a greater sense of being othered and being different" and therefore may "want to mask that more and more." He therefore felt support needed to be implemented now, to minimise these difficulties surfacing later on.

Despite the acknowledgement across the system of SEMH needs, Valerie's parents found it challenging to obtain any psychological support for Valerie as she was under statutory school age at the time of her illness. Valerie only received play therapy because her sister was referred through the NHS, and the therapist recognised her need for psychological support and added her to the waiting list. Parents expressed frustration that the system "deemed like 'oh she'll be fine.'" Moreover, parents had continued to find it challenging to access the appropriate support to address issues of self-adjustment:

> *"There's one things I am struggling to get. Like her mental health support has been great for covering things like her anxiety about the hospital. It's been really crap for covering her anxiety for about like 'I not the human that I was before, and I find it difficult to accept myself and demand that other people accept that too.' And I find it really, really difficult to find someone who truly understand that element. Because hospitals are scary, but she gets why. Like she hates the hospital, she gets it, she*

> *understands it's necessary. What she really struggles with is, she was essentially in her mind a perfect person before, she could do anything she wanted to do, she could try harder and she'd get there one day, and there are things now that she will never be able to do, and she needs to be okay with that, like there's a lot of shame attached to something that she had no control over and she's frankly remarkable anyway, like the … if anything I think of her in higher esteem than I did before now she's gone through this, but she doesn't see that in herself and it's really hard to find that kind of therapy. That's the kind of thing that's going to trigger when she hits teenage years, not her fear of needles of her worries about MRIs."* (Valerie's mother)

4.4.1.5.3 Subtheme: Family Adjustment to the New 'Normal'

In addition to the direct impact of the ABI for Valerie, the impact on her family was embedded throughout all the interviews. Parents spoke about the challenging decisions following diagnosis, as the prognosis of the operation was "a one in seven chance she was gonna die" and "a one in three chance that she would come without any other serious complications like brain bleed stroke, epileptic fits, that kind of thing." Valerie's mother talked about feeling like they were "basically choosing our child's life over her quality of life by having this operation." Contextual factors such as Covid-19 restrictions made the time around the operation more challenging, as only one parent was allowed in the hospital with Valerie. Following discharge from the hospital, the family faced a range of ongoing stressors including lack of family support due to their recent relocation, the uncertainty of Valerie's recovery, the continued reduced timetable preventing Valeries's mother from returning to work and the dual role of parent-teacher that Valerie's mother had assumed. Valerie also described changes in her relationship with her sister following ABI:

> *"And when I came back from hospital, [sister's name], my oldest sister, didn't like me anymore. She was used to playing on her own and she started being mean. So, we used to be very good close friends when I didn't have that big injury*." (Valerie)

Whilst Valerie's parents did not talk about changes within the immediate family dynamic, they identified wider difficulties within the family, with instances where Valerie's needs were not recognised or understood by family members. These all represent adjustments within the family that take a psychological toll.

The school system also recognised the psychological impact on the family system. The class teacher had taught Valerie's older sister during the time Valerie was diagnosed and treated. She talked about the child's distress at that time, not knowing if her sister was going to die. The SENCo felt that it was the responsibility of the school to support the complex adjustments the family were making.

> *"it's not just the school's responsibility to educate the child. It's all of the social. It's all of the, it's all of that - What does this mean for this child and this family for the rest of their lives? ... What are they thinking? What are they feeling? I don't think there was never really spoken to the other members .. who's supporting them? Who, who's putting that whole picture forward in terms of this as a young child and a family who thought, who thought like was mapped out in this way, and within a within a within a very short period of time, life ... life's map is looking very different?"* *(SENCo)*

The SENCo thought the poem 'Welcome to Holland' by Emily Perl Kingsley (See Appendix J) was a beautiful analogy for the situation. She spoke of the need for socio-emotional support for a child and their family following an ABI. However, she was unaware of anyone that the school could have contacted to provide that type of emotional support for the family.

4.4.2 Case 2: Leo

The total number of interviews for Leo's case study is summarised in Figure 22. Please see Table 3 (Methodology Chapter) for further details about the participants.

Figure 22.

A Visual Representation of the Participants in Case Study Two

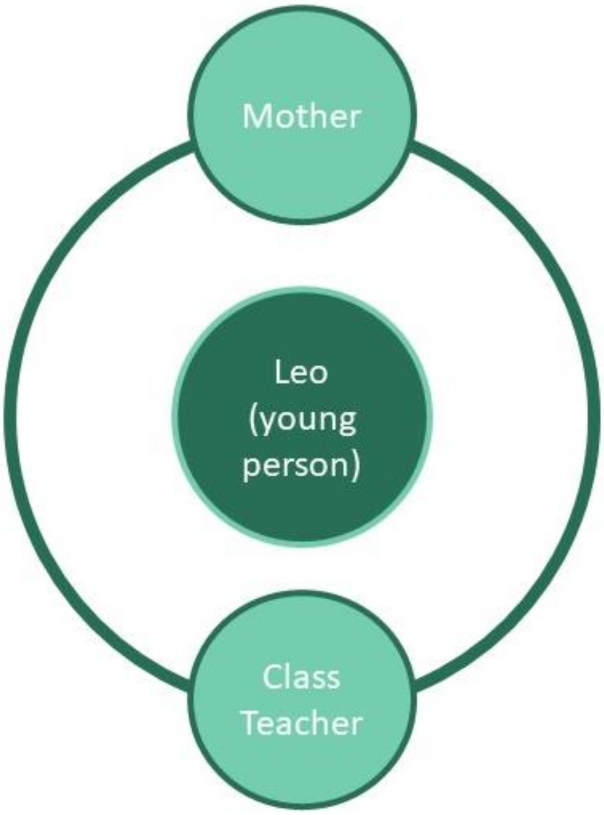
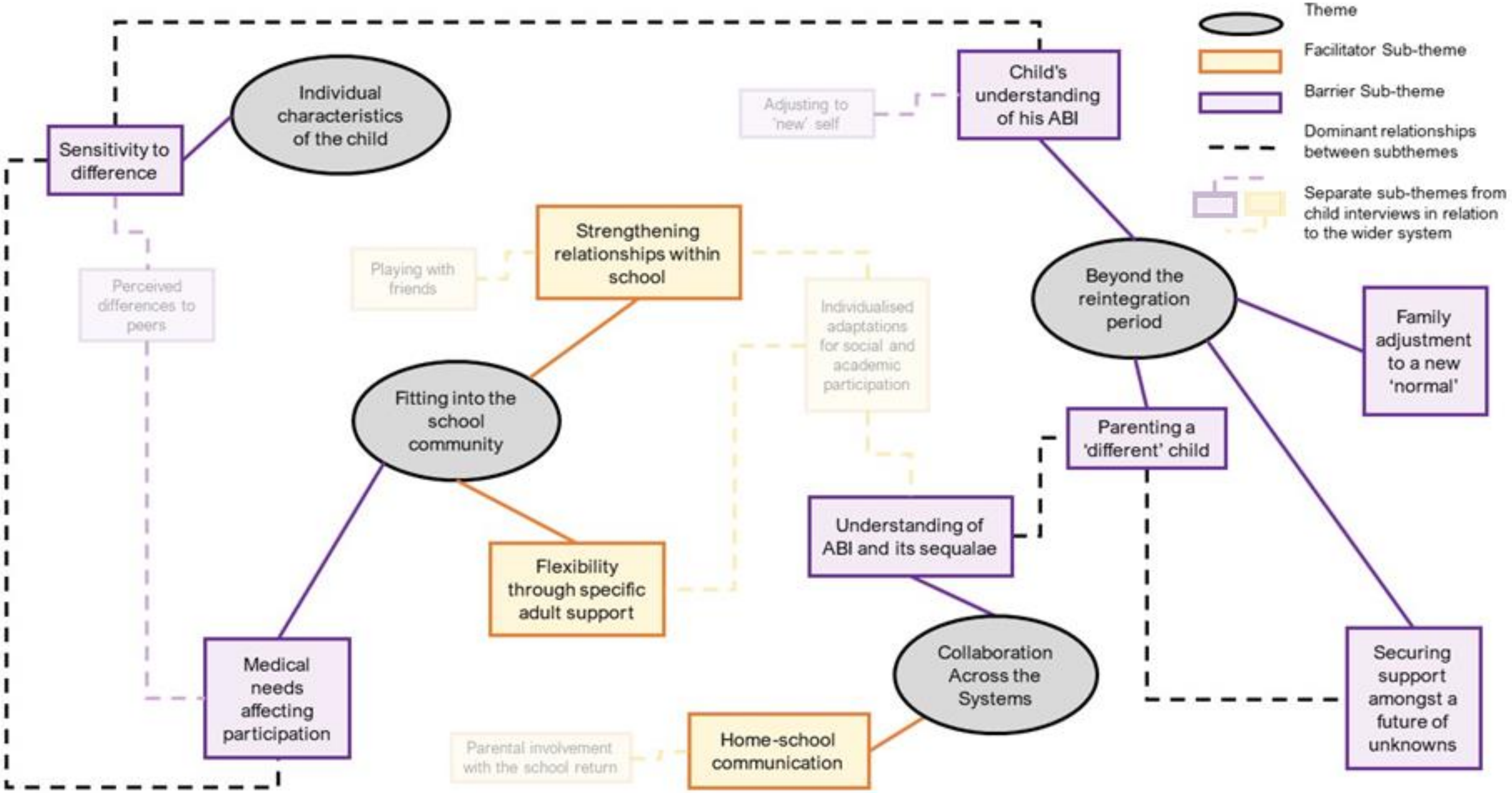


Figure 23.

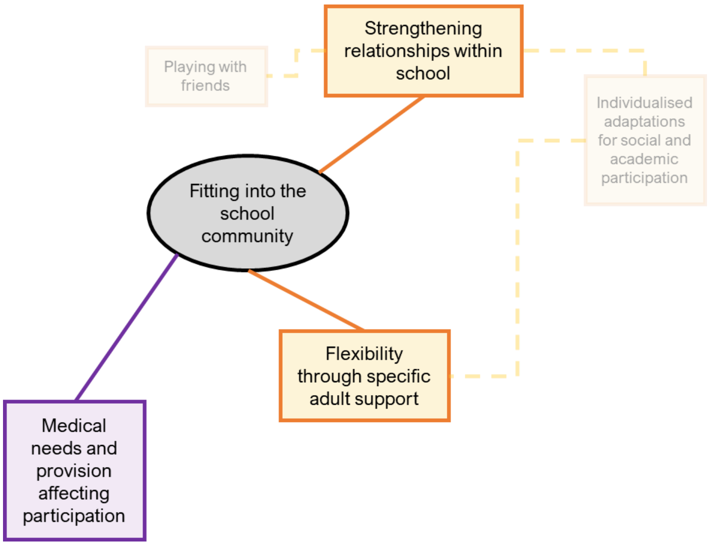
Thematic Map for Case Study Two (Leo)



4.4.2.1 Theme 1: Fitting Into the School Community

Figure 24.

Visual Depiction of Theme 1 and Subthemes



4.4.2.1.1 Subtheme: Strengthening Relationships Within School

Both home and school recognised the importance of Leo resuming relationships with peers for his wellbeing and SoSB. Leo’s mother felt that playing with his friends had helped him feel like he belonged at school. Whilst Leo was initially on a reduced timetable, he requested to stay at school:

> *“He wanted to see his friends, he was missing his friends. He got really mad and was like ‘I just want to stay, can I please stay?’ So I was like ‘okay, I'll speak to them’. And he stayed.”* (Leo’s mother)

The class teacher described how Leo had been embraced back into the class as the other children didn’t “see him as any different” to how he was prior to his injury. Leo’s class teacher felt that the young age of the children positively impacted the way they re-embraced Leo post-ABI as they were pre-occupied with just wanting to play. This helped Leo to feel included, particularly as he showed a strong desire to not wanted to be perceived as different to his peers (see subtheme: Perceived Differences to Peers).

> *"It's not like at the forefront of their mind all the time… and they're easily distracted. Like somebody brings in a new sparkly bracelet. That's the new favourite thing. But I think I just think it's like, innocent childhood really .. and to them that he's just Leo. He's just a child in their class that they like to play with."* (Leo's class teacher)

In addition to peer relationships, Leo's class teacher spoke about the importance of his relationships with key adults at school. Leo had formed a strong relationship with his one-to-one, and his class teacher felt that this had helped him to accept her presence.

> *"They all love her. But then I think Leo really likes that because he knows 'well, she's mine. She's my Miss x' in a way. So I think in that way that's why he really likes that. Because it's a different where the children are all a bit like, 'ooh, that's Leo's one-to-one'". (Leo's class teacher)*

His class teacher also spoke about the importance of Leo building a relationship with other classroom staff including herself. This supported him to feel more comfortable in the classroom and to communicate to them if he required support. By strengthening their relationship with Leo, the staff were also able to better understand his needs, wants and motivations. As such, they were able to make decisions whilst holding Leo at the centre.

> *"And so we said as long as what we do is in the best interest of Leo, that's the best we can do. And that's kind of the mantra we've gone with this year that if it's in the best interest of Leo, then that's going to work ..."* (Leo's class teacher)

4.4.2.1.2 Subtheme: Medical Needs & Provision Affecting Participation

Consistent with Leo's view that he was unable to play with his peers when he first returned to school, both adults spoke about Leo's medical needs impacting his participation and the negative effect of this on his SoSB. Leo was at risk of further head injury, and therefore needed to be careful with any physical activity. Leo's mother was worried that without adult support at break and lunch time, Leo was vulnerable to injury. At that time school informed her that they couldn't provide staff to monitor Leo during these times and therefore Leo remained indoors with a chosen peer for break and lunch. Whilst his peers enjoyed the novelty of joining Leo indoors, for Leo this was his every-day. Both Leo’s mother and class teacher acknowledged the detriment this had on Leo’s wellbeing, but the necessity of it to keep him safe at that time.

> *“So I would say probably from September to maybe January/February time, he didn't get to go outside at lunch time… he’d sit with an adult to have lunch and then him and a friend would come back to the classroom and they could play with like Lego or go on the laptops or anything, but I think not getting outside like Leo loves being outside like before his accident, he was really active. He played rugby and everything. So I think yeah, I think that that I don't think that was great for Leo. I think that did have a negative impact on him mentally because it's not nice when the rest of your class are going out. And you're staying in with one person.”* (Leo’s class teacher)

Leo’s mother expressed her frustrations with the management of Leo’s participation when he first returned to school. Firstly, she felt it was unfair that Leo couldn’t join his peers due to staffing. Leo “used to say all the time. ‘I just want to go on the big playground’” and so following discussion with school, they agreed for Leo to participate in playtimes if he wore a high-visibility vest to make him more noticeable to staff and peers. Whilst his mother reported that the high-visibility vest “made him even more angry,” it meant that Leo could at least play outside with his peers. Secondly, Leo’s mother felt that school placed her in the challenging position of having to say no to things Leo wanted to do, which negatively impacted her relationship with him.

> *“He returned back and he was here a week and they rang me asking if he could go on a bouncy castle. I was like ‘what are you serious? Absolutely not! He’s got to be guarded for the next 24 months or something like that for a full recovery. Absolutely not’. And then the week later, ‘let’s see if he can go on a slip and slide’.”* (Leo’s mother)

Leo’s mother felt that the school were asking her permission as a way of showing Leo they were “trying to include him”. However, by deferring to her when they knew he couldn’t take part, it presented mum as the ‘bad guy’ in Leo’s eyes, and the barrier to his participation.

4.4.2.1.3 Subtheme: Flexibility Through Specific Adult Support

Home and school both highlighted the importance of adult support within school. When starting back, Leo engaged in small group working with a teaching assistant during lesson time. Leo also completed activities as part of an SEN group. His class teacher perceived this to have been “good for him because those children are on a similar level to him, so in that he doesn't feel as different.” Leo was subsequently provided with a one-to-one at the start of the summer term of Year One, due to having absent seizures. Whilst the staff member was provided for medical reasons, both Leo’s mother and class teacher reflected on the positive impact it had on Leo’s participation and wellbeing at school. His class teacher thought that the one-to-one adult support was one of the most important factors in supporting Leo’s SoSB as ‘a lot of barriers have been removed for him”.

> *“But we've just noticed since having the* one-to-one support, it's been really beneficial *for him… more so for his wellbeing. I’d say academically he is very similar, but I think the wellbeing side of things it’s much better because before Miss X started, Leo was getting to go outside at lunchtime but was having to wear a bright vest – a hi-vis jacket and he hated that. But, but that was the only way everybody could see him straightaway and we knew was safe. Obviously since Miss X [one-to-one] started, he didn't have to wear the jacket and he can just go and like be free in a way but we know he’s safe and that's really helped and. Just things like if you need a brain break, … she'll …they'll get a football and they’ll go outside. Just things like that, that's really like, boosted him emotionally.”*
>
> (Leo’s class teacher)

Both Leo’s mother and class teacher talked positively about the flexibility the one-to-one had given them at school. It allowed school to make changes to his day to day working to reduce the things that he was finding hard to manage, for example, going down to phonics in foundation or completing whole class learning activities.

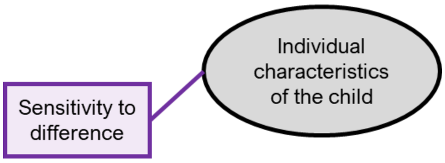
> *“So we're getting to the point now where instead of him going down there [to the foundation class], Miss X who is one to one is just taking him by himself for his phonics, because he just he just was not happy at all. Not to the point where he was like getting really angry and stuff. He was just saying like I hate going down there and when he was down there, you could see he didn't want to engage in things.”*
>
> (Leo’s class teacher)

In addition, having a one-to-one meant that Leo was able to resume activities like going out with peers at play time without wearing a high visibility jacket. This was consistent with Leo's perspective that having a one-to-one allowed him to participate in physical-based activities alongside his peers.

4.4.2.2 Theme 2: Individual Characteristics of the Child

Figure 25.

Visual Depiction of Theme 2 and Subthemes



4.4.2.2.1 Subtheme: Sensitivity to Difference

In his interview, Leo identified specific provision at school that he disliked. While these all centred on the concept of him appearing different to peers, Leo was unable to articulate this further. In contrast, both his mother and class teacher spoke more explicitly about this. Leo was described by his class teacher to be "very aware of people around him" and therefore highly sensitive to differences. As mentioned above, whilst returning to school full-time supported Leo's SoSB, Leo found it challenging to manage social situations in which he looked different to his peers e.g., wearing a high-visibility vest during play time, not participating in physical activities:

> *"He just gets frustrated when he can't do things. So like, for example, yesterday when we went to a farm on a school trip and it had like big zip wires, and obviously we have to be really, really careful with him with that. And he just gets a little bit frustrated that he can't do what everyone else is doing."* (Leo's class teacher)

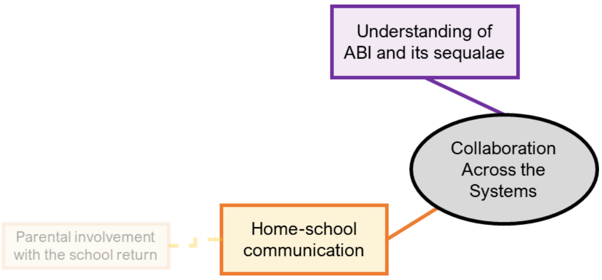
Whilst Leo focused on social situations that made him feel different, both home and school also noticed that Leo found it challenging to tolerate differences to peers in regard to his learning. School staff had noticed Leo’s mood was lower when engaging in whole class activities and felt this was because he knew he was academically behind his peers. In addition, Leo’s mother reported incidents of Leo becoming frustrated at home when he was unable to do something that his younger brother could do, like signing his name on a card. Leo’s brother was in foundation at the time and working above Leo academically, and his class teacher felt this exacerbated Leo’s awareness of difference.

While both home and school noticed Leo’s sensitivity to differences, his response to these were “polar opposite” at home and school. At school Leo typically internalised his feelings, whereas at home he showed increased dysregulation and a range of externalising behaviours. His mother reported various incidents of destroying property, violence directed towards siblings and “toddler” like tantrums. Leo’s class teacher related this masking behaviour back to Leo not wanting to draw attention to himself at school. She felt that Leo knew that “none of the other children have gone through what he's gone through” and therefore wanting to “just keep it separate and not mention it.” As such, “all the things at school that are kind of frustrating him, when he goes home to his safe place, he's just releasing them there.”

4.4.2.3 Theme 3: Collaboration Across the Systems

Figure 26.

Visual Depiction of Theme 3 and Subthemes



4.4.2.3.1 Subtheme: Understanding of ABI and its Sequalae

During the interviews, both adults acknowledged their lack of understanding around ABI. Leo's mother spoke of the difficulties planning Leo's return because neither home or school had encountered this situation before: "So the full thing of it is: I don't understand and they don't understand." Whist she acknowledged that it was no-one's fault, she felt that the lack of understanding of ABI across the systems prevented appropriate support from being implemented:

> *"There's no way I would put blame on anybody for what what's happened afterwards because we [school & parents] were both clueless, but no support has been put in place whatsoever until I lost it a couple times."* (Leo's mother)

Leo's class teacher recognised that she had to adjust her approach to teach Leo. However, she was unsure of what the best approach would look like, particularly regarding his SEMH needs. She felt that training would have been helpful for both her at present and future staff at points of transition to ensure smoother handovers as Leo progressed through the school. However, despite efforts by both home and school to access training through an ABI charity, they were unable to arrange any.

> *"I know I've been in touch with the brain charity about doing some training with school. But that's still not happened. I think that would have been really useful. Because it's like, none of us have ever experienced anything like this before. And so when, when obviously I came back from maternity leave, I kinda was in the dark a little bit. Luckily, mum was really, really good and she was like, 'Don't worry, I'm like in exactly the same position'. We're all kind of muddling through this together. And we all just wanted the best for Leo, but I do think something from them would have would have been really useful."* (Leo's class teacher)

Leo's class teacher identified that even if training was not possible, having "just a little bit of guidance" from professionals would have also been helpful, "even it was just like a sheet of paper with bullet points on." The class teacher reported having no contact with professionals other than an individual from the ABI charity. She felt that involvement from external professional would have aided her understanding of ABI and how to better support Leo at school.

Leo’s mother also spoke of her ongoing concerns with the lack of understanding of ABI at school, predominantly from a safety perspective. She noted that Leo “is here [at school] six hours a day. Somebody needs to know how to look after my kid whilst he is here.” In particular, Leo’s mother felt that some staff had a misperception of Leo’s head injury as just a concussion.

> *“I think there's a there's a perception around it … I feel like people think and feel like he’s had a bump to the head and that’s it over and done with and nothing else to be worried about. When actually there really is a lot to be worried about.”* (Leo’s mother)

This was made more challenging due to most of Leo’s difficulties being less visible or masked in school. His mother was concerned that this would affect the adaptations made within school.

4.4.2.3.2 Subtheme: Home-school Communication

Both home and school talked about the collaborative approach they had taken to support Leo when he transitioned into Year One, and the importance of communication to facilitate this. Leo’s mother met with the class teacher to problem-solve any anticipated challenges:

> *“We had lots of meetings, like she [mum] came in and we looked around the new classroom and we looked at things that would not be safe for Leo, how we could tailor it to him and all things like that.”* (Leo’s class teacher)

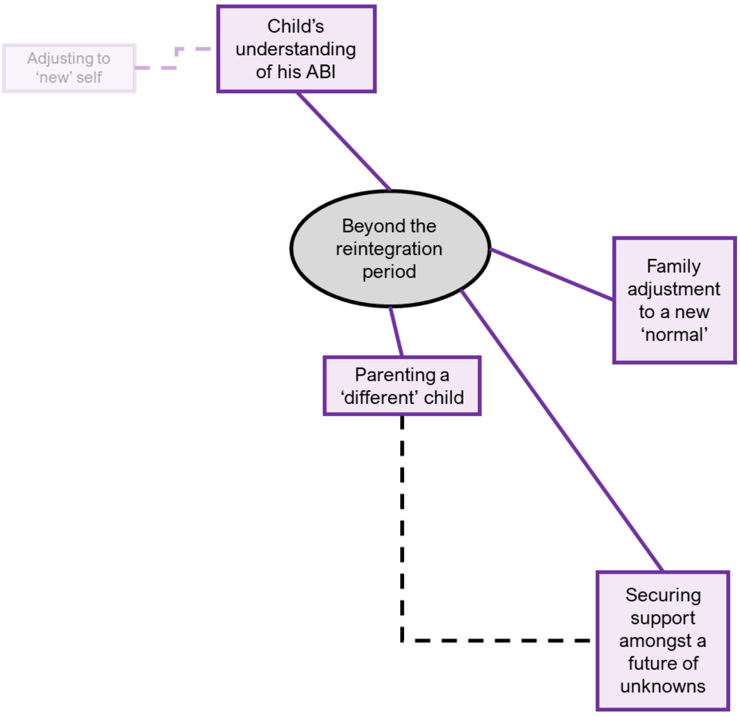
Both adults found this collaborative approach provided reassurance. The class teacher felt that she could speak to Leo’s mother to gain “a little bit of guidance.” It also allowed her to better understand Leo’s behaviour at home and implement adaptations to support this, such as sessions with an Emotional Literacy Support Assistant (ELSA). Given the unique circumstances around his injury taking place at school, strong communication provided Leo’s mother assurance that his safety was maintained throughout the day. Leo's class teacher noted that communication had been further enhanced by having a one-to-one who could take the role of home-school liaison.

> *"So I obviously I have a lot of parents to speak with. I did always speak to Leo's mum. But now that he's got that one to one it is that constant communication, which has been really good because then we know like every seizure he's had at home like we're informed."* (Leo's class teacher)

4.4.2.4 Theme 4: Beyond the Reintegration Period

Figure 27.

Visual Depiction of Theme 4 and Subthemes



4.4.2.4.1 Subtheme: Child's Understanding of His ABI

Both Leo's class teacher and mother reported challenges with Leo's retention of information and learning post-ABI, leading to increased frustrations.

> *"Prior to his accident, he could read, write his name he could, he was really clever. Write his name, reading he was just learning to read …everything, he was really clever. His colours, ABCs, etc. Well, now he gets mixed up and he forgets, really forgets."*
> (Leo's mother)

Leo's mother reported that at home Leo was unable to articulate these frustrations, and instead would become dysregulated and scream. Whilst Leo spoke of some of his post-ABI difficulties, he typically did not relate them to the fall. His class teacher questioned Leo's understanding of the accident, due to his age when it occurred. In addition, following surgery, parents did not receive support with how to communicate to Leo about his ABI. Whilst they had explained that his difficulties were due to his fall, they "initially told him he had a shark bite." Leo's lack of understanding of his ABI therefore impacted the way he adjusted to post-ABI and tolerated the adaptations in school.

Both home and school recognised the need for emotional support alongside academic intervention. Leo's class teacher felt that Leo "can be really harsh on himself" and wanted him to receive psychological support to focus on this as well as build his confidence: "we know he's behind academically, but if he's emotionally, he's not right, then that's going to kind of imbalance everything."

4.4.2.4.2 Subtheme: Parenting a 'Different' Child

This subtheme reflected the parental adjustment to having a child with an ABI. Leo's mother described how her initial calmness when she found out Leo required emergency surgery contrasted with her current emotional state ("absolute wreck") for the past twelve months. She described the realisation of the extent and permanence of Leo's difficulties to be ongoing. Immediately following surgery, Leo did not show any difficulties. However, after two days, he started to display challenges with his emotional regulation and behaviour, which progressively worsened over time. Leo's mother felt that there had been a personality change from prior to his accident when he was the “most chilled placid boy.” Whilst she saw “bits of him now,” Leo’s mother felt that she no longer knew her child. There was a sense of Leo’s mother trying to hold on to the child she knew pre-ABI; she spoke of “keeping things as normal as possible, but safely” as she didn’t want to change her relationship with Leo or treat him differently to his siblings. Challenges were associated with “grieving for a child I had” whilst “getting used to the child I’ve got.” This include adjusting expectations for her child’s future, particularly given that no two days with Leo were the same:

> *“So when you've got kids you can kind of see what they're about, do you know what I mean? We all have aspirations for our kids or our step children or whatever, but you can kind of see what they're going to be like. With Leo you can’t. I could. Now I can’t ... now I don't know what I see. Because I don't want to know because there is no prediction. And then when I got to sleep on a night, I think ‘oh I hope he’s like this tomorrow’ and then he's not, do you know what I mean. So, you're like mentally torturing yourself.”* (Leo’s mother)

She also expressed ongoing concern for the future, given his emotional dysregulation at present: “When he reaches his teenage years and goes through puberty and all that, I'm already dreading it and he is six. I should really be enjoying that, do you know what I mean?” This adjustment process was made more challenging by the perceived lack of support from professionals: “As far as I was aware, my son had a brain injury and I was left to deal with that.” Leo’s mother felt dismissed by professionals who saw the success of Leo’s physical recovery. She felt they weren’t listening to her about Leo’s personality change from “a nice quiet placid boy” to “an absolute demon.”

Moreover, Leo’s mother described complex emotions specific to the way in which Leo acquired his injury. In particular, she expressed frustration with the lack of initial support in school, when Leo had sustained his ABI there.

> *“It’s frustrating. Because it's like this. I sent my boys to school one morning, give him a kiss, a hug and fist bump. And off he went in, and you've gave me back this, but you're not helping me with this.”* (Leo’s mother)

She felt that support was not implemented in school until she had reached crisis point in the spring term of Year One.

> *"I just was like help him somebody just help him. I can't do it. I can't do it all on my own. It was more like to keep him safe over then to keep his education up. I was worried about keeping himself safe ... So obviously, his mental health because you can just see it, you can see it in Leo. If something is not put in place, he is going to absolutely go [downward whistle], do you know what I mean? But his safety as well, so obviously one bang to Leo's head and it can be fatal."* (Leo's mother)

Leo's mother also spoke of potential "what if?" moments from the events around the accident that may have led to different outcome. These 'what if?' questions were loaded with a range of strong emotions, some of which were directed towards school, adding to the already complex personal adjustment process.

4.4.2.4.3 Subtheme: Family Adjustment to a New 'Normal'

Leo's mother described the burden imposed on the whole family by the brain injury. She spoke of the unpredictability of Leo's behaviour at home and how his ABI "just completely changed everything." Leo's mother described their home life now being 'chaotic.' Family life became dependent "how Leo wakes up … [or] on how Leo responds." Leo's mother noticed "a change" in her other children following Leo's ABI. There were disruptions to his siblings' studies. One sibling left university and returned home to support her parents. One of her sons found it challenging to be at home, as he couldn't tolerate Leo's emotional outbursts. Leo also showed increased aggressive behaviour towards his younger sibling. Leo's mother described how her "full family was like dropping." She spoke about the challenge of trying to hold the "emotions from a full family" alongside her own.

In addition, Leo's mother relinquished paid employment following the accident. Nearly a year and a half on, she was unable to return to work as school rang her during the week if

Leo had a seizure. The loss of one income had significant financial implications for the entire family, such as preventing them purchasing their house. This added additional stress onto the family.

4.4.2.4.4 Subtheme: Securing Support Amongst a Future of Unknowns

Leo's mother expressed fear about Leo's future and spoke of the importance of securing stable and consistent support for him as he gets older. She described a range of unknowns for the future as "every day is new, there is no prediction. Nobody can predict what's going to happen tomorrow or next week with Leo." In particular, she expressed concern with Leo's emotional regulation at school as there had been recent reported incidents of him directing some frustrations towards his one-to-one. Leo's mother expressed concern that it was "going to happen with his friends soon" which would impact his friendships. She was worried about him "becoming segregated" because of externalising behaviours, and this affecting his SoSB.

Whilst funding wasn't discussed in detail, both Leo's mother and the class teacher acknowledged the importance of obtaining financial support long-term. At the time of the interview, school had put in an application for an EHCP. Leo's mother spoke about getting "some support for him and some support for the school" in terms of "financial relief."

> *"I feel more at ease because he's got Miss X [one-to-one]. But I know that's not an indefinite thing. So I need something where I know ... I need something for Leo where I know I can breathe and possibly look at going back to work."* (Leo's mother)

Funding was perceived to be important to ensure that Leo continued to be supported one-to-one. This was important both for Leo but also to give his mother "that bit of resting space." Leo's class teacher hoped that the EHCP would come into force during the Autumn term.

SECTION 5: Discussion

5.1 Chapter Overview

The purpose of this chapter is to discuss the key implications arising from the research findings. Firstly, a summary of the research findings and key themes is provided. Key areas of significance from the analysis of the two case studies will be discussed in the context of the two research questions and existing literature. Consideration is then given to the implications of this research for both policy and practice. Finally, the limitations of the current study will be discussed, alongside proposed areas for future research.

5.2 Summary of Findings

The research questions addressed by this study were (i) to understand how children with ABI experience barriers and facilitators to a SoSB when returning to mainstream school after an ABI, and (ii) to explore whether, and to what extent, the perceived factors affecting school belonging differ across the systems around a child with ABI. Three main themes emerged from the interviews with children: ‘A Gradual Return Process’, ‘Fitting into the School Community’ and ‘Beyond the Reintegration Process’. Within these themes, children identified a range of facilitators to their SoSB including parental involvement in the return, opportunities to play with peers and individualised adaptations to support both social and academic participation. Whilst many facilitators were identified, these children also faced barriers to their SoSB which included perceptions of being different to peers, not receiving help in school and adjusting to their post-ABI ‘new’ self.

Analysis of the parent and school staff interviews showed close similarities across both cases in the overarching themes: ‘Collaboration Across the System’, ‘Fitting in to the School Community’, ‘Individual Characteristics of the Child’ and ‘Beyond the Reintegration Process’.

An additional theme of an ‘Information-Implementation Gap’ also emerged in one case study. Both case studies identified facilitators of a SoSB to include home-school communication, and barriers to include the limited understanding of ABI and its sequalae, and family adjustment to a new ‘normal’. However, the research identified that many perceived factors impacting a SoSB were highly nuanced and case specific; things that were perceived to support the child’s SoSB in one case study (e.g., phonics intervention in the foundation class), were identified as detrimental to the wellbeing of the child in the other case study. In Case Study One (Valerie’s return to school), parents and school staff perceived the facilitators of a SoSB to be parental involvement with the school return, getting to be a child, the school community joining the child on their rehabilitation journey and balancing academic and socio-emotional development. In Case Study Two (Leo’s return to school), identified facilitators included relationships in schools and flexibility through specific adult support. Regarding perceived barriers, Case Study One identified these to be the child’s determination and sense of agency, the child’s adjustment to a ‘new’ self, anticipated challenges as the child moved through the education system, school resources and allocation, and the statutory processes not set up for children with ABI. In Case Study Two, perceived barriers included the child’s sensitivity to differences, medical needs affecting participation, the child’s understanding of his ABI, parenting a different child and securing support amongst a future of unknowns.

Notably, the themes within each case study linked closely with the children’s themes. However, whilst the children focused more on what the people around them were doing (e.g., not providing help), adult responses were more nuanced and typically focused on the impact of the wider social context (e.g., resource allocation impacting provision). In addition, as seen in the results section, the perceived barriers and facilitators to a SoSB were not mutually exclusive; the complex relationship between these factors makes it challenging to discuss them independently. Therefore, the following discussion has grouped the factors based on the most appropriate fit.

5.3 Fitting Into the School Community

5.3.1 The 'Normality' of Childhood: School, Peers & Play

Consistent with the findings from the literature review, an early return to school was viewed as important for the children's recovery as it offered them a 'sense of normality' (Mealings & Douglas, 2010). Attending school provided these children the opportunity to 'be a child' and allowed them to focus on things other than their injury (Vanclooster et al., 2021). As such, parents did not want to prevent their children from returning to school when they requested to do so. The concept of returning to 'normality' was notable, given that for Valerie she had only attended school for eight days prior to her illness. It would be easy for one to assume school to not be a 'normality' in this instance. However, it is important to recognise the meaning that school typically holds for children of this age. A narrative exists around starting school which children are often exposed to early on, particularly if they have older siblings. Starting school is viewed as "a key life cycle transition both in and outside school" (Pianta & Cox, 1999, p. 17). It is frequently presented as a rite of passage (Christensen, 1998), associated with increased status as one of the "landmarks in the process of growing up" (Brooker, 2008, p.27). A key focus in Early Childhood Education and Care (ECEC) settings is school readiness, ensuring that children have the skills and resilience to successfully navigate the school transition (Wickett, 2017, 2019). As such, preparation for school usually begins nearly a year before moving to reception class (Wickett, 2017). It is therefore important that adults do not negate the importance that school holds for even young children, and the impact that absence may have for their sense of belonging.

For both children a SoSB was strongly related to their engagement in play. Both children identified playing with peers to be their greatest motivator for returning to school, consistent with research that found reception-aged children perceived the purpose of school to be ‘play-centred’ (Brooker, 1996). However, whilst both children highlighted the importance of play, they both experienced barriers due to their ABI. For Valerie, this was related to her physical difficulties post-ABI. She was supported by her mother in school, which helped her to partake and made her feel happier. Whilst Leo was physical able, he was unable to engage in physical activity due to risk of reinjury. Despite being allowed to invite friends to join him inside, he experienced frustration at not being able to join his class at break-times. Many studies exploring SoSB provide evidence that friendships are important for older children (Appleton et al. 2006; Hamm & Faircloth, 2005; Wentzel et al. 2004). In early childhood, friendships are also important, however, they typically centre around play and compatibility of play style (Gifford-Smith et al., 2003; Howes, 2009). This may account for why Leo found it challenging to not be able to play with his peers in the way he was able to prior to his injury, despite school providing alternative opportunities to socialise. This therefore highlights the importance that play opportunities bring for children returning to school following an ABI, and the negative impact of restrictions on play for their SoSB.

5.3.2 The School Community as a Social Support Hub

Belonging is a relational phenomenon and as such it has been argued that one has to be accepted in a community in order to belong (May, 2013). In line with this, positive relationships with peers and teaching staff were perceived to be an important facilitator to a SoSB. Both families and school staff spoke of the way that the child were positively embraced by their peers on their return. The inclusiveness of her peers surprised Valerie’s parents as she had only been at school eight days before her illness, and therefore had no pre-established friendships.

This finding is interesting given that current literature has found children with SEN to be less accepted and experience greater rejection than their peers (Dyson et al., 2004; Frederickson & Furnham, 2004). Research focused specifically on children with ABI has shown that they are at high risk of both social exclusion and bullying from peers (Ilie et al., 2014). In contrast to this literature, the children in the current research did not report direct exclusions by peers. It is possible that the young age of the children in this study accounted for the difference observed, as most of the existing studies exploring peer relations and SEN have focused on older children and adolescents. As mentioned previously, at the age of four and five, children's focus appears to centre on opportunities for play (Gifford-Smith et al., 2003; Howes, 2009). These children may therefore be less attentive to other aspects of difference, compared to older children, lending itself to a more inclusive school environment.

In addition, the early return was also perceived to help the school community adjust to the child's needs post-ABI as it meant that the other children explicitly saw the difficulties the child was experiencing. Research has found that both visible and physical disabilities are more accepted by peers than less visible ones (de Boer et al., 2013), supporting the view that an early return aided their acceptance. An early return also allowed the school community to be part of the child's journey; students and staff saw the nature of the child's injuries and the adjustments that were required. As such, these adjustments became a natural part of their daily interactions with the child, creating a more inclusive community. The school community also saw the progress the child was making with their recovery, and were able to celebrate this alongside the child.

5.3.3 Specific Adaptations to Promote Participation

Research shows that children with ABI have reduced participation patterns both at school and in the community (Kocher Stalder, 2018; van Tol et al., 2011). Whilst direct exclusion (e.g., peer attitudes) appears to be less of a concern for younger children, these children may be more vulnerable to passive exclusion whereby their disabilities and limitations post-ABI hinder their participation at school. School staff reported a range of adaptations implemented to promote both social and academic participation. Specific provision to promote social participation included breakout spaces for the child and peers at lunch time, one-to-one adult supervision so the child could go outside at play and separate SEN physical education classes. Provision to promote academic participation included a higher level of in-class adult support, differentiated work and returning to the foundation stage for phonics. Whilst adaptions were largely individual to the child depending on their difficulties post-ABI, both children perceived key adult support to aid their participation. This sentiment was also shared by all adults in the study, who viewed flexible deployment of staff to be an important requisite to providing tailored support including focused academic interventions and learning breaks. Having a one-to-one also enabled approaches to be adapted in response to feedback from the children and their parents, supporting a more inclusive learning environment.

However, despite the recognised need for adaptations, they were not always implemented in school. Similar to findings from adolescents with ABI, the children typically attributed this to the adults around them not helping them (Gagnon et al., 2008). This is concerning as SoSB will likely be negatively impacted if children perceive the school staff to be unsupportive of their needs. In comparison, school staff and parents provided more nuanced perspectives. Whilst parents also attributed some lack of adaptation to staff attitudes and/or misunderstanding of ABI, they recognised the difficulties that school faced with funding. School staff further identified an information-implementation gap, where a scarcity of resources prevented identified adaptations, such as learning breaks which required an adult staff member, from being implemented.

Notably, perceived responses to adaptations were child specific. Whilst Valerie enjoyed returning to foundation to complete her phonics sessions, the same intervention was reported to be detrimental to Leo's wellbeing. For Leo, tension was observed between the interventions in place to promote his participation, and the impact of these interventions on his perception of being different to his peers. The need to fit in with peers is often associated with adolescence, whereby peer acceptance is typically a primary objective (Crosnoe, 2011; Eccles & Roeser, 2011). However, this current research suggests that its importance for younger children should not be ignored. Such findings are in keeping with evidence that even two-years-olds seek experiences of belonging through negotiated social hierarchies, membership and social boundaries (Löfdahl & Hägglund, 2012). At school, membership is often related to year groups and classes which may account for Leo's aversion to the provision that made him look like he was in a younger year group (e.g., going down to foundation for phonics, wearing a high-visibility jacket like the children in foundation). Whilst it could be argued that providing a one-to-one adult would increase perceptions of difference, for Leo this may have offered a way for him to receive the support he needed whilst remaining within the confines of his Year One class membership. This suggests that for some children the concept of inclusion is more than physical participation. Professionals must therefore consider the different individual factors that may influence a child's conceptualisation of a SoSB, and their perceptions of specific adaptations.

5.4 Collaboration Across the System

5.4.1 Understanding of ABI and its Sequalae

Consistent with the papers in the literature review (Bate et al., 2021; Diener et al., 2022; Gagnon et al., 2008; Jones et al., 2022; Roscigno et al., 2015; Sharp et al., 2006), participants in this research identified that school staff lacked sufficient understanding of ABI and its sequalae. Whilst school staff recognised their limited knowledge of ABI, they reported challenges with obtaining training, leading to a reliance on parents to provide information and deliver training. This finding is coherent with research by Jones et al. (2022) who found school staff were receptive to information about ABI but required parents to provide it. The lack of relevant teacher training is likely to leave many teachers ill-equipped to support children with ABI and their families on their return to school, leading to misperceptions and inappropriate adaptations (Davies et al., 2013; Glang et al., 2008). In keeping with this, a recent systematic review showed that there are significant levels of ableism among children with ABI (Lindsay et al., 2023). Moreover, rates of ableism are higher among younger groups (Harder et al., 2019). Given the vulnerabilities of this group of children, it is important that schools actively seek to understand ABI to minimise the risk of inappropriate or ableist provision. This involves a knowledge and understanding of ABI across the school community, including peers, parents and school staff.

In addition to school staffs' understanding of ABI, it was noted that parental understanding was also limited. Parents relied on their own individual research, any existing background knowledge and past experiences to support their understanding of ABI. This is problematic, given that school staff often rely on parents for information and advice. It highlights an important need for school staff to have adequate knowledge of ABI and its implications for learning and development, without relying on parents to provide this.

5.4.2 A "Shared" Responsibility

Consistent with previous research, all adults across the systems identified the value of a collaborative approach between home and school to support a successful reintegration (Bate et al., 2021, Roscigno et al., 2015). In particular, effective home-school communication was perceived to be important for the children's positive experience of school. High levels of communication ensured that staff were working in the most effective way for that specific child, thus supporting their participation and their SoSB. Successes were reported when parents and staff met regularly to problem-solve, when the child's views were communicated via the parents and adaptations were made in response. Whilst there were examples of successful communication practices, certain factors within the school structure posed a barrier to effective communication. Similar to reports within secondary education, barriers mainly centred around multiple teaching staff (Gagnon et al., 2008), in this case due to shared job roles and the child moving classes for interventions. Home-school communication was enhanced by having a key adult who knew the child well and could act as a constant point of liaison.

However, despite the recognised importance of a collaborative approach, there was a clear reliance on parents especially during the initial transition stage. In both case studies, parents played a pivotal role in the initial return for multiple reasons. Consistent with previous findings that families discharged directly home from hospital have to navigate their own return-to-school (Crylen, 2015; Jimenez et al., 2020), it fell to parents to decide what the return looked like. Parental involvement also included bringing the children into school on a reduced small-steps timetable, staying at school with them and ensuring their safety during this time. Greater ongoing parental involvement was related to the child's medical needs, and severity of physical symptoms post-ABI. Parental involvement in the initial stages of the return was reassuring to both the children, but also to school staff. Parents were perceived to hold the greatest knowledge about the child and their ABI, and therefore school staff were largely guided by parental views. For both families, parental involvement extended well beyond the reintegration period, due to ongoing medical needs.

Whilst there was consensus that parental involvement was helpful, and in both cases necessary for an earlier school return, it placed additional pressure on families. This is notable given that high levels of parental stress are already reported among parents of children with chronic conditions (Cousino & Hazen, 2013). It is important to recognise the additional stressors that families face following paediatric ABI, which is unexpected, sudden and often traumatic. Research from system-psychodynamics emphasises the importance of the systems being aware of potential stressors and the impact on collaborative working. With high levels of stress across systems, there is risk that both school staff and parents split off and project these uncomfortable feelings onto each other. This can lead to positioning of blame (Dunning et al., 2005), whereby parents perceive school staff to not be doing enough to support their child, and school staff perceive parental decision making to be counterproductive. By applying a systems-psychodynamic lens, professionals may seek to support schools to foster a collaborative approach to supporting the child. In particular, this research suggested the presence of uncertainty across both the home and school, leading to each system looking to the other to provide knowledge. However, both home and school have expertise of that young person which, together in collaboration, produce the fullest picture of the child and their needs. Schools' must therefore consider what a collaborative return looks like, and the way in which a "sharing" of responsibilities may impact parental stress and the home-school relationship.

5.5 Beyond the Reintegration Period

5.5.1 A Future of Unknowns and Anticipated Challenge

The trajectory of recovery for paediatric ABI is largely unpredictable (Ewing, 2006; Ownsworth 2014); injury can interrupt, slow or stop developmental processes and difficulties can emerge as the child develops and 'new' skills become active (Glang et al., 2004). In line with this, both families expressed concerns with their child's future, particularly around the multiple ‘unknowns’. Notably, both children also expressed their own concerns with the future. Despite only being in Year One, Leo identified worries about secondary education. Regarding school, all parents highlighted the importance of securing support for their child early on, in order to ensure they continued to receive appropriate care throughout their education. Parents were concerned that without ongoing support, the necessary provision wouldn’t be implemented as the children got older, due to their difficulties being hidden or masked. Valerie’s parents were also concerned that new adults may not understand their child’s potentially changing needs. Research shows that many people hold misperceptions of the nature of head injury, particularly around their long-term implications and potential trajectory (Canto et al., 2014). Difficulties had already emerged following the transition to Year One, attributed to staff members being less aware or understanding of Valerie’s needs. Therefore, it was important for them that long-term provision was established.

All adults in this research placed importance on the statutory process and obtaining an EHCP to provide security and certainty for the children. However, staff reported the lengthy statutory process and need to show evidence of the assess, plan, do, review made obtaining an EHCP more challenging. At the time of interview, over a year after their return-to-school, neither child had an EHCP. This remained a source of frustration for parents in particular, who felt that an EHCP would enable school to implement better adaptations to meet their child’s needs, and in Valerie’s case, increase both the quantity and quality of time in school.

5.6 The Need to Take a Wider Systemic Lens

5.6.1 Unique Family Factors

An identified limitation in the literature review was the lack of consideration given to social and cultural factors. By only focusing on two case studies, this research provided exploration into how unique social and cultural factors impact families during the reintegration process. Having English as a first language and parental understanding of ABI, due to educational backgrounds or personal interest, enabled parents to communicate more efficiently with medical professionals and school staff. This made it easier for parents to understand both the prognosis as well as advocate for provision in school. Parental involvement in the return to school was afforded by the child being in a two-parent household, as one parent was able to focus on the school return whilst the other parent took care of their other children and/or worked. The attitudes and accommodations of parental employers was also noted to be critical in providing flexibility to parents at this time. Valerie's parents identified that had this not been the case, their child wouldn't have returned to school as early as they did. This was significant given the perceived importance of an early return for the child's reintegration and SoSB.

In addition, whilst some socio-cultural factors made the transition somewhat easier, others brought additional challenges including a recent relocation, parents caring for younger sibling(s), the level of social and family support and parental wellbeing. Previous research has identified that a failure to consider the family context may result in professionals implementing unhelpful provision (Clark et al., 2008; Roscigno et al., 2015). Professionals must therefore seek to understand the socio-cultural factors unique to families with a child with ABI and consider their impact on both the reintegration process and the ways in which they may affect the child's overall SoSB. As such, there is a need for professionals to take a holistic view when working with families of a child with ABI, utilising biopsychosocial models which reflect a wider systemic understanding of a family's situation.

5.6.2 Ongoing Adjustments Across the System

An overarching narrative across all the interviews was that of adjustments needing to occur across all levels of the system. These adjustments had an emotional impact on all those involved, and appeared to also influence the way in which a SoSB was perceived. Adjustments for school staff, parents and the child are considered in turn, linking to their impact on the child’s SoSB.

5.6.2.1 School Staff Adjustment

This study identified a range of adjustments that school staff need to make when supporting children with ABI, particularly regarding the balance of academic and social considerations. By interviewing two staff members within one school, this research highlighted that school staff may hold different perspectives regarding the priority for children with ABI. Whilst the SENCo acknowledged that interventions needed to promote the holistic development of a child, the class teacher felt that academic catch-up was of priority. Differing priorities are seen in a range of organisations, like schools, whereby members can hold beliefs about the primary task which differ to both the actual task of the organisation (Lawrence, 1977) and to each other (Obholzer & Roberts, 1994). Challenges can therefore emerge with collaborative working as discrepancies in the perceived primary role lead to conflicting objectives and disrupt collective functioning (Rice, 1969). It is important that school staff recognise that they may hold competing priorities in relation to their perceived roles, so that they can work collaboratively to adjust their practice to implement provision that is in the best interests of the child.

The focus on academic development from the teacher is consistent with perceptions of the traditional teacher role to provide children with the skills to make academic progress. It may also reflect the current legislative pressures on teaching staff that may direct focus towards academic attainment, including emphasis on the Year One phonics screener and the Year Two SATS. More recently, the Covid-19 educational recovery has also put pressure on teachers to provide academic catchup (DfE, 2022). Given that children with ABI miss valuable time in school due to their hospitalisation and recovery, it is understandable that a teacher's focus may be on academic interventions. However, in providing interventions to catch up missed learning, these children miss out on social opportunities which can impact their social development, peer relationships and class participation. To support a child's SoSB, it is important that school staff understand the child's holistic needs and adjust their practice accordingly.

It should be noted that the dominant focus on academic attainment was not the case for both teachers interviewed, suggesting the presence of other factors at play such as individual staff attitudes and school ethos. Such findings warrant further investigation to explore how differing perceptions of school staff may impact both the support a child receives in school, and the child's perception of belonging.

5.6.2.2 Parental and Familial Adjustment

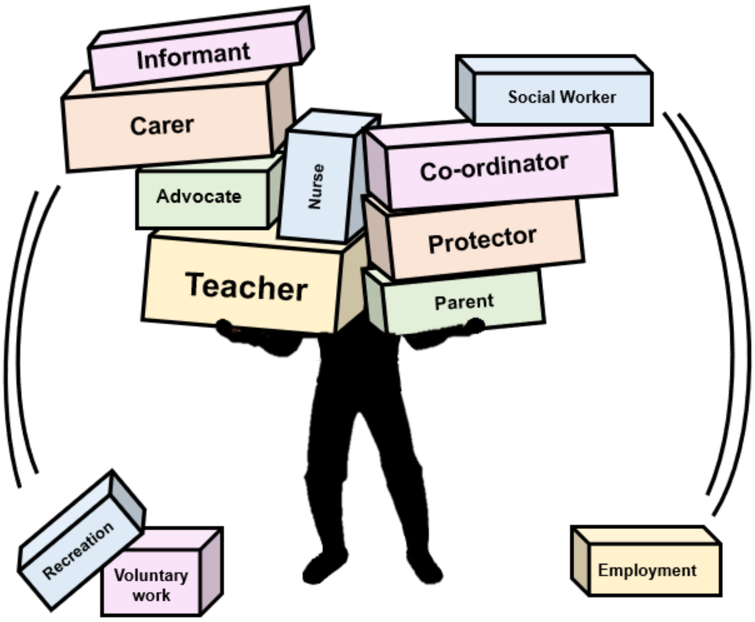
Recognised throughout the interviews was the impact of paediatric ABI on the family homeostasis, leading to the adjustment process becoming a shared family experience. A range of emotions were present throughout the parent interviews including anguish, relief, grief, helplessness, determination, anger. These emotions were complex and confusing at times. Consistent with the literature (Tyerman et al., 2017), parents spoke of multiple changes including changed family relationships, loss of income and higher rates of psychological distress. Parents described a grieving process, and the challenges of adjusting their expectations and hopes for their child's future. The experience of grief was greater for Leo's mother, who described changes to her son's personality post-ABI. This is consistent with findings by

Yehene et al. (2021) that parental-perceived behavioural changes are linked to greater parental grief reactions. Increased behavioural difficulties following an ABI significantly disrupt family functioning and increase parental distress (Anderson et al., 2005; Taylor et al., 2001), suggesting that families may experience differences in their adjustment process depending on the needs of their child. Therefore, those working with families need to be aware of the emotional toll that comes from non-finite loss experiences.

Alongside grieving for the ‘lost’ child, Leo’s mother also described trying to understand her current child and their changed relationship. The need for parents to reconstruct their view of their child and new ways of relating has been found to be more prominent for parents of children with ABI than children with other chronic illnesses (Fisher et al., 2001; Coffey et al., 2006). With the sudden on-set of ABI, parents were required to respond to their child’s emerging needs and as such experienced changes to their parental roles and responsibilities (Ownsworth, 2014; Schönberger et al., 2010). Parents assumed a range of quasi-professional roles including, but not limited to, carer (rather than caregiver), social worker, advocate, information-giver, teacher and co-ordinator (See Figure 28). When initially returning to school, parents also reported the need to take a ‘protector’ role, remaining alert to risks of further injury and guarding their children (Kirk et al., 2015; Jones et al., 2010). This involved accompanying their child into school. The role of protector appeared to be amplified by the lack of understanding of ABI within school, leaving parents concerned for their child’s safety whilst at school. This was especially the case for Leo’s mother, as his accident had occurred at school. Valerie’s mother also reported taking on a learning support assistant role in the reception classroom, facilitating Valerie’s inclusion in the educational setting. This ensured that Valerie was able to return to school at the time she did. Parents embraced these roles because it was necessary for their child’s recovery and development. However, there was a sense of uncertainty and sometimes inadequacy in these unfamiliar roles, leading to additional parental strain at a time of already understandably high stress.

Figure 28.

Depiction of Some of the Parental Roles and Responsibilities Post-ABI



In addition to the roles that parents had assumed following their child's ABI, they also relinquished previously valued roles, including employment (see Figure 28). Multiple studies have found that in two-parent households, one parent will typically cease employment to be primary caregiver in order for their partner to remain in full time employment (Tam et al., 2015). This was observed in both case studies, as both children were on reduced timetables. It is notable that the changes to parental roles and responsibilities were not specific to the transition period. Instead, they continued to shift across the children's recovery journey. At the time of interview, over a year after the return-to-school, parental availability remained a necessity for both children; Valerie remained on a reduced timetable and whilst Leo had returned to school fulltime, his mother was frequently called to collect him during the school week due to medical concerns. As such, both households relied on one income, impacting financial stability. Moreover, Valerie's father described how Valerie's mother remained her primary teacher due to the lack of provision in school. Frustrations related to this were noted, as there was a view that sometimes by taking up these roles, others had abridged their responsibilities. Whilst Valerie's mother reported that she would happily throw all her time and energy into supporting her daughter to learn, she required support from school to know what topics to be teaching at home. This again highlighted the need for collaborative working. Social psychology posits that role identities are important for self-conception (Stryker and Serpe 1982; Thoits 1983, 1986). As such, shifting identity-related roles raise concerns for parental adjustment following paediatric ABI, particularly given that often parents relinquish the activities that positively impact their self-concept and wellbeing e.g., employment and social recreation. There is a need for professionals to consider how ongoing, multiple and changing roles impact parental identity and parental wellbeing following paediatric ABI. There is also a role for schools to consider how their decision making around provision may be inadvertently placing further demands on caregivers that are detrimental to their adjustment.

Moreover, given the loss of equilibrium for the entire family and likelihood of poorer family functioning (Analytis et al., 2022), further consideration should be given to the impact for siblings of children with ABI. With parental shifts in roles and responsibilities, changes in family routines and parental attentions, the relationship between a parent and their other children will inevitably be altered (CBIT & Nasen, 2018). However, despite the recognised impact on siblings, a recent scoping review by Vallee et al. (2023) identified a paucity of research on this issue. Whilst out the remit of the current study, this merits further investigation.

5.6.2.3 Child Adjustment

Following an ABI, children have to reconstruct their sense of self, often related to changes to physical ability, appearance (e.g., scarring) and academic performance (Vanclooster et al., 2019; Jones et al., 2022). The current research identified differences in the level of awareness of the two children in this study, which appeared to impact their adjustment post-ABI and their experience of a SoSB. Valerie demonstrated a greater understanding of her ABI and its impact on her existing needs. She could articulate why the specific adaptations were in place, and was able to tolerate things that made her different to her peers, such as going down to foundation for interventions or having a reduced timetable. In contrast, Leo showed a reduced understanding of his ABI. Despite recognising some areas of need (e.g., his memory), Leo primarily focused on how his membership within the class had been disrupted. Research suggests that poorer awareness increases levels of distress post-ABI (Hoofien et al., 2004). Ownsworth & Oei (1998) attributed this to individuals not understanding when they encounter episodes of failure. Muenchberger et al. (2008) suggested that individuals "need to make sense of the profound changes associated with their injuries and come to some understanding regarding their processes of identity transition following injury" (referenced in Segal, 2010, p. 298). If a child does not understand the personal identity changes they are experiencing post-ABI, they may seek to hold onto their previous identities such as class membership.

Given the impact that awareness appears to have on how the children conceptualised a SoSB, it is useful to hypothesise about why such differences in awareness were observed. One possibility is that level of awareness was reflective of differences in maturation in regard to the children's introspection. Greater introspection would have enabled Valerie to reflect on her own motivations and priorities. As provision at lunchtime provided Valerie with key social opportunities, her focus was likely shifted towards the academic side of school where she didn't feel she was able to participate. In contrast, Leo appeared to be more extrospective. It is possible that poor introspection may lead children to conceptualise a SoSB in a more egocentric way, as seen with Leo's focus on perceived difference (Cheek & Pronin, 2021).

In addition to individual differences, the circumstances surrounding a child's injuries are likely to also contribute to their level of awareness. Valerie's parents had some time, albeit brief, to somewhat prepare her for what may happen as a result of the operation. In contrast, the sudden nature of Leo's accident at school meant that both parents and Leo had no time to prepare or process what was happening. Moreover, Valerie's injuries were more apparent to others, but also to herself. When she first started back at school, she was unable to independently mobilise. She therefore couldn't join in with her peers in the same way as before and required adaptations to facilitate this. In contrast, Leo's difficulties were less obvious likely contributing to confusion as to why he couldn't play with his peers, even though he deemed himself physically able.

The approach that parents take when communicating to their children will also impact their level of understanding. Valerie's parents sought to be open with Valerie and keep her as informed as possible throughout. This would have inevitably impacted her level of understanding around her illness, the operation and her ABI. In contrast, there was a sense that Leo's parents were unsure of how much information to share with him. Leo's mother recalled initially telling Leo that he had been bitten by a shark. Similar responses are often seen with difficult concepts such as death where adults exclude children from conversations, often either in a bid to protect them or because they do not know how to address the situation (Moore & Moore, 2010). The current research suggests that 'childism' may negatively impact a child's awareness and adjustment following ABI, with wider implications for how they perceive a SoSB. As such, there are key implications for the way in which adults treat children as agentic.

This research shows that children as young as four are capable of understanding what has happened to them and raises the possibility that informing them in a clear but age-appropriate way may actually support their adjustment following an ABI.

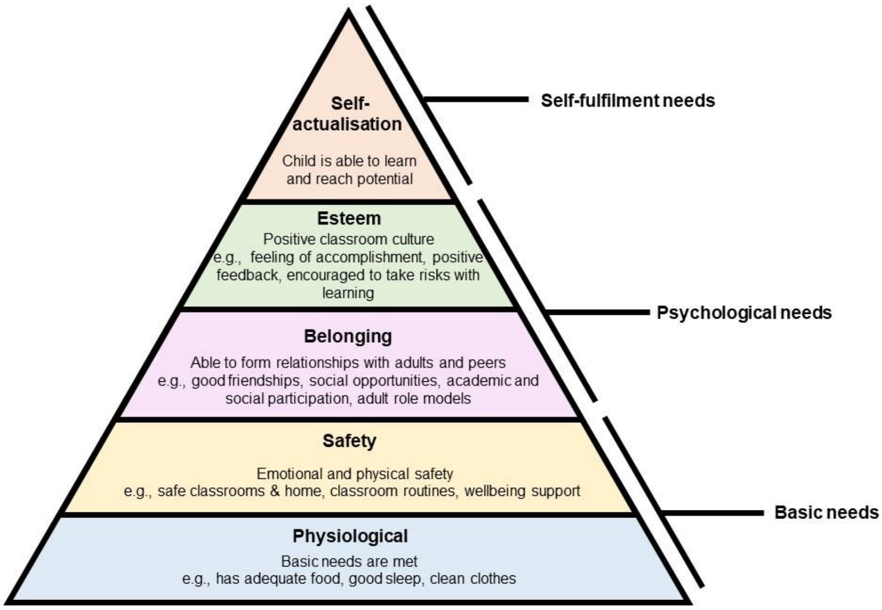
Moreover, the way in which parents have processed and understood the situation will further impact on their child's understanding. If parents are unable to process what has happened, they will subsequently be unable to support their children to do so. This view is supported by research that has found poorer parental adjustment to be linked to negative long-term child outcomes including executive dysfunction (Potter et al., 2011; Yeates et al., 2010). Given that the onus typically falls on parents to communicate to their child about their ABI, there is scope for professionals to support parents during this time to process the experience and help explain this to their children.

5.7 School Belonging and the Adjustment Process

Given the adjustments that children with ABI must undergo, it is important to consider the role that a SoSB may play, particularly for those who may be experiencing poorer adjustment. A SoSB is deemed to be an important construct for typically developing children and adolescents (see Figure 29), and is linked to a range of positive social, emotional and academic outcomes (Neel & Fuligni, 2013; Pittman & Richmond, 2007). Whilst minimal research to date have explored the effect of school belonging for primary school-aged children (Wagle et al., 2018), these studies also indicate its importance. Recent research by Palikara et al. (2021) showed that for eight-to-ten-year-olds, a SoSB was closely linked to their socio-emotional wellbeing. This current study adds to this research literature, demonstrating that a SoSB is also important for children as young as reception age.

Figure 29.

Maslow's Hierarchy of Needs Adapted for 'School'



Moreover, adding to existing literature on reintegration following an ABI, this research suggests that a SoSB is valuable for young children's adjustment following an ABI. According to the Social Identity Model of Identity Change (Jetten & Panchana, 2012), previously shown in Figure 2, group membership is a protective factor for one's wellbeing following a life-changing transition. Consistent with this, research focusing on recovery following an ABI has shown that group membership supports one's adjustment (Muldoon et al., 2019). Research from adults with ABI shows that the development of positive self-identity predicted better quality of life post-ABI (Vickery et al., 2005). Although this research was conducted with adults, it is likely that a similar effect is observed with children. As such, there is an argument for SoSB being critical for a child's self-identity adjustment when returning to school. Whilst returning to school offers children with ABI a sense of normality and gives them back an identity as a student, a SoSB provides children with a stable and positive sense of identity at a point of great instability in their personal and family lives. This may be of particularly pertinence for younger children, for whom their identity as a pupil at school if often a dominant narrative. This therefore emphasises the need for support across all levels of the system, to ensure that adults looking after children with ABI are equipped to facilitate a SoSB to promote positive self-identity and post-ABI adjustment.

5.8 Implementations and Recommendations for Policy and Practice

5.8.1 Implications for Policy

5.8.1.1 Upskilling Educational Professionals in Schools

This study highlights the importance of the systems around a child with ABI working collaboratively to support their return. However, successful collaboration is contingent on the systems understanding the implications of ABI, and being able to devise and implement adaptations for the child's individual needs. As mentioned above, lack of educator knowledge was a significant perceived barrier to the child receiving support to enable participation at school. This same assertion was present in research dating back over at least 15 years (Bate et al., 2021; Diener et al., 2022; Gagnon et al., 2008; Jones et al., 2022; Roscigno et al., 2015; Sharp et al., 2006), suggesting sedentary to little progress has occurred since then. Social inertia is problematic for the inclusivity of children with ABI in mainstream schools. Lack of knowledge and understanding within the school system increase the risk of institutional level ableism (i.e., lack of supports and accommodations, and lack of awareness of ABI) (Glang et al., 2008; Lindsay et al., 2023). Whilst teaching training courses give some attention to SEN, there is no specific training on ABI. School teachers are therefore reliant on information from parents or from external professionals, who are often cited to be inaccessible due to a scarcity of resources. Given both the high prevalence of childhood ABI and medical advances, it is likely that educators will continue to encounter these children more and more in mainstream provisions. Therefore, it is fundamental that local and national political administrators of education update training course requirements to reflect this need to upskill educators in this area.

5.8.1.2 A Role for Educational Psychologists

As emphasised in recent guidance (N-ABLES, 2021), EPs are well placed to support the reintegration process for children returning to school following an ABI. There is a clear role for EPs to utilise their knowledge of child development, systemic working, trauma-informed practices, and consultation skills to support schools at multiple levels. Such support could include guidance documents with general information around ABI, bespoke training packages, consultation-based working with school-home and therapeutic work with families and children. However, despite the range of work that EPs can actually offer, this research indicated possible misconceptions around the EP role and their ability to support this group of children. EP involvement was only sought in one case, in preparation for an EHCP application. In addition, while school staff recognised a need for training on ABI, they were unaware that the Educational Psychology Service could support with this. This therefore suggests a need for Educational Psychology Services to advertise more explicitly as part of the local offer, to ensure that schools are aware of different ways that the EPS can support them to meet the needs of CYP with ABI. Moreover, there are a range of freely available resources from charities that schools can utilise, but do not appear aware of. A key role for EPs may be to provide clear signposting to resources like these that are available to teaching staff to support their work with children with ABI.

An additional consideration could be the way in which EP work is offered to schools. As highlighted in this research, schools have limited resources which may also prevent them seeking external professional support. An established part of the EP role is to support school communities following a critical incident (DFEE, 2000). Whilst critical incident work usually centres on the immediate response to an event, long-term critical incident work has been documented for key incidents such as the Grenfell Fire in which EPs supported schools with the one-year anniversary (Kerslake & Roller, 2021). Given that EPs would be available to support schools following an incident in which a child is hospitalised with an ABI, it seems logical that EPs could also play a key role in supporting the school community to adjust and support the child's return to school. At present, critical incident policies sit alongside wider LAs emergency procedures (Beeke, 2011). There is scope for LAs to revise their critical incident policy, to reflect the need to offer support to schools at the point of reintegration in addition to the point of initial incident.

For EPs to better support children with ABI in schools, there also needs to be a purposive drive to upskill EPs in LAs. Multiple studies have found that EPs self-report feeling ill-equipped to support the reintegration of children with ABI into education (Bozic & Morris, 2005; Ball & Howe, 2011). This is unsurprising given that EP training courses provide little direct teaching on this area of practice (Misheva, 2020; Bozic & Morris, 2005). Yet, ABI is one of the most common neuropsychological conditions that EPs encounter (Mackay, 2005; Misheva, 2020), raising questions as to why teaching is so limited. Training courses across England need to increase their teaching input on child neuropsychology, and support EPs to be both competent and confident to utilise their existing knowledge and abilities to work with CYP with ABI (Hooper, 2006).

5.8.1.3 Statutory Procedures and a Long-term ABI Strategy

This research highlighted the benefits of early reintegration. However, access to resources, particularly through current statutory procedures, were identified as a barrier to the children's return to school. The short timeframe between hospitalisation and returning to school for many children with ABI is inconsistent with the need for schools to demonstrate response to intervention over time outlined in the CoP (2015). This research suggests the need for a separate pathway to the current statutory EHCP process, for schools to access a ‘reintegration grant’ to support the initial transition period. Interim funding would reduce the pressure on parents who otherwise may provide the provision themselves, such as accompanying children into school. A funding plan to support the child to access school would then allow school to assess the child’s needs following the statutory graduated response and enable a clear evaluation of whether long-term provision through an EHCP is needed.

Moreover, there is a need for a national protocol to record and monitor these children to ensure they continue to receive the provision they require. Preliminary enquiries by the researcher into practices in their LA showed that there were no central records of children with ABI in the LA. As such, unless a child has an EHCP, they are not being monitored by the SEN team throughout their time in education and again the onus falls to parents to advocate for their child. Many children transition to new year groups or educational settings (e.g., starting primary or secondary school) without information about their ABI being communicated to staff members. This is particularly the case for children discharged straight home from hospital who may not have any professional involvement beyond discharge. The possibility of children with ABI getting ‘lost’ in the educational system is highly problematic given the long-term sequalae of ABI and the way in which difficulties can emerge over time. Challenges were identified in the current research when one child transitioned from Reception to Year One. Therefore, one can anticipate that greater challenges may emerge as the child gets older and the demands placed on them in school increase. Based on their research findings, McKinlay et al. (2016) argued that children with ABI should have support plans that are updated frequently, particularly at points of transition within education. The current study supports this view, but argues further that such support plans need to be implemented via a statutory framework and overseen at LA level to ensure children with ABI receive ongoing monitoring and targeted support where needed across their education, independent of obtaining an EHCP. Such view was previously recognised through a bill proposed to parliament in 2021 that requested a 'Brain Injury Strategy' setting out a strategy for meeting the needs of those with ABI through service provision (Acquired Brain Injury Bill, 2021).

5.8.2 Implications for Practice

5.8.2.1 Listening to the Voice of the Child

In line with the Declaration of the Rights of the Child, all children, including those with a disability, have the right to voice their opinion on issues that affect them (Sinclair, 2002). Parents of children with disability are often relied upon to share their children's perspectives, however, this is not equivalent to the voice of the child (Garth & Aroni, 2003). The current research provides evidence that children as young as six, when facilitated to do so, can provide unique insight into their experiences and perspectives. Whilst there were similarities in the perceived factors affecting SoSB, both children in this research identified factors that were unique to them. Therefore, when considering how to foster a SoSB for children with ABI transitioning back to school, it is important that we gain the children's views. Children are experts in their own lives (Clark & Moss, 2001), and as such, professionals must create opportunities for children to express their views. This research also demonstrates the utility of drawing on approaches from Personal Construct Psychology by using resources such as the Bear Feeling Cards (Qcards, 2010) to facilitate difficult conversations and/or elicit the views of younger children (Butler & Green, 2007).

Moreover, professionals need to utilise these children's views to inform the provision in school. All too often we speak about the 'voices' of marginalised groups. However, it is not enough to just hear these voices; we must actively listen to what these children have to say and utilise it in a meaningful way to positively influence adaptations and professional practice. As identified in this research, one academic intervention may support the emotional wellbeing of one child, but be detrimental to another (e.g., going down to foundation for phonics lessons). By listening to these children and making adjustments where possible (e.g., having individual phonics sessions outside the main classroom), schools can make small changes that have huge impact on a child's wellbeing and overall perception of school.

5.8.2.2 School Leading the Return

There is a clear need for professionals to recognise the emotional journey for families following an ABI, and the roles and responsibilities that parents are often left to navigate. Schools must therefore seek to work in ways that do not exacerbate parental stress during an already challenging time. The current research highlights a need for a paradigm shift, in which schools take the lead with the return. This includes staff taking the onus to learn and understand about ABI prior to the child's return, seeking external professional training or advice without relying on parents to provide it, and developing a transition plan that can be proposed to parents. Such practices will increase the fluidity of the transition for children, as well as reassure parents that their child's needs are understood. As parents are often overprotective after a paediatric ABI, school staff need to demonstrate to parents that they are competent and confident to support their child. Taking the lead with the return process not only reduces parental demands but is also likely to increase parental confidence in the school's ability to manage their child being back at school.

Notably, this does not negate the importance of parental involvement and ongoing home-school collaboration. Parents can, and should, be involved in the decision making regarding their child’s school return. Indeed, this research emphasised its importance, not only for parental sense of control at a time of great instability, but also because caregivers offer unique insights into their child, their family and the things that will be helpful. What it does mean, however, is that schools should not rely on parents to instigate and plan the return.

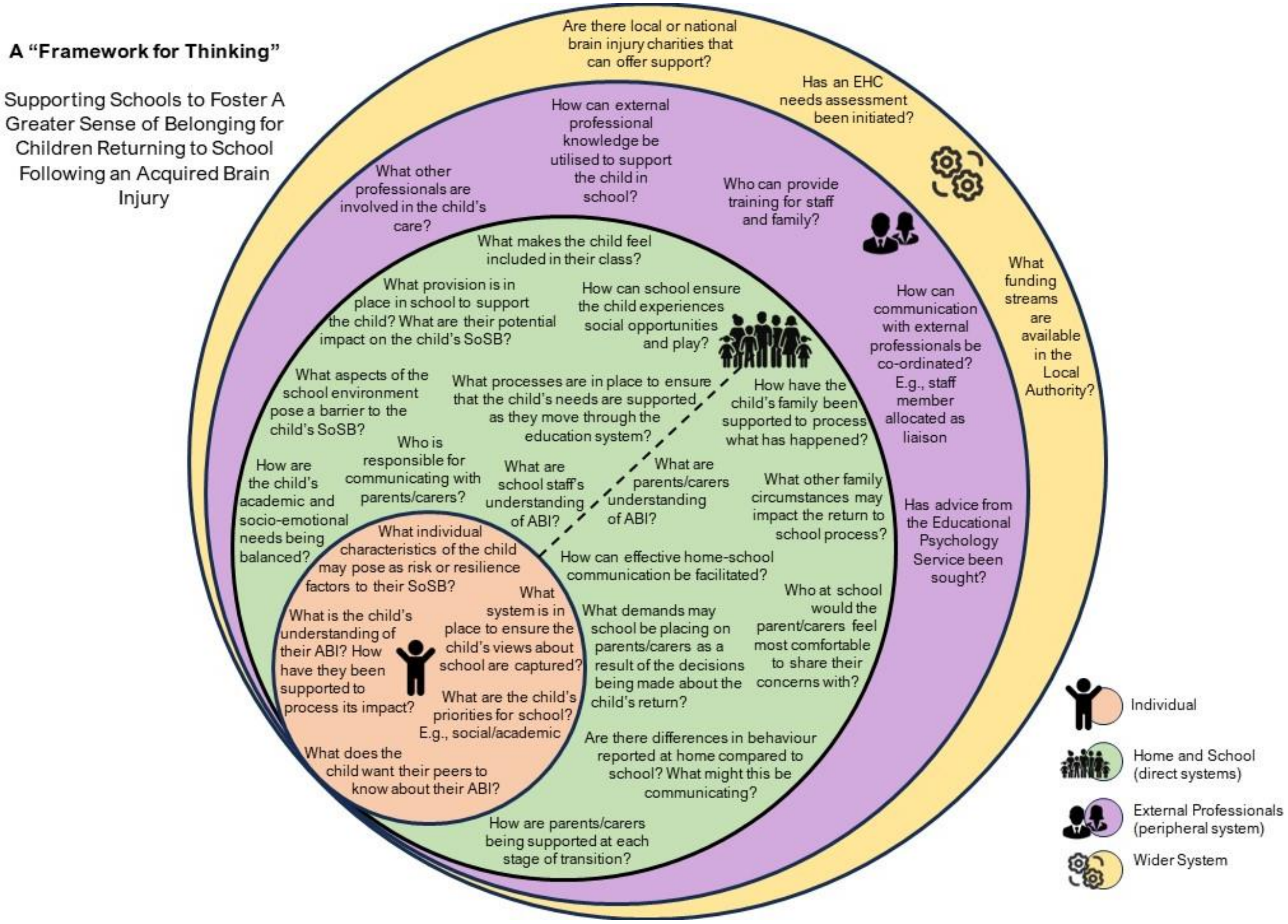
As highlighted by this research, ‘taking the lead’ also applies to smaller actions following the initial transition, which make the school return easier for the child and their family. For example, initiating communication, keeping parents up to date on curriculum topics and sending work home when children are on a reduced timetable. In addition, this research suggests that there needs to be a key adult to act as liaison with home and school. Schools should identify the individual best placed to take on this role, ideally someone who knows the child well and is able to form a supportive relationship with both the child and their caregivers.

5.8.2.3 Long-Term Individualised Approaches to Foster a SoSB

Previous research highlighted the need for ongoing individualised support for children returning to school following an ABI (Bate et al., 2021; Crylen, 2015; Diener et al., 2022; Gagnon et al., 2008; Mealing & Douglas, 2010; Robson et al., 2005; Roscigno et al., 2015; Sharp et al. 2006). This research adds to this evidence base, and suggests that when fostering a SoSB for these children, an individualised approach is also necessary. Whilst there were similarities in the overall themes identified, including the importance of fitting into the school community, home-school collaboration and support beyond the reintegration processes, many of the perceived facilitators and barriers were case specific. These related to individual characteristics of the child influencing their conceptualisation of a SoSB, and contextual factors within both the family and school environments. Based on the results in this study, the researcher has developed a framework consisting of open-ended questions that offer direction for educational professionals when considering how to foster a SoSB for children with ABI (See Figure 30). Given the recognised importance of taking a systemic approach to supporting these children, this framework includes considerations at individual, home, school and wider systemic levels (Bronfenbrenner, 1994).

Figure 30.

Proposed 'Framework for Thinking' to Support Educational Professional to Foster a Greater SoSB for Children With ABI



Please note, these questions are not exhaustive; instead, they are intended as a stimulus to guide educational professionals' thinking when supporting the reintegration of children with ABI back into mainstream school. It is envisioned that this framework will be used as a prompt during home-school consultations to refine the level of demands placed on parents, and support the design and implementation of positive adaptations that foster a greater SoSB for children with ABI.

5.9 Research Evaluation and Implications for Future Research

5.9.1 Transferability

A strength of this study is that it gained the views of different members within a system (child, parents and school staff), which enabled a holistic and ecosystemic exploration of the school reintegration process. This provided insight into the differences in perceptions about a SoSB across the systems, and a greater understanding of how these are negotiated to inform the support a child receives. Moreover, although unintentional, there were clear similarities between the two children in this study. Both children were white British, from nuclear families, in reception at the time of their ABI and in Year One at the time of interview. In addition, both children transitioned from hospital straight home. These similarities allowed for a greater comparison across cases, and highlighted a range of individual and family factors that also impacted the school return. The research findings, therefore, highlight a range of areas that schools should consider when supporting a SoSB for children with ABI. However, due to the small sample size and the methodology used, no claims can be made as to how representative the narratives reported in this study are of children with ABI in the wider population. Future research could seek to capture the views of more children returning to school following an ABI and key adults around them, in order to extend these findings across a range of different socio-cultural backgrounds.

Additionally, whilst this research demonstrates the importance of a SoSB for even young children with ABI, there are challenges with transferring the findings to older children. As both children sustained their ABI during the reception year, they arguably had limited experience in the mainstream environment. It is possible therefore that their conceptualisation of a SoSB would be qualitatively different if they had spent longer at school and perhaps been more embedded in the school system. It is also recognised that the return-to-school process may look different for older children, particularly in relation to parental involvement. Whilst this was perceived to be a key facilitator to the child's SoSB in the current study, it is likely to hold different meaning to older children and adolescents. Future research is needed to better understand the factors that may impact a SoSB for children in Key Stages Two and Three.

It is also important to recognise that whilst there were identified challenges with the transition, returning to school was largely a positive experience for the two children in this study. Both children reported feeling happy at school and identified a range of things that facilitated their SoSB. However, there are families whose transition experience is not a positive one. Some families may have not wanted to be part of this research because they felt unable or unready to share their experiences. This includes children who may have initially returned to school, but not managed in the mainstream environment. Research is therefore needed to capture the experiences of this group of children, to deepen our understanding of factors at play within these situations.

5.9.2 Study Design

This research only sought children who had returned to school in the last two years following their ABI, in order to minimise retrospective accounts which are identified to be more prone to recall bias (Talari & Goyal, 2020). However, as mentioned in the methodology section, the researcher was contacted by a range of parents and school staff who wanted to share their experiences, but where the children had returned to school at least three years prior and therefore did not meet the inclusion criteria. The current research highlights the overwhelming adjustments that children with ABI and their families experience. Similar to previous research (Bate et al., 2021), there were ongoing unresolved issues over a year after the children's return to school, suggesting that the two-year time scale used in this research may have been scant. Additionally, given the high levels of parental stress during this time, it may be that families do not feel in a position to be able to take part in research at this stage of their journey. Future research could therefore extend these parameters. Moreover, whilst a transition may be initially successful, challenges can emerge as the child moves through the education system. Therefore, there is also value in utilising a longitudinal design to follow the school reintegration journey for these children and explore how a SoSB changes as they progress through the education system. In addition, as this research focused on perceptions of a SoSB, only interview data was collected. Future research may wish to adopt multiple data collection methods, such as incorporating school observations, to offer additional insight into the current practices within schools and how they impact on the child's SoSB.

Moreover, as mentioned in the discussion section, further research is needed to explore the impact of paediatric ABI for siblings. The current research highlights the way in which paediatric ABI disrupts the entire family system, including changes to sibling relationships with both the child with ABI and their parents. Given that SoSB is important for children with ABI, it is likely to also play a protective role for siblings. Future research should explore this further, as currently there is a dearth of literature on sibling adjustment following paediatric ABI (Vallee et al., 2023).

5.10 Conclusion

This research sought to answer two questions, ‘how do children with ABI experience barriers and facilitators to a SoSB when returning to mainstream school after an ABI?’ and ‘to what extent do the perceived factors affecting school belonging differ across the systems around a child with ABI?’. The aim was that by addressing the above research questions, this research would provide insight into how educators and related professionals can effectively nurture a SoSB for CYP returning to school after sustaining an ABI. Overall, children provided a unique insight into the perceived factors impacting a SoSB. Whilst there were similarities between the children’s responses, there were also notable differences in the way their perceived a SoSB. This linked to circumstances specific to injury, the child’s level of understanding of their ABI and unique characteristics. In addition, whilst parents and school staff showed high levels of similarities in the perceived factors impacting the child’s SoSB, again some differences were noted. These required careful negotiation to ensure a strong collaborative home-school approach was taken. Due to the study design, this research also identified a range unique socio-cultural factors that also impacted return-to-school process. Moreover, the research findings suggest that a SoSB is a protective factor for young children following an ABI, given the range of adjustments that need to occur across all levels of the system. A SoSB may therefore offer children a stable identity, at a time of great instability in their personal and family lives.

Overall, these findings suggest that to foster a SoSB for children returning to school following an ABI, there needs to be consideration at all levels of the system. In line with existing research, these findings highlight the need for a highly individualised approach to fostering a SoSB for children with ABI reintegrating back into mainstream school. This research demonstrates that it is not the case of a child with ABI fitting back into the school environment. Instead, the entire school system must move with the child. With this in mind, the author developed a framework consisting of prompting questions for professionals to utilise to guide their thinking around how to foster a SoSB for children with ABI in mainstream schools. In addition, this research raises a range of key implications for professional practice. Firstly, given that children's conceptualisation of a SoSB is highly individual, it is important that professionals understand each child with ABI's own priorities regarding school. The current research shows that children as young as six can provide unique insight into their experiences and perspectives. This research therefore calls for professionals to actively listen to these children when supporting their return-to-school, ensuring that they adjust provision accordingly. Moreover, given the significant stressors placed on families following paediatric ABI, a paradigm shift is needed in which schools take the lead with planning and implementing the return to school. The author suggests that alongside the recommendations for changes to teacher training so that school staff are confident and competent to lead the school return, EPs could play a key role in supporting schools due to their relevant expertise. Lastly the author suggests that changes to policy are needed, to develop a long-term ABI strategy that not only provides a separate initial funding stream to support children to return to school but ensures that LAs are monitoring these children throughout the course of their educational journey.

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SECTION 7: Appendices

7.1 Appendix A: Critical Appraisals of Included Articles

The guiding principles underpinning the framework developed by Spencer et al. (2004) argue that research should be:

- **contributory** in advancing wider knowledge or understanding about policy, practice, theory or a particular substantive field;
- **defensible in design** by providing a research strategy that can address the evaluative questions posed;
- **rigorous in conduct** through the systematic and transparent collection, analysis and interpretation of qualitative data;
- **credible in claim** through offering well-founded and plausible arguments about the significance of the evidence generated

The guiding principles have been used to identify 18 appraisal questions to aid an assessment. These are reported below group by relevant themes:

Sample

1. How well defended is the sample design/ target selection of cases/documents?
2. Sample composition/case inclusion – how well is the eventual coverage described?

Design, Data collection & Auditability

3. How defensible is the research design?
4. H ow well was the data collection carried out?
5. How adequately has the research process been documented?

Analysis, Finding and Reporting

6. How well has detail, depth and complexity (i.e. richness) of the data been conveyed?
7. How well has diversity of perspective and content been explored?
8. Contexts of data sources – how well are they retained and portrayed?
9. How well has the approach to, and formulation of, the analysis been conveyed?
10. How clear and coherent is the reporting?
11. How clear are the links between data, interpretation and conclusions – i.e. how well can the route to any conclusions be seen?
12. How credible are the findings?
13. How has knowledge been extended by the research?
14. How well does the evaluation address its original aims and purpose?
15. Scope for drawing wider inference – how well is this explained?
16. How clear is the basis of evaluative appraisal?

Ethics, Reflexivity and Neutrality

17. What evidence is there of attention to ethical issues?
18. How clear are the assumptions/theoretical perspectives/values that have shaped the form and output of the evaluation?

Critical Summary of the Final Thirteen Articles in the Literature Review

Paper	Aims	Sample		Design, Data collection & Auditability	Analysis, Finding and Reporting	Ethics, Reflexivity and Neutrality
		Participants	Demographics of the CYP with ABI			
Bate et al. (2021) UK	To explore the experiences of educators in the UK in facilitating a return to school post-ABI	- 10 educators in 5 mainstream primary and secondary schools in London (3 schools) or South-east England (2 schools) who had facilitated the return of 5 YP with ABI. + 5 SENCOS + 4 classroom practitioners + 1 educator in a pastoral role - No educators had professional experience of ABI - 4 educators knew the child pre-injury	- YP had severe ABI, as determined by spending more than 28 days in hospital - Year group of child on return ranged from Year 3 to Year 7 - Time between ABI and return to school ranged from 4 to 16 months - YP had returned to mainstream education 6 to 18 months prior - 3 children returned to same school	- Small qualitative design - Semi-structured interviews recorded and transcribed verbatim, and thematic analysis used, in keeping with research aims. - Large variety of ages of children questions their ability to draw conclusions across such a varied sample. - Quotations used throughout to demonstrate themes. - The data that support the findings of this study are available on request from the corresponding author.	- Did not acknowledge or reflect upon the social factors affecting the CYP. - Only captured the views of educators, and not family members or the children. - Only three children had returned to the same school, impacting the level of understanding of the child and their needs pre-ABI - Aimed to increase validity through triangulation with multiple participants.	- Multiple coders to increase trustworthiness of data analysis as inter-coder reliability was obtained. - Article explicitly stated the researcher's ontological position - Ethical approval for the study was granted by the Research Ethics Committee in the Division of Human Communication Sciences, University of Sheffield. However, there was no further mention of ethics.
Crylen (2015) USA	- To understand the experiences of school re-entry from the perspectives of the parents	- Parents of YP with ABI – no other information provided - Professionals in medical, educational, and family services (not reported on) - Information interviews with a hospital educators and case manager at an ABI council also conducted.	- 4 YP with TBI aged between 10 and 13 years of age - All injuries obtained from either RTA or sports-related incident. - 3 YP remained in hospital for over 2 months; 1 YP was not admitted to hospital	- Small qualitative design - Semi-structured interviews - Study was grounded in ethnographic analysis - Children were closer in age than some of the other studies. - Information gathering interviews with a hospital educators and case manager at an ABI council also conducted.	- Reported the families living situation/ composition. - No information provided about the parents in this study, which limits the conclusions drawn. - Severity of ABI not acknowledged. - No information on inclusion criteria.	- Position of researcher not explicit - No reference to ethics
Diener et al. (2022) USA	To explore the processes of community reintegration of children and families at least one year after an ABI	- 14 outpatient or community service providers (2 occupational therapists, 2 physical therapists, 4 speech & language therapists, 2 neuro-psychologists, 3	- 6 children who had sustained ABI, cause of injury not stated - 3 male and 3 female - Age range at time of injury: 11 months to 16 years	- Small qualitative design - Semi-structured interviews - Thematic Analysis - Large variety of ages of children questions their ability to draw conclusions across such a varied sample.	- Did not acknowledge or reflect upon the social factors affecting the CYP. - Caregivers were predominantly female (mothers, aunt, grandmother).	- Multiple coders to increase trustworthiness of data analysis - Research is indicative of a constructivist position, but this was not explicit.

		school counsellors, 1 recreational providers) - 8 caregivers of 6 children (1 aunt, 5 mothers, 1 father, 1 grandmother)	- Time range since injury when interviews took place: 14 months to 9 years.	- All participants were from same geographical region and under the same service providers. Therefore impacted by the unique strengths and weaknesses of the provision in that area.	- Wide timeframe since injury, questions their ability to draw conclusions across such a varied sample. - The researchers included a community engagement session with 10 parents and one adult survivor or ABI – to inform their interview questions, recruitment strategies and procedural issues. This increased their validity. - Small qualitative study. The authors acknowledge the views may not represent broader views of communities, particularly outside the USA where the systems are different.	
Gagnon et al. (2008) Canada	To explore the specific service needs of adolescents after a mild ABI	- 15 adolescents - At least one parent of the adolescent (13 mothers and 2 fathers)	- 15 Adolescents aged 12-16 at time of interview, with a diagnosis of mild TBI, sustained in the previous year (3-15 months) - 5 females and 10 males - All participants had finished their episode of care at time of interviews	- Small qualitative design - Individual semi-structured interviews. - Qualitative phenomenological study. - All adolescents, impacting transferability to younger children.	- Did not acknowledge or reflect upon the social factors affecting the CYP. - Caregivers were predominantly mothers - Only focused on adolescents, impacting transferability to younger children	- Multiple coders to increase trustworthiness of data analysis - Stated that authors were of various epistemological positions - The study received approval from the Institutional Review Boards of the two participating centres. No comments on how ethics was upheld.
Gfroerer et al. (2008) USA	To determine whether parents believe schools provided necessary support to their children who sustained traumatic brain injuries.	- 66 primary caregivers of children who met the study criteria	- 66 YP - 46 males and 18 females, 2 not specified - Severity of injury was moderate (70%) and severe (30%) as determined by the Glasgow Coma scale - students were in middle and high school (62%)	- more participants that the other studies - Interviews - Back to school interview was used. - Researchers only interviewed parents because they felt that children are not likely to be strong informants regarding	- Did not acknowledge or reflect upon the social factors affecting the CYP. - Reported the ethnicity of the participants, although the sample was not diverse. - Also reported percentages of the reported support needed, which provided additional information. However, it was	- Position of researcher not explicit - No mention of ethics.

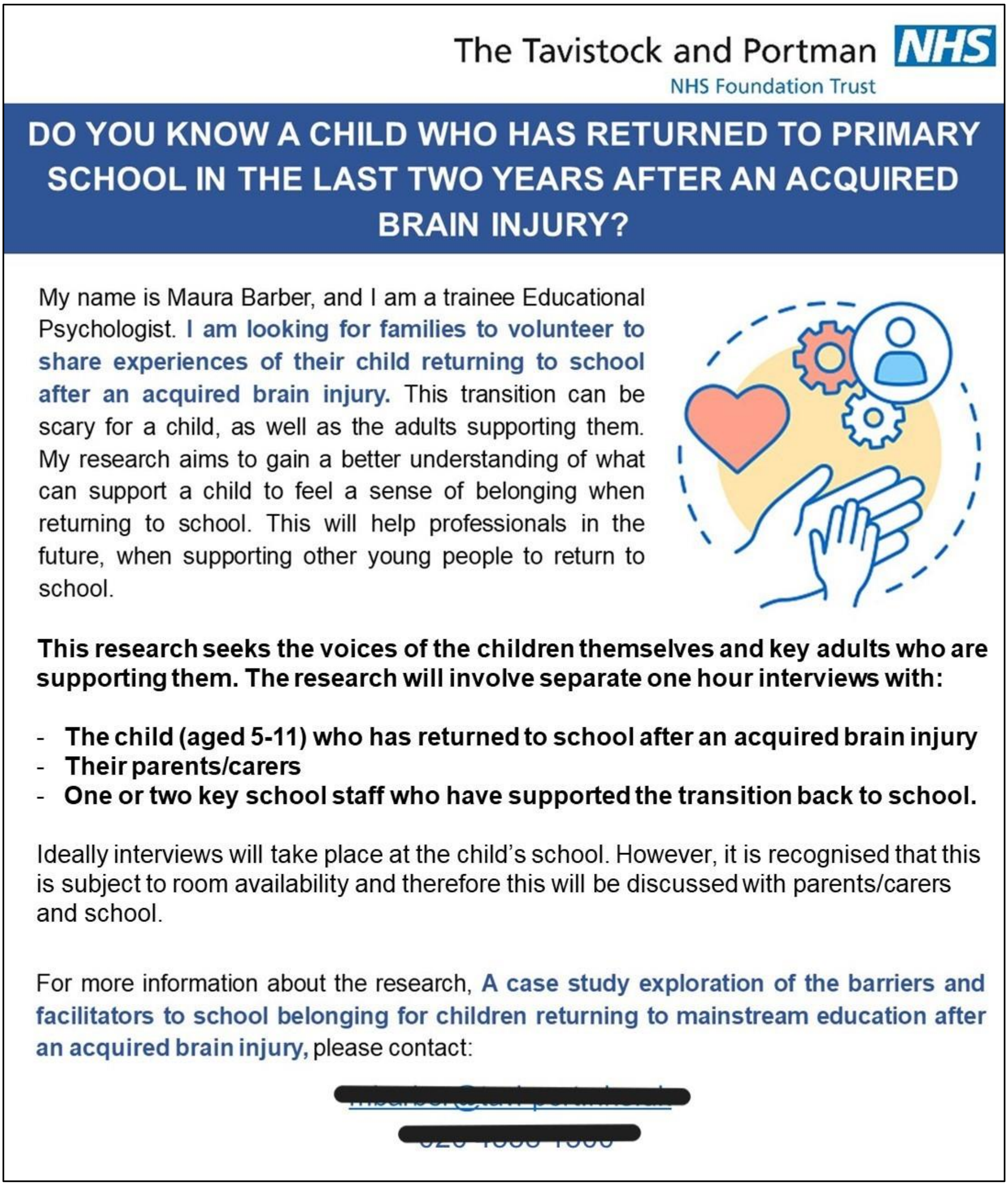
			or elementary school (38%) - ethnicity: white (86%), black (11%) and multiracial (3%)	their educational accommodations. - Some participants withdrew as they felt their child no longer needed support, potentially biasing the sample.	unclear in the interviews how much space was given to qualitatively gaining parents views. Important to think about the percentages and what information may be lost by these discrete categories.	
Jimenez et al. (2020) USA	To explore Hispanic parents' experiences during their child's transitions of care after TBI	- 15 mothers of YP who sustained an ABI - Most mothers from rural areas - Most mothers had limited English proficiency	- 15 Hispanic children aged 0-17 at time of ABI - YP hospitalised for 24 hours or longer at a single level 1 trauma centre	- Small qualitative design - Semi-structured interviews - Thematic content analysis - Large variety of ages of children, questions their ability to draw conclusions across such a varied sample. - Families predominantly from rural areas, which may impact how they receive support compared to Hispanic families in more urban areas. - Interviews were audio recorded and transcribed in the language in which the interview was done, ensuring that no information was lost in translation.	- Reflected upon the family culture and impact of language on the transition process. - Focused only on Hispanic families. - Only captured the views of mothers.	- Multiple coders to increase trustworthiness of data analysis - Position of researcher not explicit - Institutional review board approval sought.
Jones et al. (2021) UK	To explore the educational support needs of injured children and families during the transition process	- 13 CYP with ABI - 19 parents (5 parents were of CYP who were too young or who declined to partake) – 17 mothers, 1 father and 1 guardian.	- 18 CYP discharged from major trauma centre within the previous 12 months - Severity of injury was >8 of Injury Severity Score - Time since injury ranged from 1 to 12.5 months - 11 male and 7 female	- Small qualitative design - Semi-structured interviews conducted either jointly or separately - Thematic Analysis in keeping with research aims and exploratory nature of the research. - Purposive sampling identified, but not elaborated on how participants were obtained. - Supplementary materials were provided increasing the transparency of the research	- Did not acknowledge or reflect upon the social factors affecting the CYP. - Wide timeframe since injury, questions their ability to draw conclusions across such a varied sample. -	- Position of researcher not explicit - The study was approved by the National Health Service (NHS), North West-Greater Manchester South Research Ethics Committee (REC reference 17/NW/0615) and the Health Research Authority. - Children were asked for assent, in line with ethics
Mealings and Douglas (2010)	To hear the stories of three male adolescent	- The three adolescent males who had a TBI	- 3 male who sustained an ABI from a road traffic collision (time since	- Small qualitative design - In-depth interviews	- **Reported the family composition and living situation.**	- **Multiple coders to increase trustworthiness of data analysis**

Australia	students as they reflected on their experiences of what it was like to go back to school after sustaining a severe TBI.	- Ages at time of interview were 14, 17 and 18 years.	injury ranged from 1 year 5 months to 3 years 4 months). - Length of post traumatic amnesia was greater than one week all from road traffic accidents (RTAs). - All had active rehabilitation programmes (inpatient stay of 2 to 5 months). - All students had been back at school after their TBI for at least 6 months.	- Data analysed using grounded theory.	**- Only focused on adolescents, impacting transferability to younger children** **- All participants were male, further impacting transferability to female adolescents.**	**- Position of researcher not explicit**
Robson et al. (2005) Australia	To explore the experiences and perceptions of parents of children with TBI in the transition from hospital to home.	- Six two-parent families took part, with at least one other sibling in addition to the injured child - One caregiver from each family took part - Interviews conducted approximately 6 months after discharge.	- YP aged between 2 and 15 years who had ABI and attending an ABI clinic or rehabilitation hospital in Brisbane - 5 females and 1 male - Only TBIs included; all sustained a closed head injury - Severity of TBI: severe (n=3) and moderate (n=3) on the Glasgow coma scale. YP hospitalised between 6 10 109 days with median of 13 days.	- Small qualitative design - Semi-structured interviews - Phenomenological approach. - Thematic content analysis used.	- Reported the family composition and living situation. - Interviewed mothers and fathers which allowed them to identify differing responses between the two cohorts - Analysis was limited to just the parents, yet there are so many people within the system that support YP. - Some parents may be experiencing PSTD or trauma, which may impact the way that they understand their experiences. Not reflected upon.	- Multiple coders to increase trustworthiness of data analysis - Position of researcher not explicit
Roscigno et al. (2015) USA	To understand how both unique and common experiences during reintegration were explained by parents to influence the family	- 42 parents from 37 families.	- YP needed to be 6-18 years of age at time of TBI - Categorised with moderate to severe TBI on Glasgow Coma scale - YP needed to be able to take part in interviews - YP were at least 4 months and no greater	- Small qualitative design, but more families than most of the other studies. - 2 semi-structured interviews, between 4 and 36 months injury and 20 to 48 months post-injury. - Descriptive phenomenology. - Some participants withdrew as they felt their child no longer needed support, potentially biasing the sample.	- Reported the family socio-economic status, and the family composition. - Relatively socially privileged groups of parents, impacting the application of conclusions to families of differing SES. - Secondary analysis so the initial interviews may have not been as targeted to the aims of the research, as they	- Multiple coders to increase trustworthiness of data analysis - Position of researcher not explicit - The secondary analysis was conducted in accordance with all established ethical criteria for the conduct of research on humans via

			than 36 months post TBI	- The second interview allowed parents to give feedback on the investigators summary of themes, ensuring greater accuracy of the represented views.	would have been if it was a primary study.	Institutional Review Board approval
Sharp et al. (2006) Australia	To explore longitudinally, the return to school experiences of adolescents and the experiences of their family	- 8 families of YP who had accessed a brain injury rehabilitation unit in Sydney. This included: + 10 Primary caregivers (7 mothers, 2 fathers, 1 stepmother) + 6 YP who had sustained ABI + some siblings	- 8 adolescents aged between 14 and 19 years who all sustained recent severe injury as classified by the Glasgow Coma Scale - ABI sustained by passenger RTA (n=3), pedestrian RTA (n=1), bicycle equipment failure (n=2) and arteriovenous malformation (n=2). - 3 females and 5 males - Age range at injury was 14-17 years, 5 months (mean age at injury was 15 years, 11 months)	- Small qualitative design - In-depth interviews conducted over a 2-year period (number of interviews ranged from 1 to 5, depending on family situations). - Analysed using grounded theory. Often grounded theory is explanatory, but this research was exploratory. - Interviews ranged from 1 – 4 hours in length. This is quite a disparity.	- Interviews over a period of 2 years allowed for data across the transition period to be collected. - Did not acknowledge or reflect upon the social factors affecting the CYP.	- Researchers kept a reflective journal - Institutional approval for the study was obtained from the three brain injury rehabilitation units that were sites of recruitment, the University of Western Sydney and the University of Sydney.
Vanclooster et al. 2019 Belgium	To explore perspectives of childhood brain tumour survivors on reintegration back into school over a 2 year period	- 5 children who had previous had surgery for a brain tumour	- 5 children aged 8-10 at time of inclusion - 3 male and 2 female. - Children who attended the same mainstream school as before their illness. They had to be back at school for longer than 6 months, but no less than 3 years prior - Children had finished their cancer treatment with good prognosis - All children had surgery. Four children also had chemotherapy and/or radiotherapy.	- Small qualitative design - Semi-structured interviews, 3 times over 2 years - Analysed using qualitative content analysis - All audiotapes were transcribed verbatim - Inductive thematic analysis approach allowing for exploration of individual experiencing without requiring a theoretical framework. - Researchers provided significant detail on the analysis process, increasing transparency. - The researchers pursued data triangulation by gathering case-specific documentation as	- Interviews over a period of 2 years allowed for data across the transition period to be collected, so that an understanding of the processes and changes was gained. - Did not acknowledge or reflect upon the social factors affecting the CYP. - Severity of ABI not acknowledged.	- Researchers kept a reflective journal argued to make her aware of her own role and perspective - throughout the study - The study was approved by the ethical committees of the UZ Brussel and the UZ Gent (Reference Number BUN 143201421097).

				an objective source of information in addition to conducting interviews.		
Vanclooster et al. 2021 Belgium	Using the International Classification of Functioning, Disability and Health – Children and Youth framework to describe experiences of childhood brain tumour survivors	- 5 children (as above) - 9 parents - 28 teachers - 14 health professionals	- Same as above	- Small qualitative design, but more participants than most of the other studies. - Participants were from across the system. - Semi-structured interviews, 3 times over 2 years - Analysed using qualitative content analysis	- Multiple case study design with longitudinal follow-up - Interviews over a period of 2 years allowed for data across the transition period to be collected - Did not acknowledge or reflect upon the social factors affecting the CYP. - Severity of ABI not acknowledged.	- Researchers used the ICF-CY as a theoretical framework to apply to the data extracted from the interviews

7.2 Appendix B: Recruitment Advert



The Tavistock and Portman NHS
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DO YOU KNOW A CHILD WHO HAS RETURNED TO PRIMARY SCHOOL IN THE LAST TWO YEARS AFTER AN ACQUIRED BRAIN INJURY?

My name is Maura Barber, and I am a trainee Educational Psychologist. **I am looking for families to volunteer to share experiences of their child returning to school after an acquired brain injury.** This transition can be scary for a child, as well as the adults supporting them. My research aims to gain a better understanding of what can support a child to feel a sense of belonging when returning to school. This will help professionals in the future, when supporting other young people to return to school.

This research seeks the voices of the children themselves and key adults who are supporting them. The research will involve separate one hour interviews with:

- **The child (aged 5-11) who has returned to school after an acquired brain injury**
- **Their parents/carers**
- **One or two key school staff who have supported the transition back to school.**

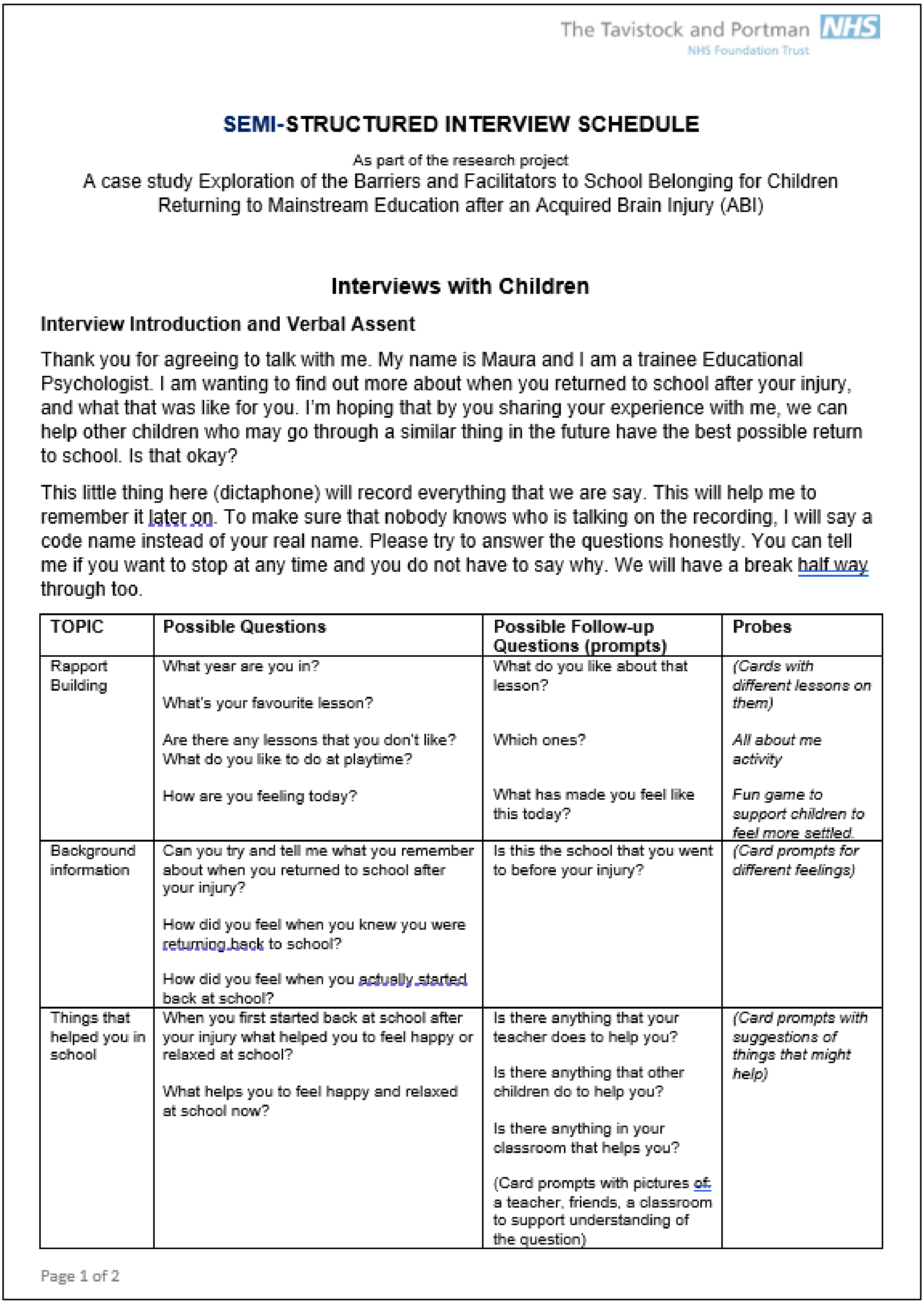
Ideally interviews will take place at the child's school. However, it is recognised that this is subject to room availability and therefore this will be discussed with parents/carers and school.

For more information about the research, **A case study exploration of the barriers and facilitators to school belonging for children returning to mainstream education after an acquired brain injury,** please contact:

[redacted]

[redacted]

7.3 Appendix C: Semi-Structured Interview Questions



The Tavistock and Portman NHS
NHS Foundation Trust

SEMI-STRUCTURED INTERVIEW SCHEDULE

As part of the research project
A case study Exploration of the Barriers and Facilitators to School Belonging for Children Returning to Mainstream Education after an Acquired Brain Injury (ABI)

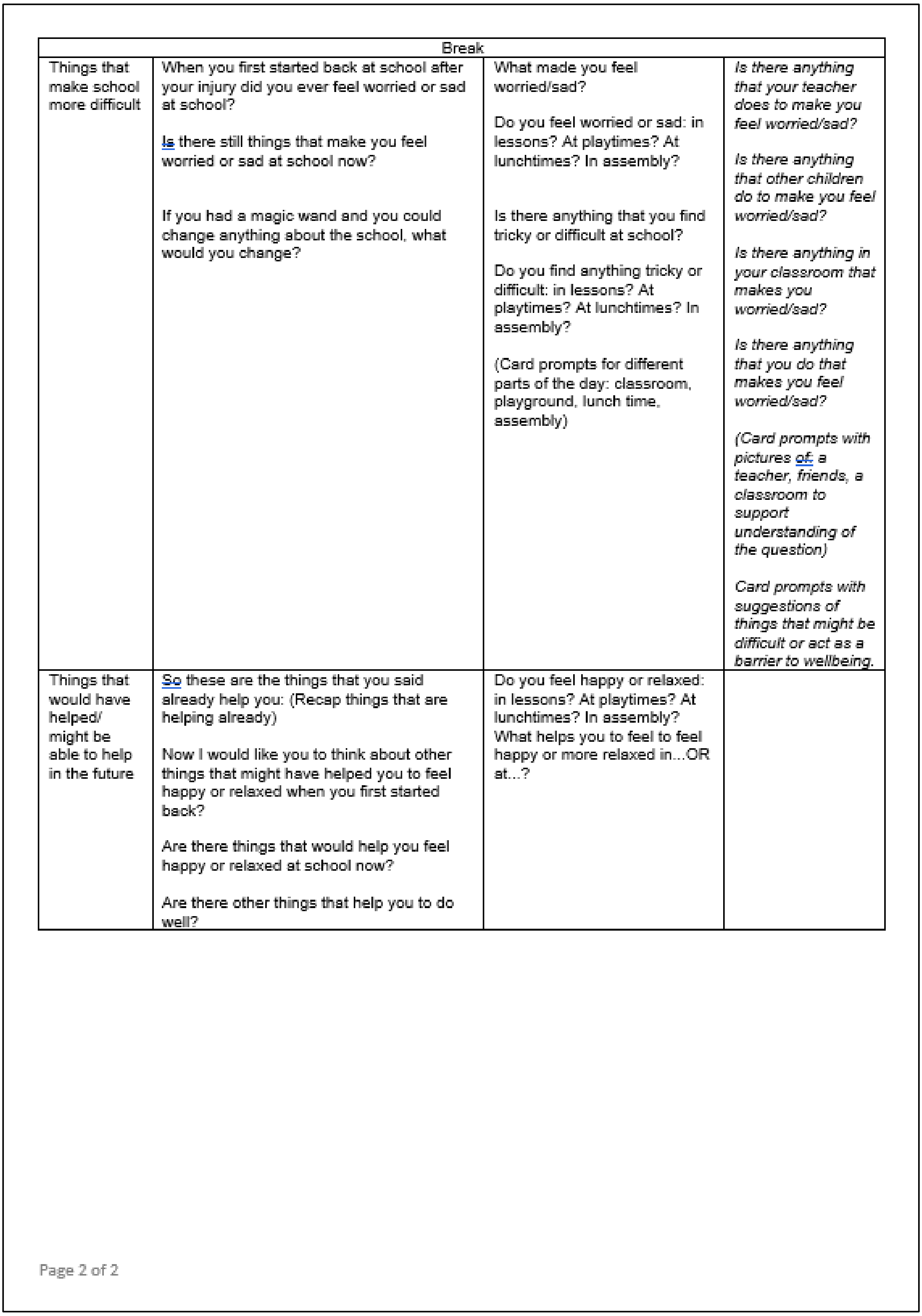
Interviews with Children

Interview Introduction and Verbal Assent

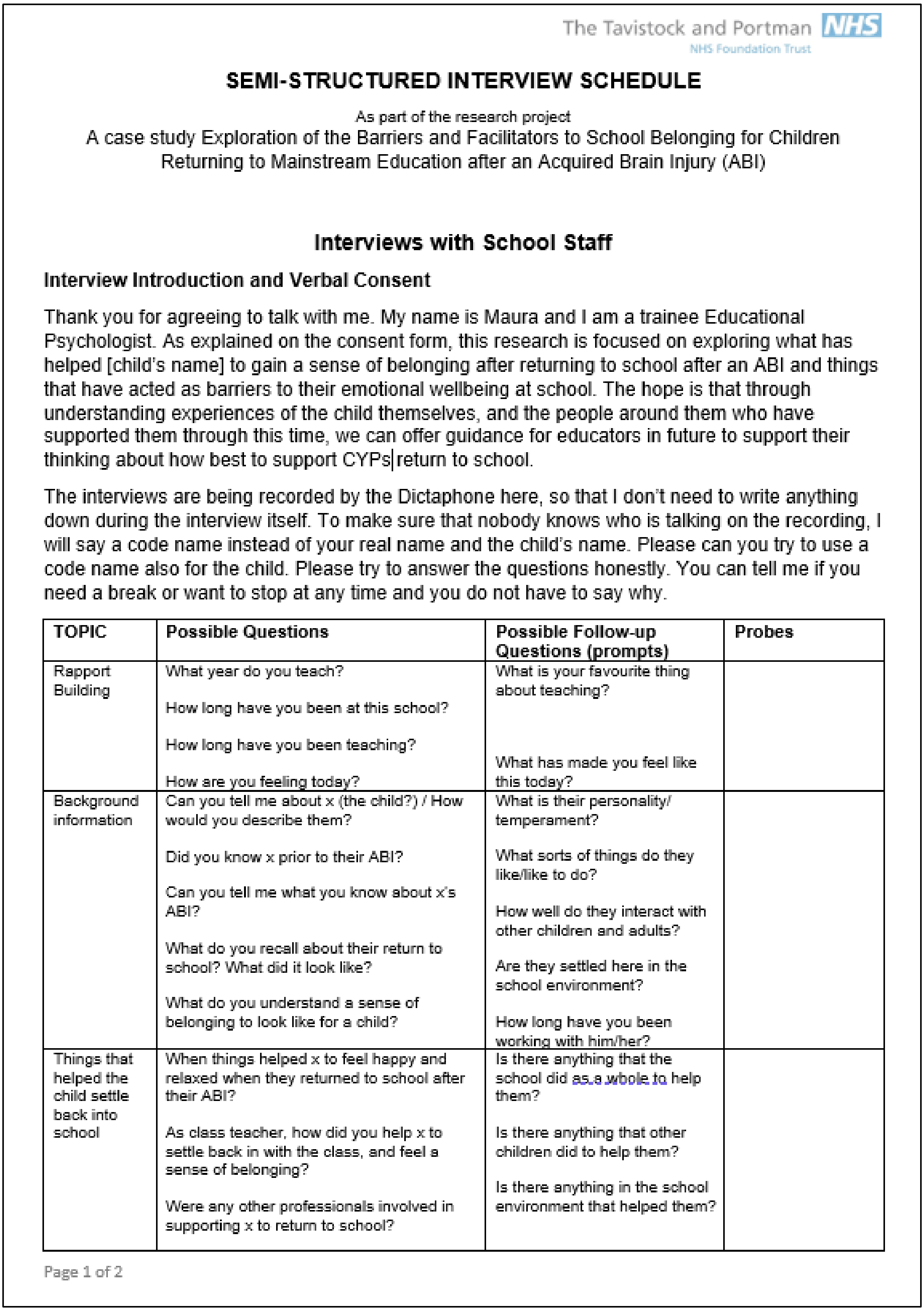
Thank you for agreeing to talk with me. My name is Maura and I am a trainee Educational Psychologist. I am wanting to find out more about when you returned to school after your injury, and what that was like for you. I'm hoping that by you sharing your experience with me, we can help other children who may go through a similar thing in the future have the best possible return to school. Is that okay?

This little thing here (dictaphone) will record everything that we are say. This will help me to remember it later on. To make sure that nobody knows who is talking on the recording, I will say a code name instead of your real name. Please try to answer the questions honestly. You can tell me if you want to stop at any time and you do not have to say why. We will have a break half way through too.

TOPIC	Possible Questions	Possible Follow-up Questions (prompts)	Probes
Rapport Building	What year are you in? What's your favourite lesson? Are there any lessons that you don't like? What do you like to do at playtime? How are you feeling today?	What do you like about that lesson? Which ones? What has made you feel like this today?	*(Cards with different lessons on them)* *All about me activity* *Fun game to support children to feel more settled.*
Background information	Can you try and tell me what you remember about when you returned to school after your injury? How did you feel when you knew you were returning back to school? How did you feel when you actually started back at school?	Is this the school that you went to before your injury?	*(Card prompts for different feelings)*
Things that helped you in school	When you first started back at school after your injury what helped you to feel happy or relaxed at school? What helps you to feel happy and relaxed at school now?	Is there anything that your teacher does to help you? Is there anything that other children do to help you? Is there anything in your classroom that helps you? (Card prompts with pictures of: a teacher, friends, a classroom to support understanding of the question)	*(Card prompts with suggestions of things that might help)*



Break			
Things that make school more difficult	When you first started back at school after your injury did you ever feel worried or sad at school? Is there still things that make you feel worried or sad at school now? If you had a magic wand and you could change anything about the school, what would you change?	What made you feel worried/sad? Do you feel worried or sad: in lessons? At playtimes? At lunchtimes? In assembly? Is there anything that you find tricky or difficult at school? Do you find anything tricky or difficult: in lessons? At playtimes? At lunchtimes? In assembly? (Card prompts for different parts of the day: classroom, playground, lunch time, assembly)	*Is there anything that your teacher does to make you feel worried/sad?* *Is there anything that other children do to make you feel worried/sad?* *Is there anything in your classroom that makes you worried/sad?* *Is there anything that you do that makes you feel worried/sad?* *(Card prompts with pictures of, a teacher, friends, a classroom to support understanding of the question)* *Card prompts with suggestions of things that might be difficult or act as a barrier to wellbeing.*
Things that would have helped/ might be able to help in the future	So these are the things that you said already help you: (Recap things that are helping already) Now I would like you to think about other things that might have helped you to feel happy or relaxed when you first started back? Are there things that would help you feel happy or relaxed at school now? Are there other things that help you to do well?	Do you feel happy or relaxed: in lessons? At playtimes? At lunchtimes? In assembly? What helps you to feel to feel happy or more relaxed in...OR at...?	



The Tavistock and Portman NHS
NHS Foundation Trust

SEMI-STRUCTURED INTERVIEW SCHEDULE

As part of the research project
A case study Exploration of the Barriers and Facilitators to School Belonging for Children Returning to Mainstream Education after an Acquired Brain Injury (ABI)

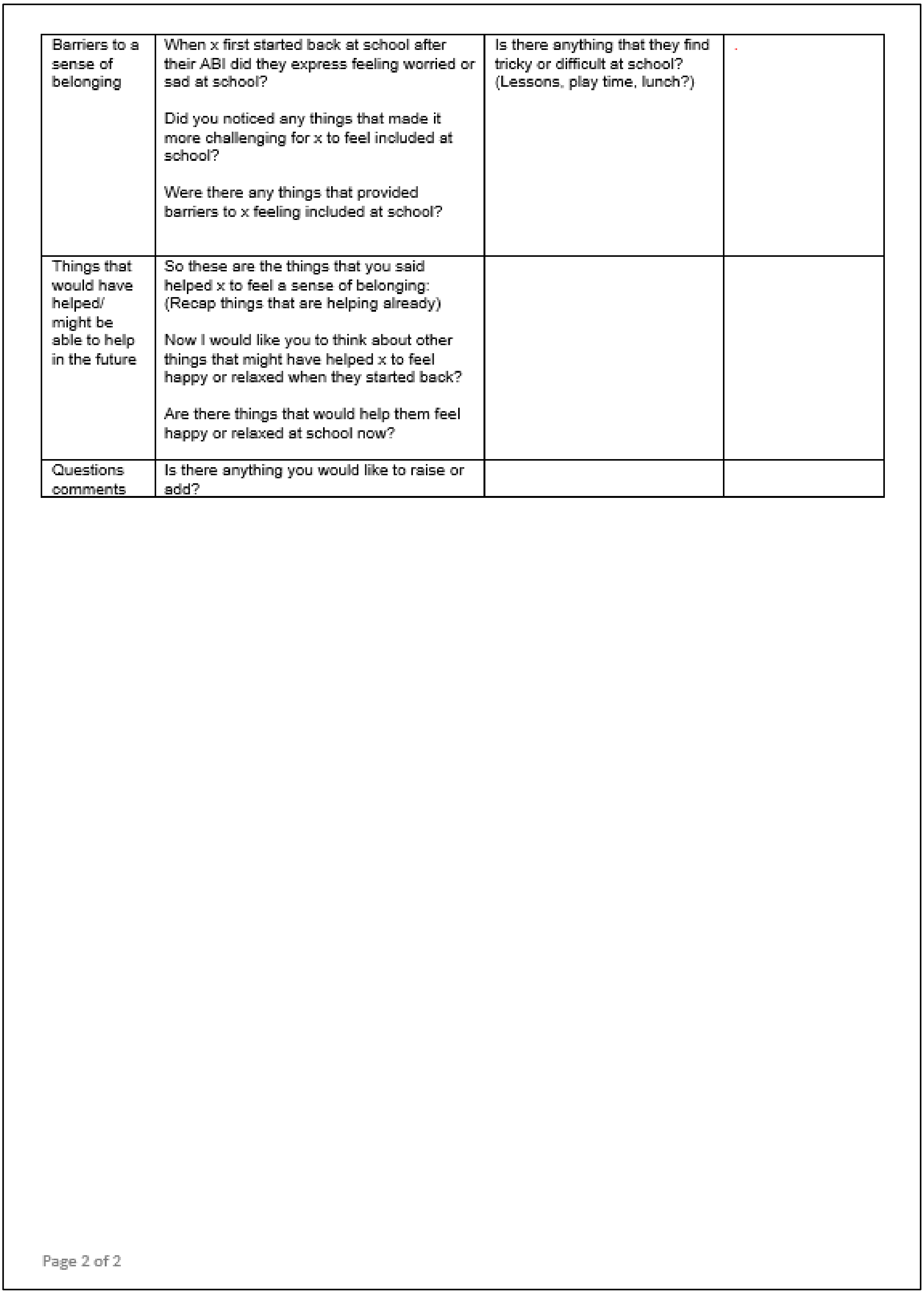
Interviews with School Staff

Interview Introduction and Verbal Consent

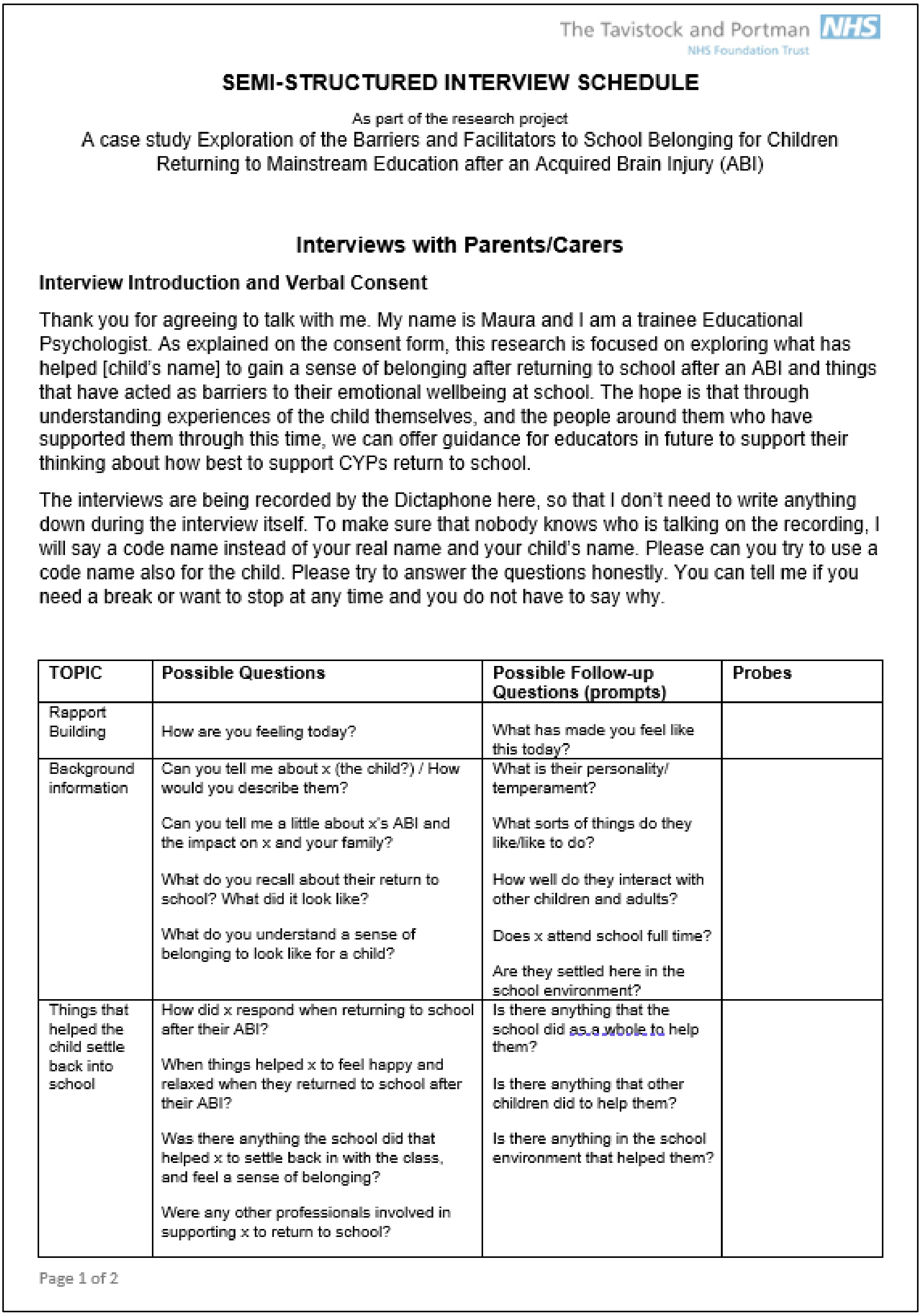
Thank you for agreeing to talk with me. My name is Maura and I am a trainee Educational Psychologist. As explained on the consent form, this research is focused on exploring what has helped [child's name] to gain a sense of belonging after returning to school after an ABI and things that have acted as barriers to their emotional wellbeing at school. The hope is that through understanding experiences of the child themselves, and the people around them who have supported them through this time, we can offer guidance for educators in future to support their thinking about how best to support CYPs return to school.

The interviews are being recorded by the Dictaphone here, so that I don't need to write anything down during the interview itself. To make sure that nobody knows who is talking on the recording, I will say a code name instead of your real name and the child's name. Please can you try to use a code name also for the child. Please try to answer the questions honestly. You can tell me if you need a break or want to stop at any time and you do not have to say why.

TOPIC	**Possible Questions**	**Possible Follow-up Questions (prompts)**	**Probes**
Rapport Building	What year do you teach? How long have you been at this school? How long have you been teaching? How are you feeling today?	What is your favourite thing about teaching? What has made you feel like this today?	
Background information	Can you tell me about x (the child?) / How would you describe them? Did you know x prior to their ABI? Can you tell me what you know about x's ABI? What do you recall about their return to school? What did it look like? What do you understand a sense of belonging to look like for a child?	What is their personality/ temperament? What sorts of things do they like/like to do? How well do they interact with other children and adults? Are they settled here in the school environment? How long have you been working with him/her?	
Things that helped the child settle back into school	When things helped x to feel happy and relaxed when they returned to school after their ABI? As class teacher, how did you help x to settle back in with the class, and feel a sense of belonging? Were any other professionals involved in supporting x to return to school?	Is there anything that the school did as a whole to help them? Is there anything that other children did to help them? Is there anything in the school environment that helped them?	



Barriers to a sense of belonging	When x first started back at school after their ABI did they express feeling worried or sad at school? Did you noticed any things that made it more challenging for x to feel included at school? Were there any things that provided barriers to x feeling included at school?	Is there anything that they find tricky or difficult at school? (Lessons, play time, lunch?)	
Things that would have helped/ might be able to help in the future	So these are the things that you said helped x to feel a sense of belonging: (Recap things that are helping already) Now I would like you to think about other things that might have helped x to feel happy or relaxed when they started back? Are there things that would help them feel happy or relaxed at school now?		
Questions comments	Is there anything you would like to raise or add?		



The Tavistock and Portman NHS
NHS Foundation Trust

SEMI-STRUCTURED INTERVIEW SCHEDULE

As part of the research project
A case study Exploration of the Barriers and Facilitators to School Belonging for Children Returning to Mainstream Education after an Acquired Brain Injury (ABI)

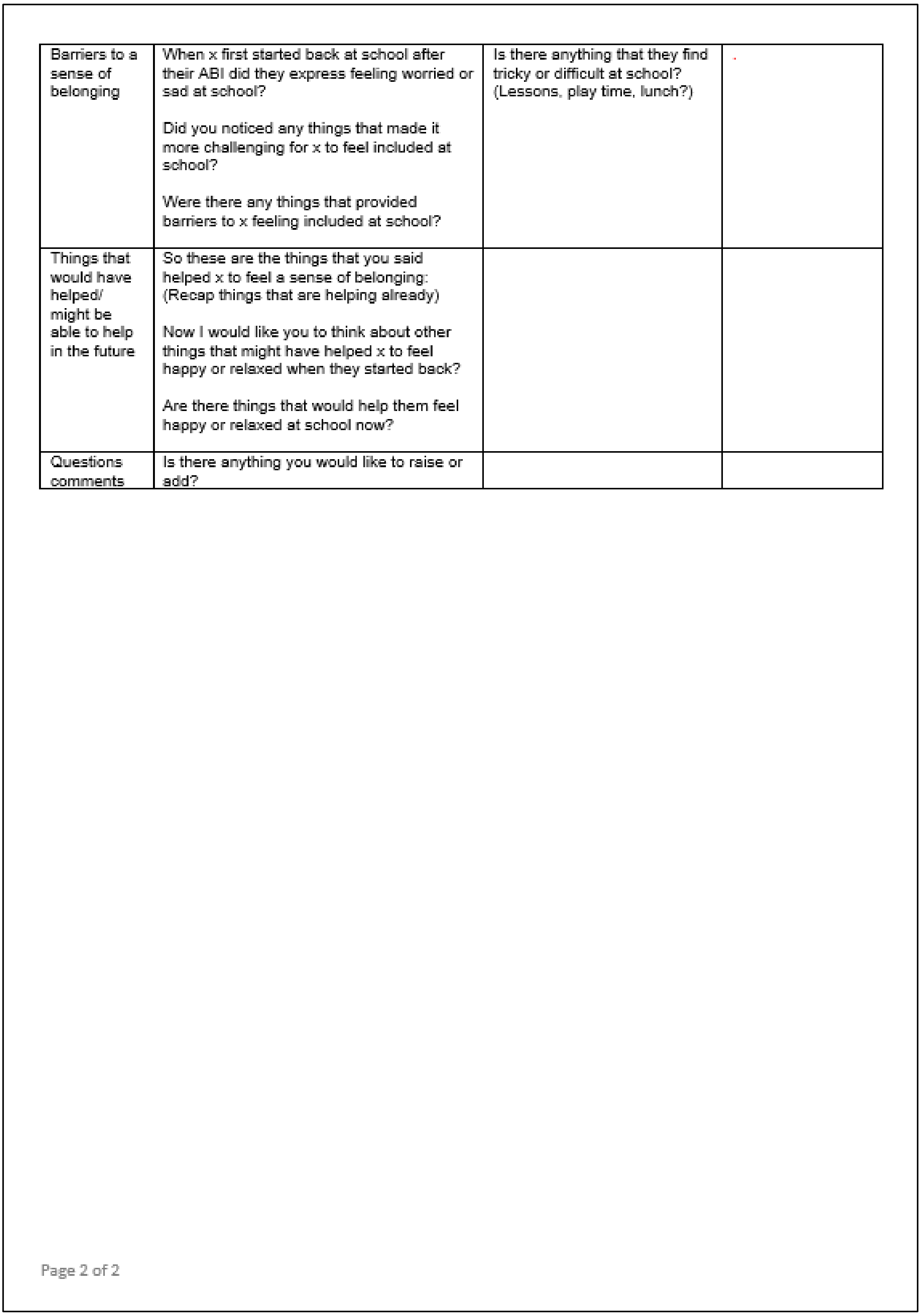
Interviews with Parents/Carers

Interview Introduction and Verbal Consent

Thank you for agreeing to talk with me. My name is Maura and I am a trainee Educational Psychologist. As explained on the consent form, this research is focused on exploring what has helped [child's name] to gain a sense of belonging after returning to school after an ABI and things that have acted as barriers to their emotional wellbeing at school. The hope is that through understanding experiences of the child themselves, and the people around them who have supported them through this time, we can offer guidance for educators in future to support their thinking about how best to support CYPs return to school.

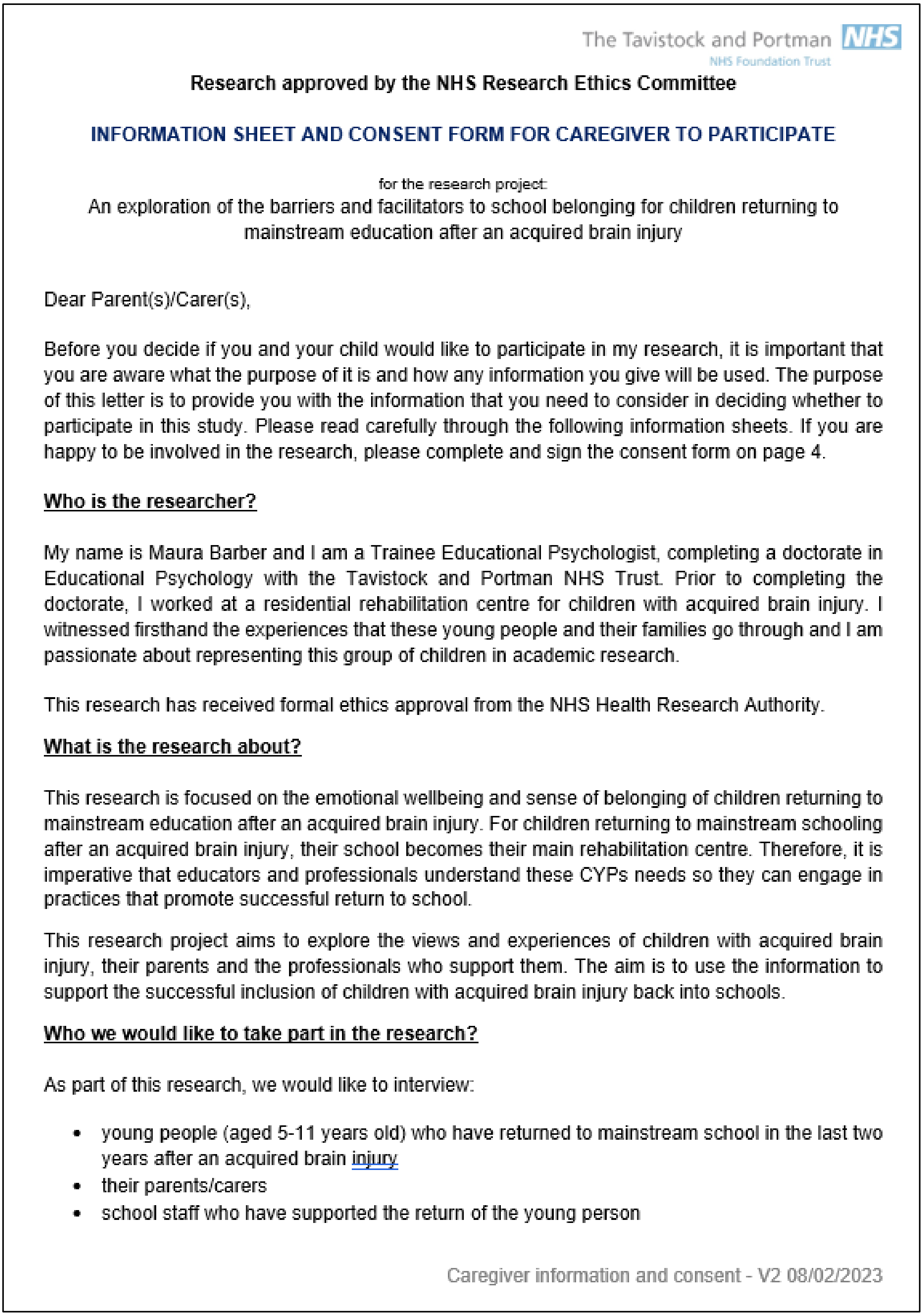
The interviews are being recorded by the Dictaphone here, so that I don't need to write anything down during the interview itself. To make sure that nobody knows who is talking on the recording, I will say a code name instead of your real name and your child's name. Please can you try to use a code name also for the child. Please try to answer the questions honestly. You can tell me if you need a break or want to stop at any time and you do not have to say why.

TOPIC	Possible Questions	Possible Follow-up Questions (prompts)	Probes
Rapport Building	How are you feeling today?	What has made you feel like this today?	
Background information	Can you tell me about x (the child?) / How would you describe them? Can you tell me a little about x's ABI and the impact on x and your family? What do you recall about their return to school? What did it look like? What do you understand a sense of belonging to look like for a child?	What is their personality/ temperament? What sorts of things do they like/like to do? How well do they interact with other children and adults? Does x attend school full time? Are they settled here in the school environment?	
Things that helped the child settle back into school	How did x respond when returning to school after their ABI? When things helped x to feel happy and relaxed when they returned to school after their ABI? Was there anything the school did that helped x to settle back in with the class, and feel a sense of belonging? Were any other professionals involved in supporting x to return to school?	Is there anything that the school did as a whole to help them? Is there anything that other children did to help them? Is there anything in the school environment that helped them?	



Barriers to a sense of belonging	When x first started back at school after their ABI did they express feeling worried or sad at school? Did you noticed any things that made it more challenging for x to feel included at school? Were there any things that provided barriers to x feeling included at school?	Is there anything that they find tricky or difficult at school? (Lessons, play time, lunch?)	
Things that would have helped/ might be able to help in the future	So these are the things that you said helped x to feel a sense of belonging: (Recap things that are helping already) Now I would like you to think about other things that might have helped x to feel happy or relaxed when they started back? Are there things that would help them feel happy or relaxed at school now?		
Questions comments	Is there anything you would like to raise or add?		

7.4 Appendix D: Adult Participant Information Sheets and Consent



The Tavistock and Portman NHS
NHS Foundation Trust

Research approved by the NHS Research Ethics Committee

INFORMATION SHEET AND CONSENT FORM FOR CAREGIVER TO PARTICIPATE

for the research project:

An exploration of the barriers and facilitators to school belonging for children returning to mainstream education after an acquired brain injury

Dear Parent(s)/Carer(s),

Before you decide if you and your child would like to participate in my research, it is important that you are aware what the purpose of it is and how any information you give will be used. The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study. Please read carefully through the following information sheets. If you are happy to be involved in the research, please complete and sign the consent form on page 4.

Who is the researcher?

My name is Maura Barber and I am a Trainee Educational Psychologist, completing a doctorate in Educational Psychology with the Tavistock and Portman NHS Trust. Prior to completing the doctorate, I worked at a residential rehabilitation centre for children with acquired brain injury. I witnessed firsthand the experiences that these young people and their families go through and I am passionate about representing this group of children in academic research.

This research has received formal ethics approval from the NHS Health Research Authority.

What is the research about?

This research is focused on the emotional wellbeing and sense of belonging of children returning to mainstream education after an acquired brain injury. For children returning to mainstream schooling after an acquired brain injury, their school becomes their main rehabilitation centre. Therefore, it is imperative that educators and professionals understand these CYPs needs so they can engage in practices that promote successful return to school.

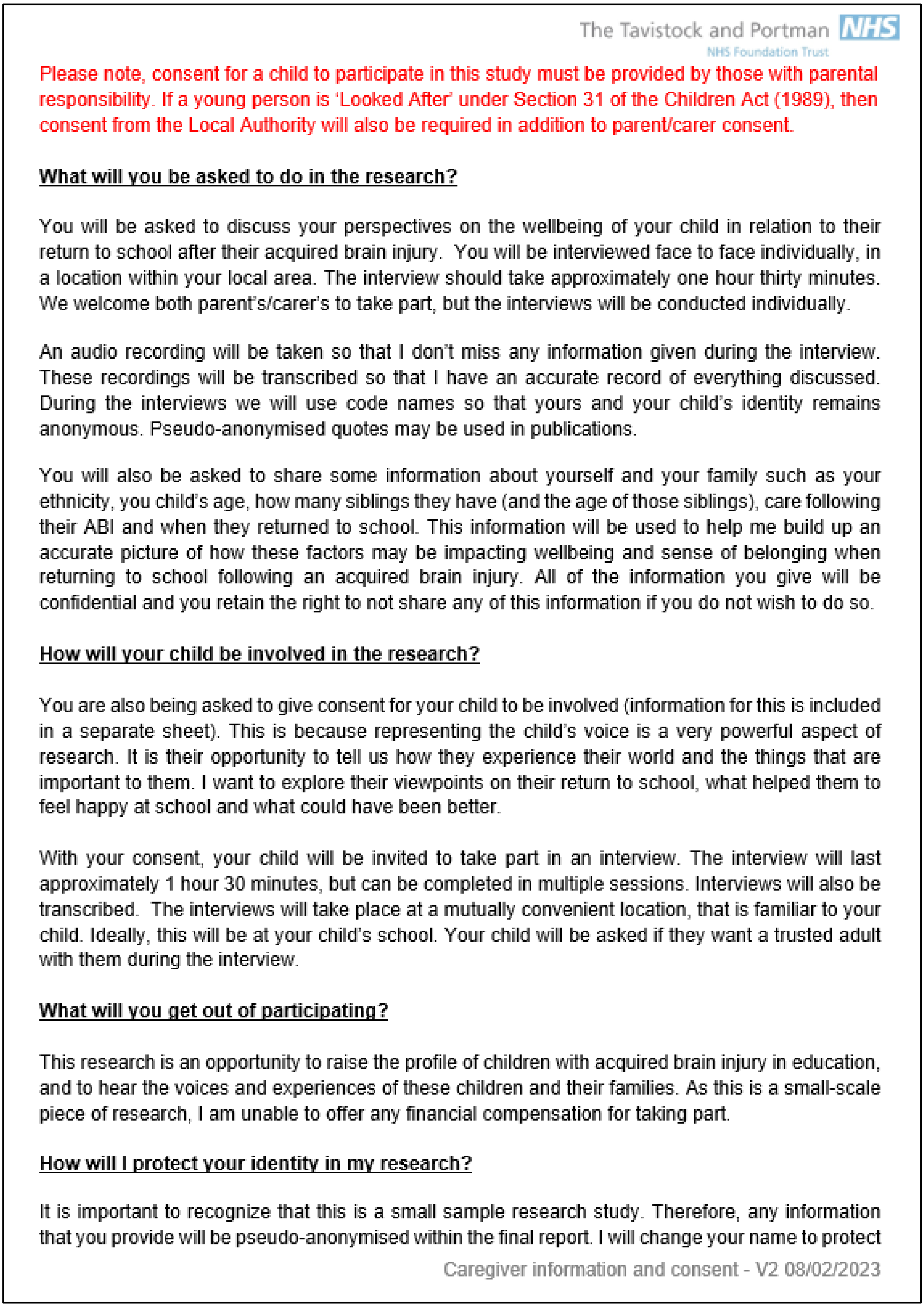
This research project aims to explore the views and experiences of children with acquired brain injury, their parents and the professionals who support them. The aim is to use the information to support the successful inclusion of children with acquired brain injury back into schools.

Who we would like to take part in the research?

As part of this research, we would like to interview:

- young people (aged 5-11 years old) who have returned to mainstream school in the last two years after an acquired brain injury
- their parents/carers
- school staff who have supported the return of the young person

Caregiver information and consent - V2 08/02/2023



The Tavistock and Portman NHS
NHS Foundation Trust

Please note, consent for a child to participate in this study must be provided by those with parental responsibility. If a young person is 'Looked After' under Section 31 of the Children Act (1989), then consent from the Local Authority will also be required in addition to parent/carer consent.

What will you be asked to do in the research?

You will be asked to discuss your perspectives on the wellbeing of your child in relation to their return to school after their acquired brain injury. You will be interviewed face to face individually, in a location within your local area. The interview should take approximately one hour thirty minutes. We welcome both parent's/carer's to take part, but the interviews will be conducted individually.

An audio recording will be taken so that I don't miss any information given during the interview. These recordings will be transcribed so that I have an accurate record of everything discussed. During the interviews we will use code names so that yours and your child's identity remains anonymous. Pseudo-anonymised quotes may be used in publications.

You will also be asked to share some information about yourself and your family such as your ethnicity, you child's age, how many siblings they have (and the age of those siblings), care following their ABI and when they returned to school. This information will be used to help me build up an accurate picture of how these factors may be impacting wellbeing and sense of belonging when returning to school following an acquired brain injury. All of the information you give will be confidential and you retain the right to not share any of this information if you do not wish to do so.

How will your child be involved in the research?

You are also being asked to give consent for your child to be involved (information for this is included in a separate sheet). This is because representing the child's voice is a very powerful aspect of research. It is their opportunity to tell us how they experience their world and the things that are important to them. I want to explore their viewpoints on their return to school, what helped them to feel happy at school and what could have been better.

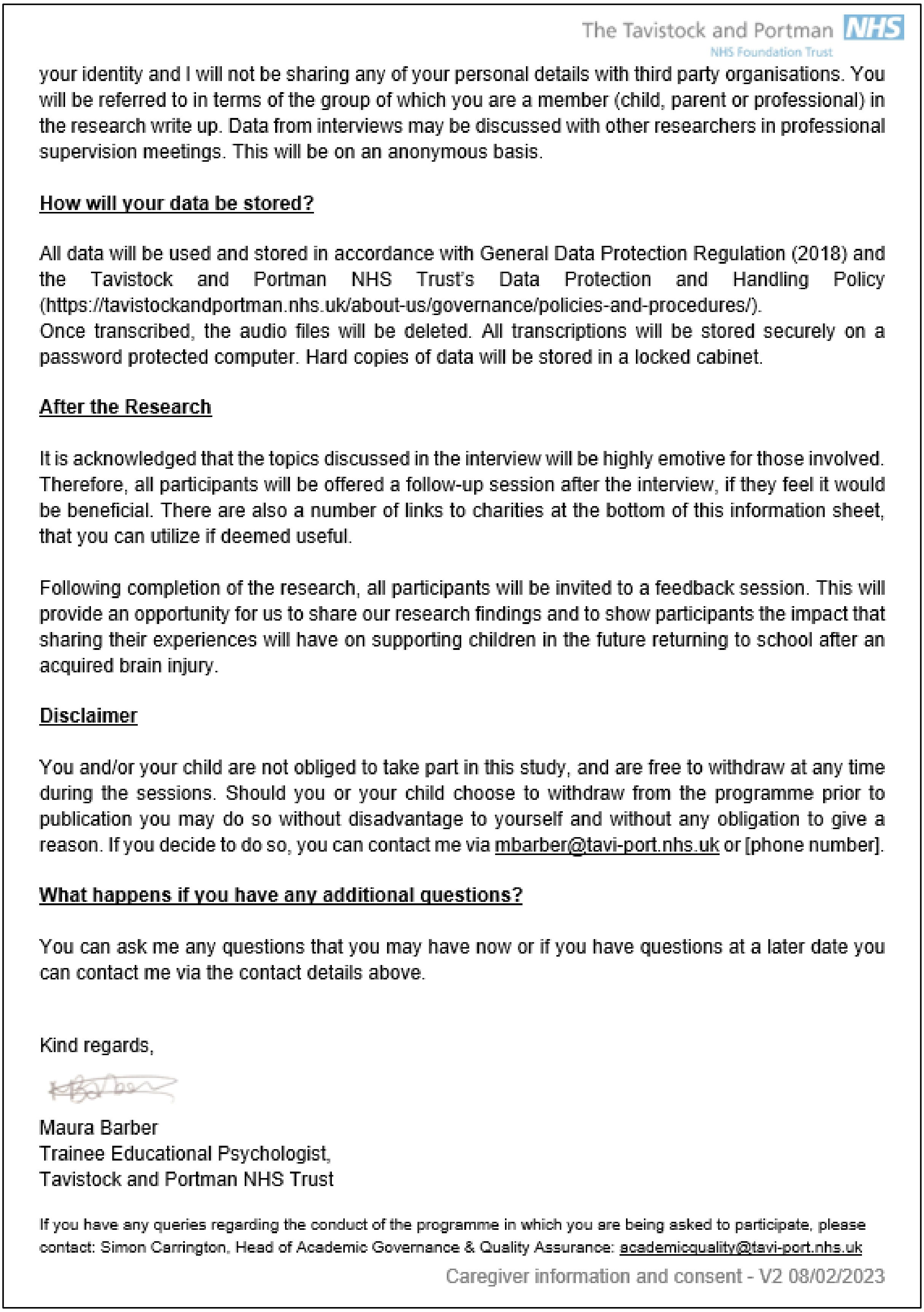
With your consent, your child will be invited to take part in an interview. The interview will last approximately 1 hour 30 minutes, but can be completed in multiple sessions. Interviews will also be transcribed. The interviews will take place at a mutually convenient location, that is familiar to your child. Ideally, this will be at your child's school. Your child will be asked if they want a trusted adult with them during the interview.

What will you get out of participating?

This research is an opportunity to raise the profile of children with acquired brain injury in education, and to hear the voices and experiences of these children and their families. As this is a small-scale piece of research, I am unable to offer any financial compensation for taking part.

How will I protect your identity in my research?

It is important to recognize that this is a small sample research study. Therefore, any information that you provide will be pseudo-anonymised within the final report. I will change your name to protect



The Tavistock and Portman NHS
NHS Foundation Trust

your identity and I will not be sharing any of your personal details with third party organisations. You will be referred to in terms of the group of which you are a member (child, parent or professional) in the research write up. Data from interviews may be discussed with other researchers in professional supervision meetings. This will be on an anonymous basis.

How will your data be stored?

All data will be used and stored in accordance with General Data Protection Regulation (2018) and the Tavistock and Portman NHS Trust's Data Protection and Handling Policy (https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/).
Once transcribed, the audio files will be deleted. All transcriptions will be stored securely on a password protected computer. Hard copies of data will be stored in a locked cabinet.

After the Research

It is acknowledged that the topics discussed in the interview will be highly emotive for those involved. Therefore, all participants will be offered a follow-up session after the interview, if they feel it would be beneficial. There are also a number of links to charities at the bottom of this information sheet, that you can utilize if deemed useful.

Following completion of the research, all participants will be invited to a feedback session. This will provide an opportunity for us to share our research findings and to show participants the impact that sharing their experiences will have on supporting children in the future returning to school after an acquired brain injury.

Disclaimer

You and/or your child are not obliged to take part in this study, and are free to withdraw at any time during the sessions. Should you or your child choose to withdraw from the programme prior to publication you may do so without disadvantage to yourself and without any obligation to give a reason. If you decide to do so, you can contact me via mbarber@tavi-port.nhs.uk or [phone number].

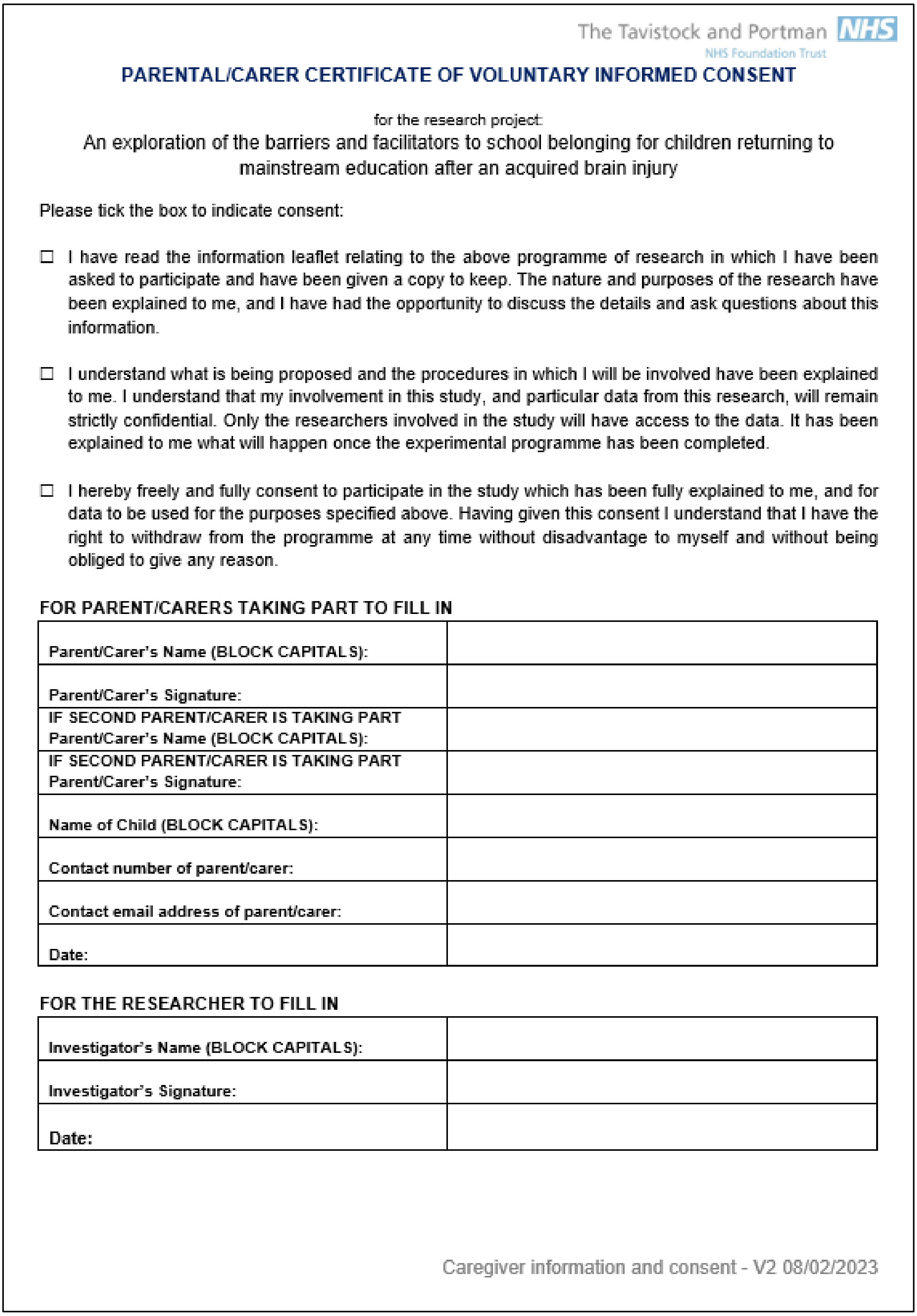
What happens if you have any additional questions?

You can ask me any questions that you may have now or if you have questions at a later date you can contact me via the contact details above.

Kind regards,

Maura Barber
Trainee Educational Psychologist,
Tavistock and Portman NHS Trust

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact: Simon Carrington, Head of Academic Governance & Quality Assurance: academicquality@tavi-port.nhs.uk



The Tavistock and Portman NHS
NHS Foundation Trust

PARENTAL/CARER CERTIFICATE OF VOLUNTARY INFORMED CONSENT

for the research project:
An exploration of the barriers and facilitators to school belonging for children returning to mainstream education after an acquired brain injury

Please tick the box to indicate consent:

☐ I have read the information leaflet relating to the above programme of research in which I have been asked to participate 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 the data. It has been explained to me what will happen once the experimental programme has been completed.

☐ I hereby freely and fully consent to participate in the study which has been fully explained to me, and for data to be used for the purposes specified above. Having given this consent I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without being obliged to give any reason.

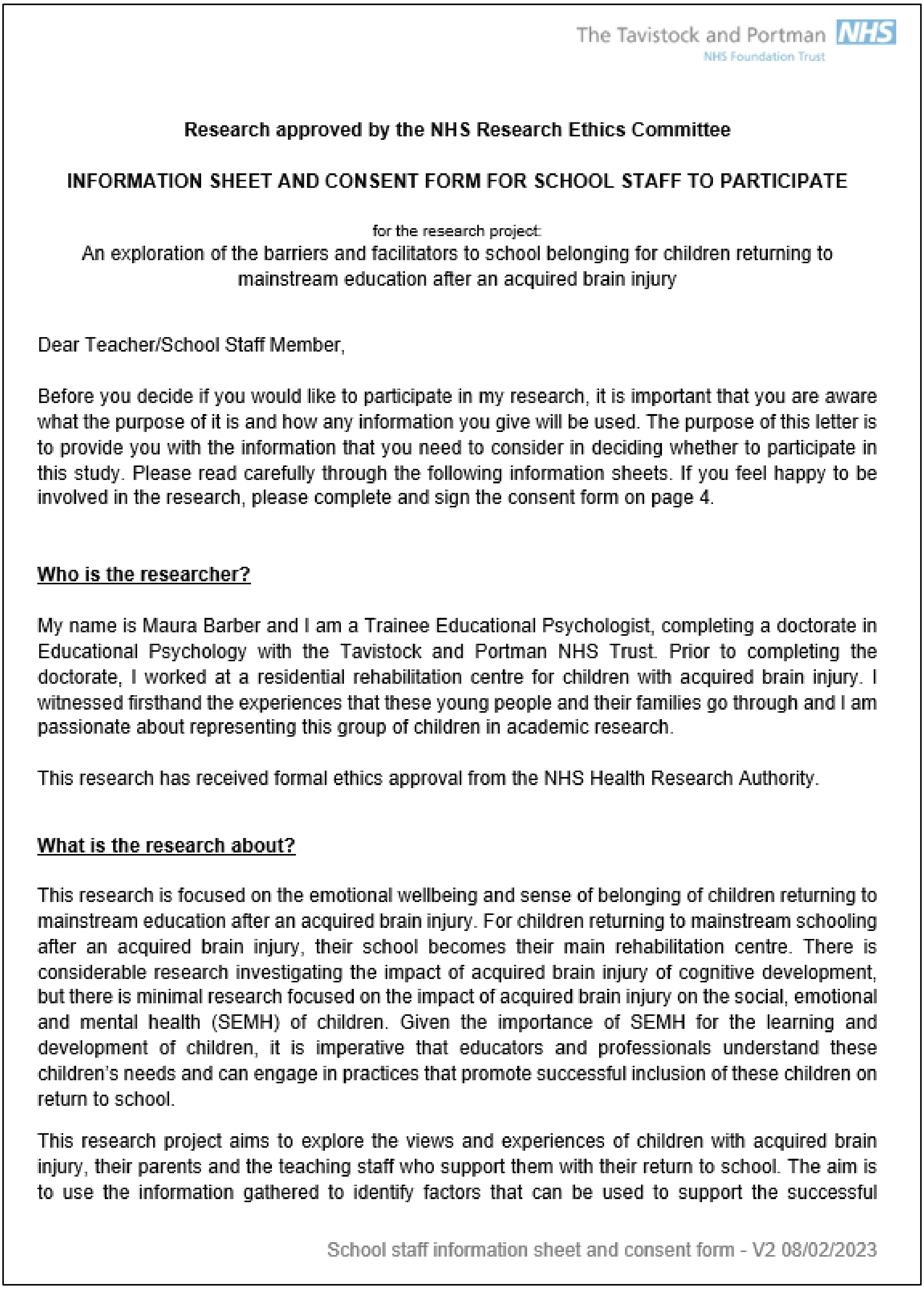
FOR PARENT/CARERS TAKING PART TO FILL IN

Parent/Carer's Name (BLOCK CAPITALS):	
Parent/Carer's Signature:	
IF SECOND PARENT/CARER IS TAKING PART Parent/Carer's Name (BLOCK CAPITALS):	
IF SECOND PARENT/CARER IS TAKING PART Parent/Carer's Signature:	
Name of Child (BLOCK CAPITALS):	
Contact number of parent/carer:	
Contact email address of parent/carer:	
Date:	

FOR THE RESEARCHER TO FILL IN

Investigator's Name (BLOCK CAPITALS):	
Investigator's Signature:	
Date:	

Caregiver information and consent - V2 08/02/2023



The Tavistock and Portman NHS
NHS Foundation Trust

Research approved by the NHS Research Ethics Committee

INFORMATION SHEET AND CONSENT FORM FOR SCHOOL STAFF TO PARTICIPATE

for the research project:
An exploration of the barriers and facilitators to school belonging for children returning to mainstream education after an acquired brain injury

Dear Teacher/School Staff Member,

Before you decide if you would like to participate in my research, it is important that you are aware what the purpose of it is and how any information you give will be used. The purpose of this letter is to provide you with the information that you need to consider in deciding whether to participate in this study. Please read carefully through the following information sheets. If you feel happy to be involved in the research, please complete and sign the consent form on page 4.

Who is the researcher?

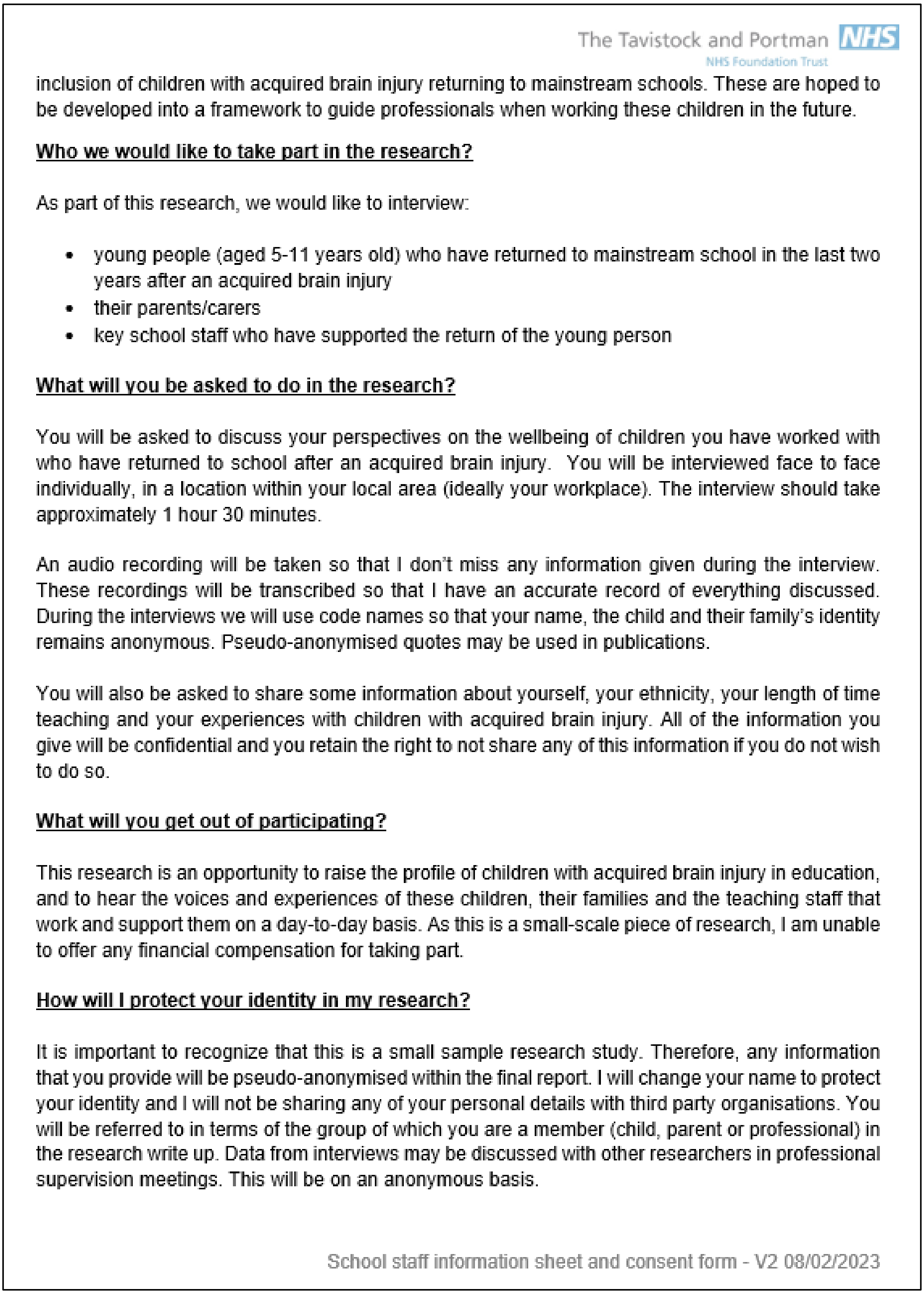
My name is Maura Barber and I am a Trainee Educational Psychologist, completing a doctorate in Educational Psychology with the Tavistock and Portman NHS Trust. Prior to completing the doctorate, I worked at a residential rehabilitation centre for children with acquired brain injury. I witnessed firsthand the experiences that these young people and their families go through and I am passionate about representing this group of children in academic research.

This research has received formal ethics approval from the NHS Health Research Authority.

What is the research about?

This research is focused on the emotional wellbeing and sense of belonging of children returning to mainstream education after an acquired brain injury. For children returning to mainstream schooling after an acquired brain injury, their school becomes their main rehabilitation centre. There is considerable research investigating the impact of acquired brain injury of cognitive development, but there is minimal research focused on the impact of acquired brain injury on the social, emotional and mental health (SEMH) of children. Given the importance of SEMH for the learning and development of children, it is imperative that educators and professionals understand these children's needs and can engage in practices that promote successful inclusion of these children on return to school.

This research project aims to explore the views and experiences of children with acquired brain injury, their parents and the teaching staff who support them with their return to school. The aim is to use the information gathered to identify factors that can be used to support the successful



inclusion of children with acquired brain injury returning to mainstream schools. These are hoped to be developed into a framework to guide professionals when working these children in the future.

Who we would like to take part in the research?

As part of this research, we would like to interview:

- young people (aged 5-11 years old) who have returned to mainstream school in the last two years after an acquired brain injury
- their parents/carers
- key school staff who have supported the return of the young person

What will you be asked to do in the research?

You will be asked to discuss your perspectives on the wellbeing of children you have worked with who have returned to school after an acquired brain injury. You will be interviewed face to face individually, in a location within your local area (ideally your workplace). The interview should take approximately 1 hour 30 minutes.

An audio recording will be taken so that I don't miss any information given during the interview. These recordings will be transcribed so that I have an accurate record of everything discussed. During the interviews we will use code names so that your name, the child and their family's identity remains anonymous. Pseudo-anonymised quotes may be used in publications.

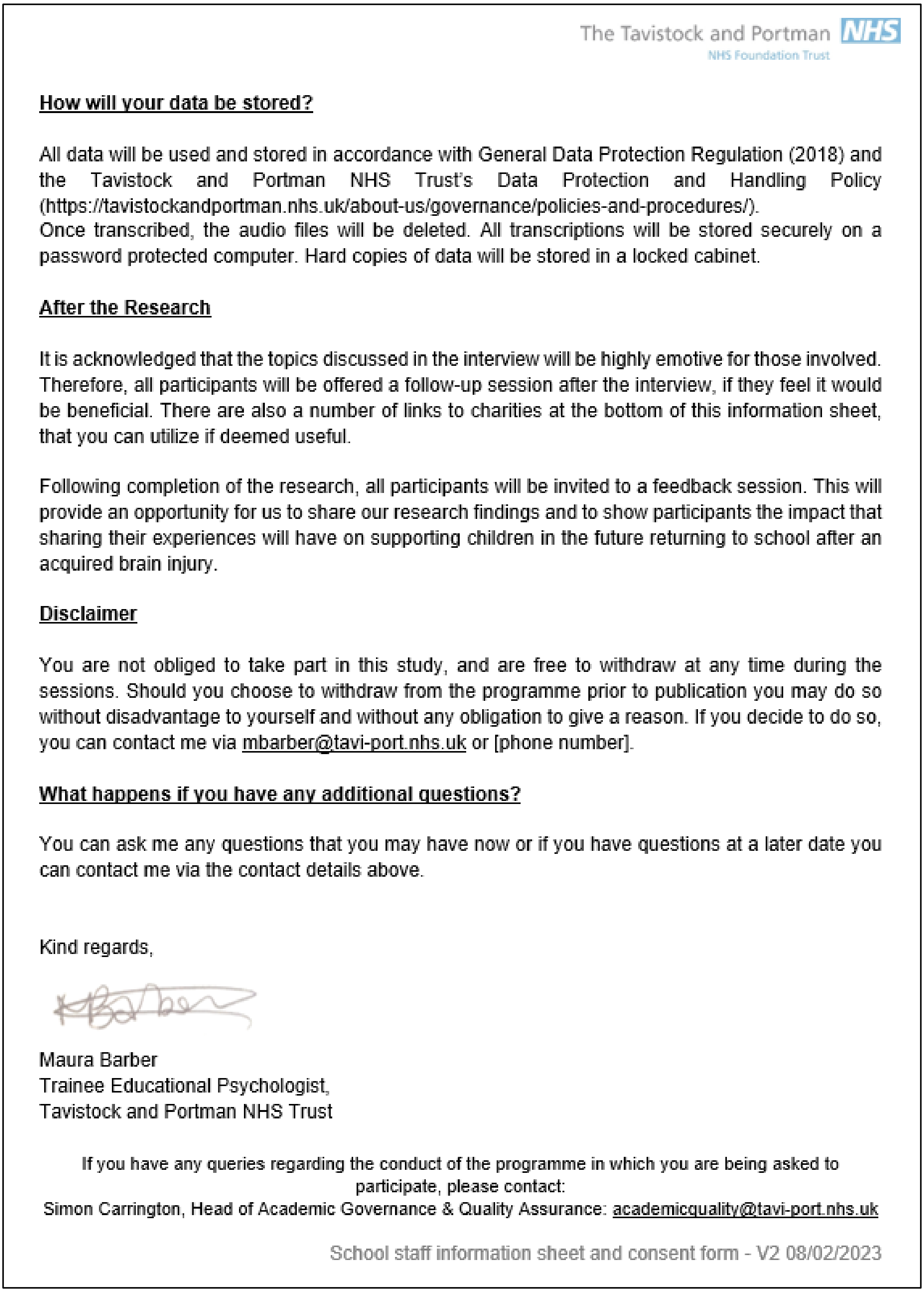
You will also be asked to share some information about yourself, your ethnicity, your length of time teaching and your experiences with children with acquired brain injury. All of the information you give will be confidential and you retain the right to not share any of this information if you do not wish to do so.

What will you get out of participating?

This research is an opportunity to raise the profile of children with acquired brain injury in education, and to hear the voices and experiences of these children, their families and the teaching staff that work and support them on a day-to-day basis. As this is a small-scale piece of research, I am unable to offer any financial compensation for taking part.

How will I protect your identity in my research?

It is important to recognize that this is a small sample research study. Therefore, any information that you provide will be pseudo-anonymised within the final report. I will change your name to protect your identity and I will not be sharing any of your personal details with third party organisations. You will be referred to in terms of the group of which you are a member (child, parent or professional) in the research write up. Data from interviews may be discussed with other researchers in professional supervision meetings. This will be on an anonymous basis.



How will your data be stored?

All data will be used and stored in accordance with General Data Protection Regulation (2018) and the Tavistock and Portman NHS Trust's Data Protection and Handling Policy (https://tavistockandportman.nhs.uk/about-us/governance/policies-and-procedures/).
Once transcribed, the audio files will be deleted. All transcriptions will be stored securely on a password protected computer. Hard copies of data will be stored in a locked cabinet.

After the Research

It is acknowledged that the topics discussed in the interview will be highly emotive for those involved. Therefore, all participants will be offered a follow-up session after the interview, if they feel it would be beneficial. There are also a number of links to charities at the bottom of this information sheet, that you can utilize if deemed useful.

Following completion of the research, all participants will be invited to a feedback session. This will provide an opportunity for us to share our research findings and to show participants the impact that sharing their experiences will have on supporting children in the future returning to school after an acquired brain injury.

Disclaimer

You are not obliged to take part in this study, and are free to withdraw at any time during the sessions. Should you choose to withdraw from the programme prior to publication you may do so without disadvantage to yourself and without any obligation to give a reason. If you decide to do so, you can contact me via mbarber@tavi-port.nhs.uk or [phone number].

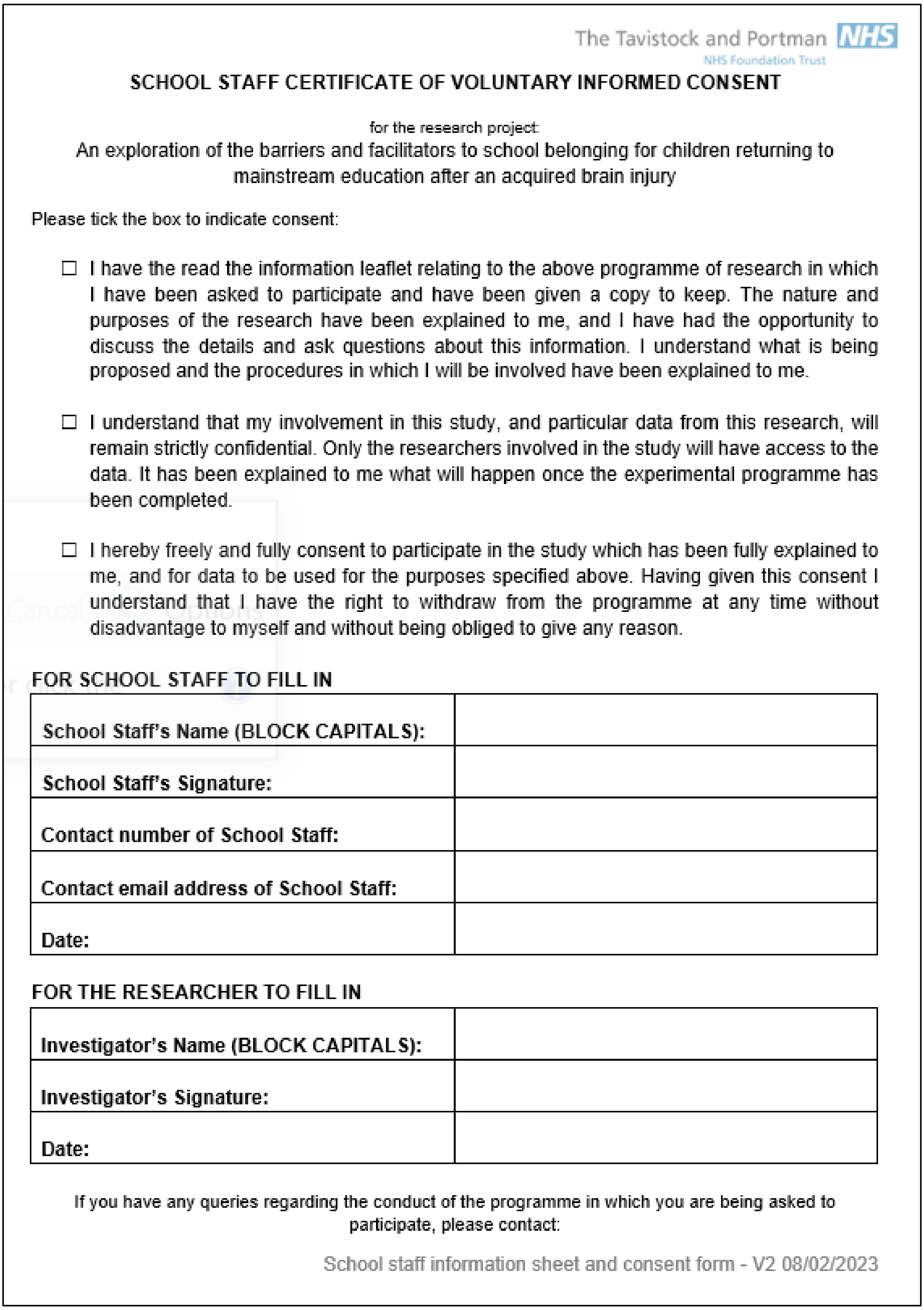
What happens if you have any additional questions?

You can ask me any questions that you may have now or if you have questions at a later date you can contact me via the contact details above.

Kind regards,

Maura Barber
Trainee Educational Psychologist,
Tavistock and Portman NHS Trust

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:
Simon Carrington, Head of Academic Governance & Quality Assurance: academicquality@tavi-port.nhs.uk



The Tavistock and Portman NHS
NHS Foundation Trust

SCHOOL STAFF CERTIFICATE OF VOLUNTARY INFORMED CONSENT

for the research project:
An exploration of the barriers and facilitators to school belonging for children returning to mainstream education after an acquired brain injury

Please tick the box to indicate consent:

☐ I have the read the information leaflet relating to the above programme of research in which I have been asked to participate 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 the data. It has been explained to me what will happen once the experimental programme has been completed.

☐ I hereby freely and fully consent to participate in the study which has been fully explained to me, and for data to be used for the purposes specified above. Having given this consent I understand that I have the right to withdraw from the programme at any time without disadvantage to myself and without being obliged to give any reason.

FOR SCHOOL STAFF TO FILL IN

School Staff's Name (BLOCK CAPITALS):	
School Staff's Signature:	
Contact number of School Staff:	
Contact email address of School Staff:	
Date:	

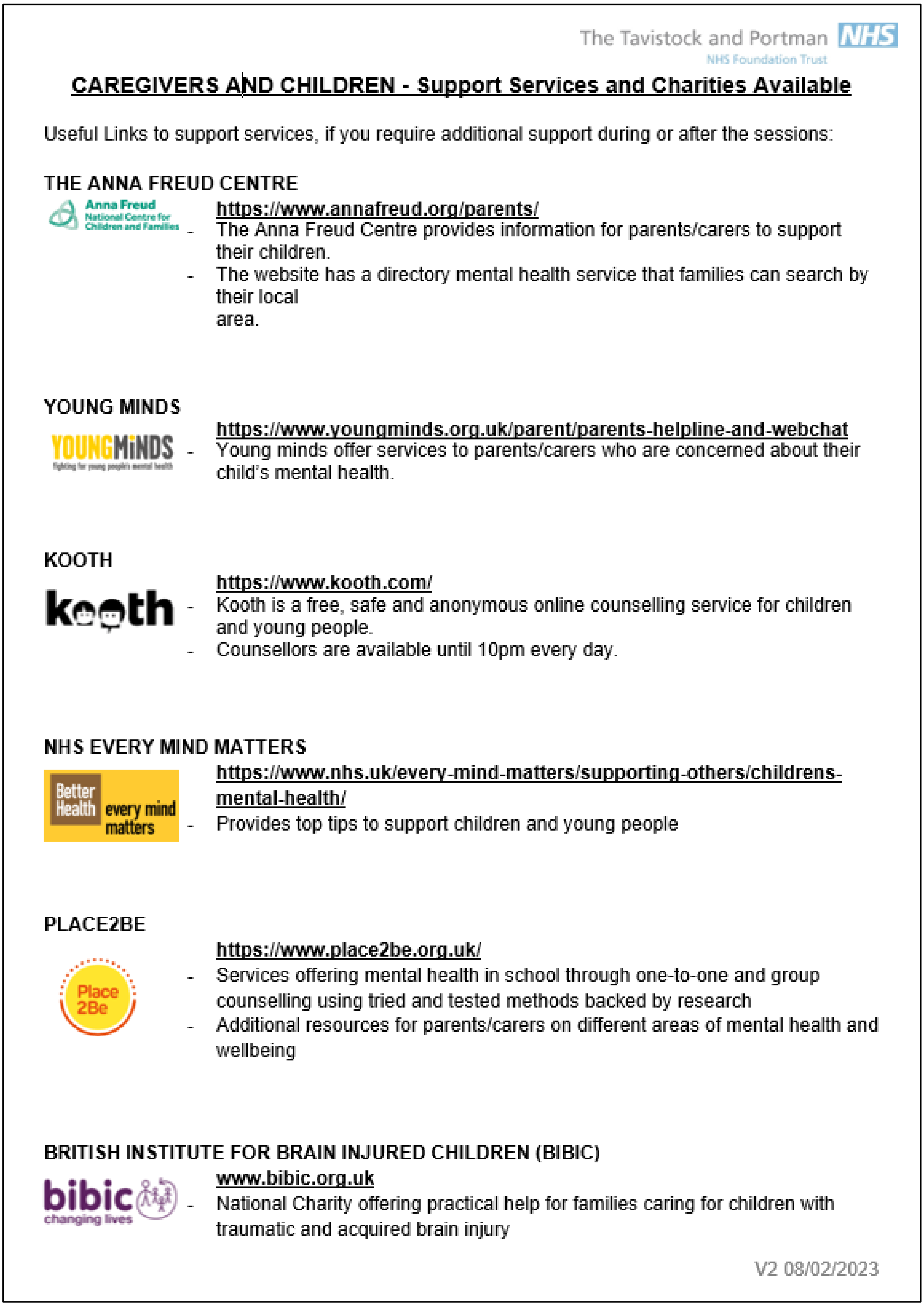
FOR THE RESEARCHER TO FILL IN

Investigator's Name (BLOCK CAPITALS):	
Investigator's Signature:	
Date:	

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact:

School staff information sheet and consent form - V2 08/02/2023

7.5 Appendix E: Debrief Signposting Sheet



The Tavistock and Portman NHS
NHS Foundation Trust

CAREGIVERS AND CHILDREN - Support Services and Charities Available

Useful Links to support services, if you require additional support during or after the sessions:

THE ANNA FREUD CENTRE

https://www.annafreud.org/parents/

- The Anna Freud Centre provides information for parents/carers to support their children.
- The website has a directory mental health service that families can search by their local area.

YOUNG MINDS

https://www.youngminds.org.uk/parent/parents-helpline-and-webchat

- Young minds offer services to parents/carers who are concerned about their child's mental health.

KOOTH

https://www.kooth.com/

- Kooth is a free, safe and anonymous online counselling service for children and young people.
- Counsellors are available until 10pm every day.

NHS EVERY MIND MATTERS

https://www.nhs.uk/every-mind-matters/supporting-others/childrens-mental-health/

- Provides top tips to support children and young people

PLACE2BE

https://www.place2be.org.uk/

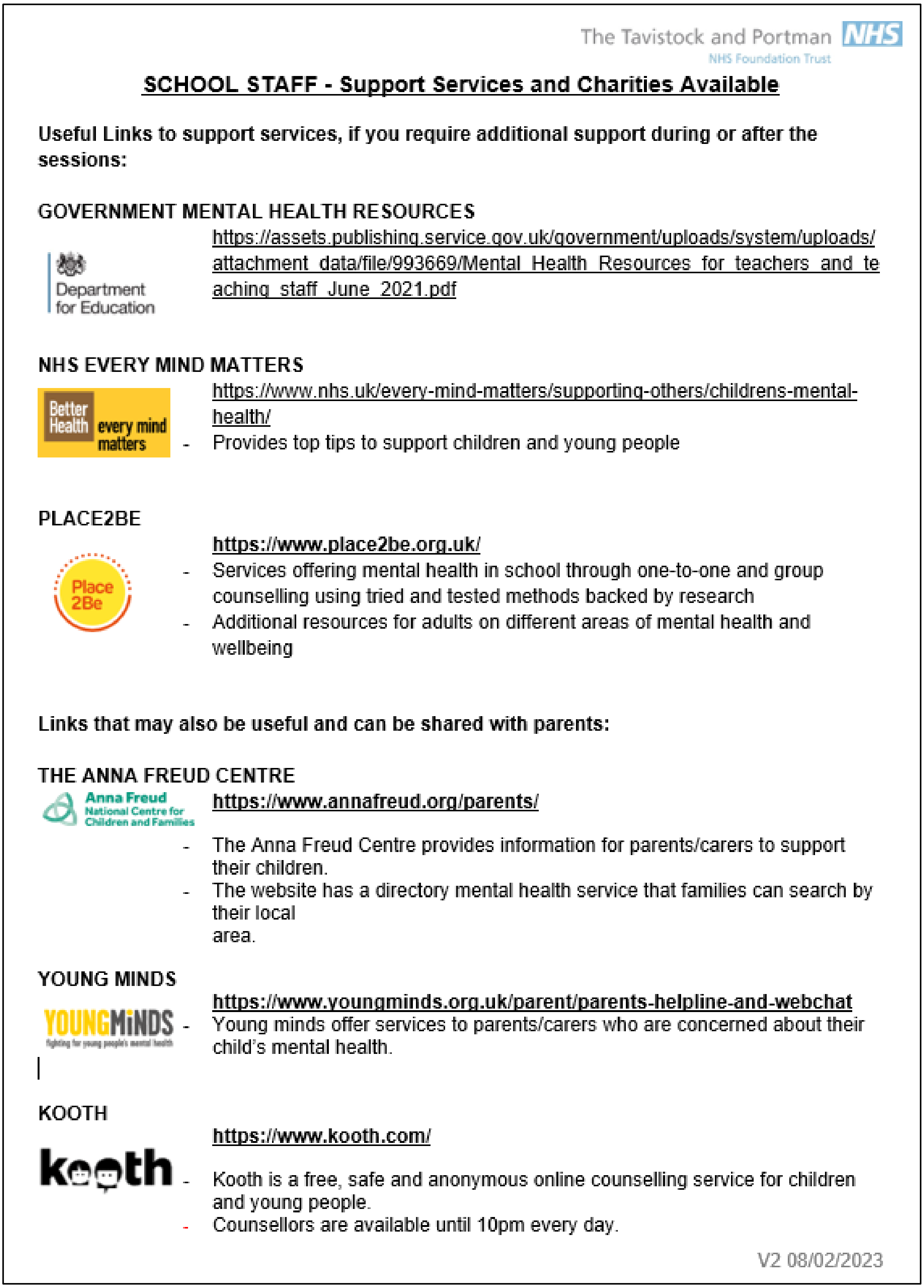
- Services offering mental health in school through one-to-one and group counselling using tried and tested methods backed by research
- Additional resources for parents/carers on different areas of mental health and wellbeing

BRITISH INSTITUTE FOR BRAIN INJURED CHILDREN (BIBIC)

www.bibic.org.uk

- National Charity offering practical help for families caring for children with traumatic and acquired brain injury

V2 08/02/2023



The Tavistock and Portman NHS
NHS Foundation Trust

SCHOOL STAFF - Support Services and Charities Available

Useful Links to support services, if you require additional support during or after the sessions:

GOVERNMENT MENTAL HEALTH RESOURCES

Department for Education

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/993669/Mental_Health_Resources_for_teachers_and_teaching_staff_June_2021.pdf

NHS EVERY MIND MATTERS

Better Health every mind matters

https://www.nhs.uk/every-mind-matters/supporting-others/childrens-mental-health/

- Provides top tips to support children and young people

PLACE2BE

Place 2Be

https://www.place2be.org.uk/

- Services offering mental health in school through one-to-one and group counselling using tried and tested methods backed by research
- Additional resources for adults on different areas of mental health and wellbeing

Links that may also be useful and can be shared with parents:

THE ANNA FREUD CENTRE

Anna Freud National Centre for Children and Families

https://www.annafreud.org/parents/

- The Anna Freud Centre provides information for parents/carers to support their children.
- The website has a directory mental health service that families can search by their local area.

YOUNG MINDS

YOUNGMINDS fighting for young people's mental health

https://www.youngminds.org.uk/parent/parents-helpline-and-webchat

- Young minds offer services to parents/carers who are concerned about their child's mental health.

KOOTH

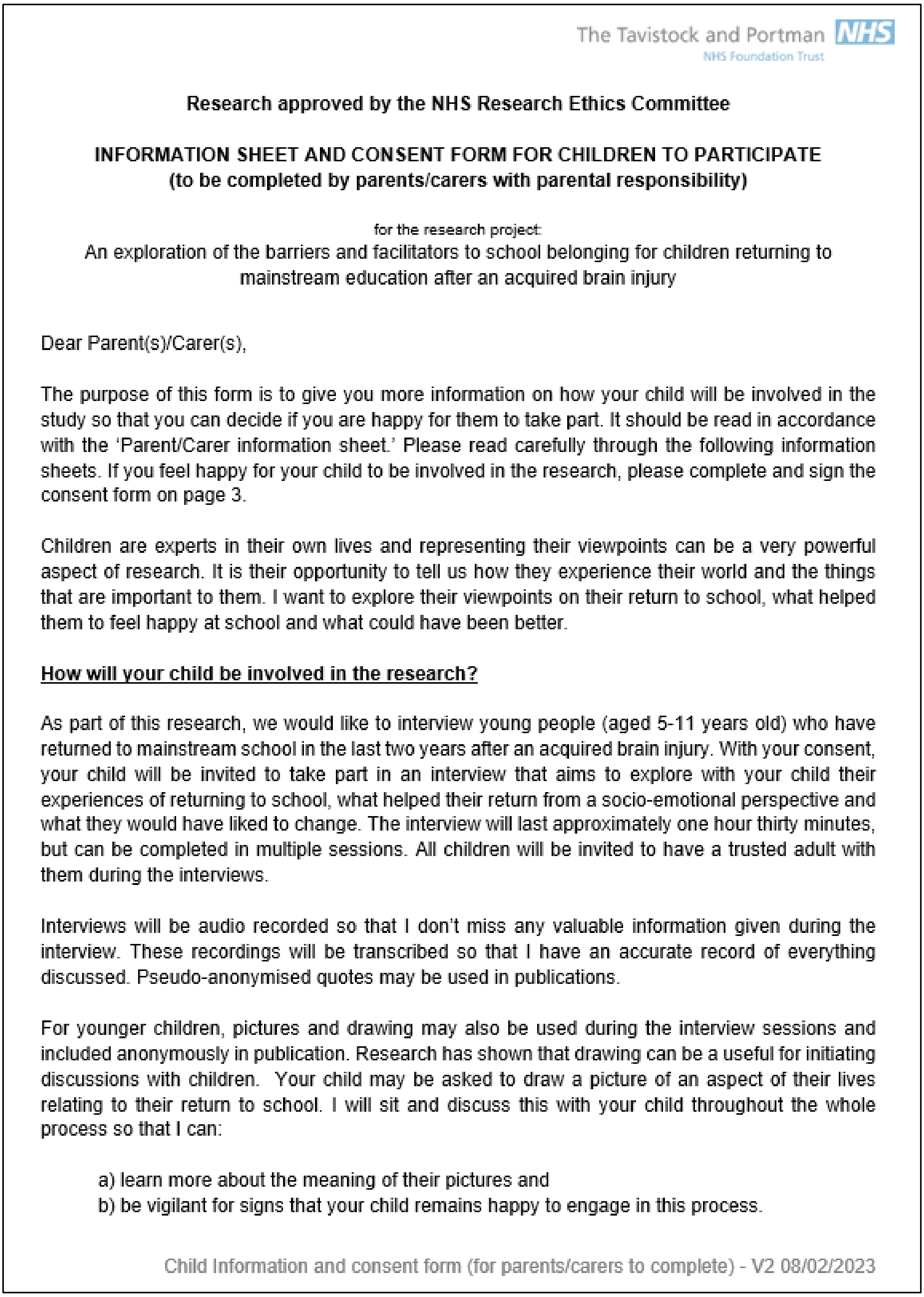
kooth

https://www.kooth.com/

- Kooth is a free, safe and anonymous online counselling service for children and young people.
- Counsellors are available until 10pm every day.

V2 08/02/2023

7.6 Appendix F: Child Participant Information Sheets and Consent



The Tavistock and Portman NHS
NHS Foundation Trust

Research approved by the NHS Research Ethics Committee

INFORMATION SHEET AND CONSENT FORM FOR CHILDREN TO PARTICIPATE
(to be completed by parents/carers with parental responsibility)

for the research project:
An exploration of the barriers and facilitators to school belonging for children returning to mainstream education after an acquired brain injury

Dear Parent(s)/Carer(s),

The purpose of this form is to give you more information on how your child will be involved in the study so that you can decide if you are happy for them to take part. It should be read in accordance with the 'Parent/Carer information sheet.' Please read carefully through the following information sheets. If you feel happy for your child to be involved in the research, please complete and sign the consent form on page 3.

Children are experts in their own lives and representing their viewpoints can be a very powerful aspect of research. It is their opportunity to tell us how they experience their world and the things that are important to them. I want to explore their viewpoints on their return to school, what helped them to feel happy at school and what could have been better.

How will your child be involved in the research?

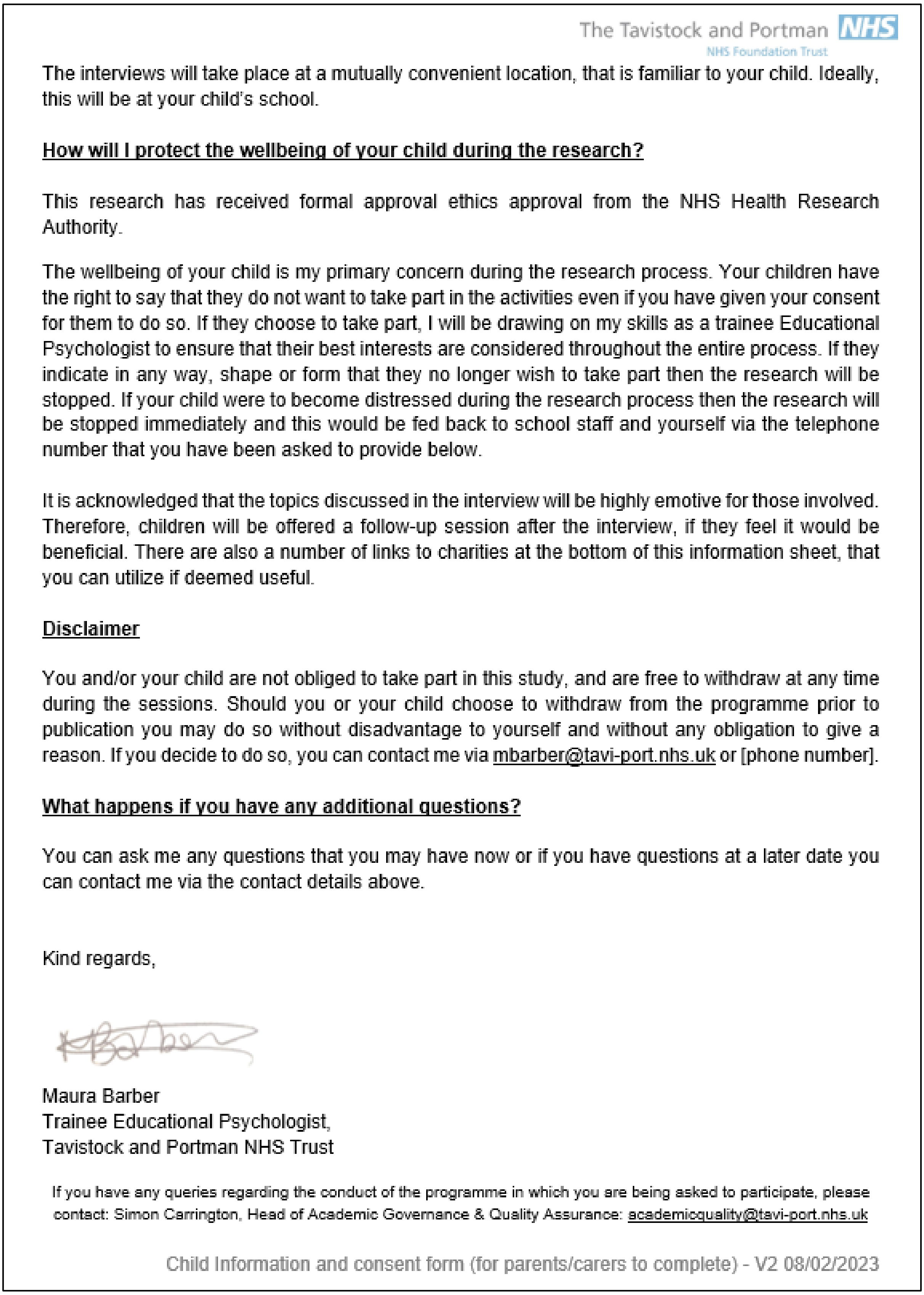
As part of this research, we would like to interview young people (aged 5-11 years old) who have returned to mainstream school in the last two years after an acquired brain injury. With your consent, your child will be invited to take part in an interview that aims to explore with your child their experiences of returning to school, what helped their return from a socio-emotional perspective and what they would have liked to change. The interview will last approximately one hour thirty minutes, but can be completed in multiple sessions. All children will be invited to have a trusted adult with them during the interviews.

Interviews will be audio recorded so that I don't miss any valuable information given during the interview. These recordings will be transcribed so that I have an accurate record of everything discussed. Pseudo-anonymised quotes may be used in publications.

For younger children, pictures and drawing may also be used during the interview sessions and included anonymously in publication. Research has shown that drawing can be a useful for initiating discussions with children. Your child may be asked to draw a picture of an aspect of their lives relating to their return to school. I will sit and discuss this with your child throughout the whole process so that I can:

a) learn more about the meaning of their pictures and
b) be vigilant for signs that your child remains happy to engage in this process.

Child Information and consent form (for parents/carers to complete) - V2 08/02/2023



The interviews will take place at a mutually convenient location, that is familiar to your child. Ideally, this will be at your child's school.

How will I protect the wellbeing of your child during the research?

This research has received formal approval ethics approval from the NHS Health Research Authority.

The wellbeing of your child is my primary concern during the research process. Your children have the right to say that they do not want to take part in the activities even if you have given your consent for them to do so. If they choose to take part, I will be drawing on my skills as a trainee Educational Psychologist to ensure that their best interests are considered throughout the entire process. If they indicate in any way, shape or form that they no longer wish to take part then the research will be stopped. If your child were to become distressed during the research process then the research will be stopped immediately and this would be fed back to school staff and yourself via the telephone number that you have been asked to provide below.

It is acknowledged that the topics discussed in the interview will be highly emotive for those involved. Therefore, children will be offered a follow-up session after the interview, if they feel it would be beneficial. There are also a number of links to charities at the bottom of this information sheet, that you can utilize if deemed useful.

Disclaimer

You and/or your child are not obliged to take part in this study, and are free to withdraw at any time during the sessions. Should you or your child choose to withdraw from the programme prior to publication you may do so without disadvantage to yourself and without any obligation to give a reason. If you decide to do so, you can contact me via mbarber@tavi-port.nhs.uk or [phone number].

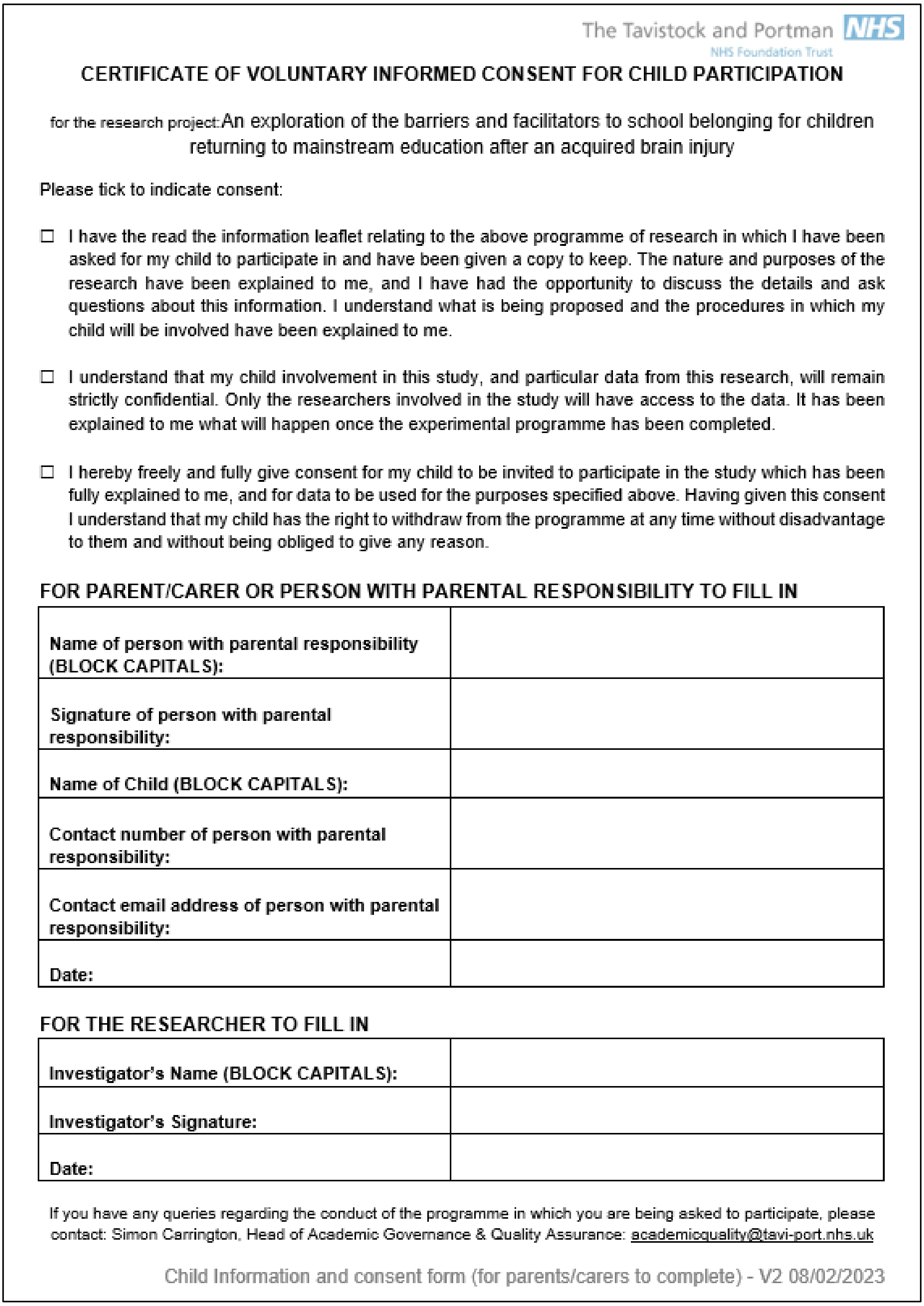
What happens if you have any additional questions?

You can ask me any questions that you may have now or if you have questions at a later date you can contact me via the contact details above.

Kind regards,

Maura Barber
Trainee Educational Psychologist,
Tavistock and Portman NHS Trust

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact: Simon Carrington, Head of Academic Governance & Quality Assurance: academicquality@tavi-port.nhs.uk



The Tavistock and Portman NHS
NHS Foundation Trust

CERTIFICATE OF VOLUNTARY INFORMED CONSENT FOR CHILD PARTICIPATION

for the research project: An exploration of the barriers and facilitators to school belonging for children returning to mainstream education after an acquired brain injury

Please tick to indicate consent:

☐ I have the read the information leaflet relating to the above programme of research in which I have been asked for my child to participate in 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 my child will be involved have been explained to me.

☐ I understand that my child 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 the data. It has been explained to me what will happen once the experimental programme has been completed.

☐ I hereby freely and fully give consent for my child to be invited to participate in the study which has been fully explained to me, and for data to be used for the purposes specified above. Having given this consent I understand that my child has the right to withdraw from the programme at any time without disadvantage to them and without being obliged to give any reason.

FOR PARENT/CARER OR PERSON WITH PARENTAL RESPONSIBILITY TO FILL IN

Name of person with parental responsibility (BLOCK CAPITALS):	
Signature of person with parental responsibility:	
Name of Child (BLOCK CAPITALS):	
Contact number of person with parental responsibility:	
Contact email address of person with parental responsibility:	
Date:	

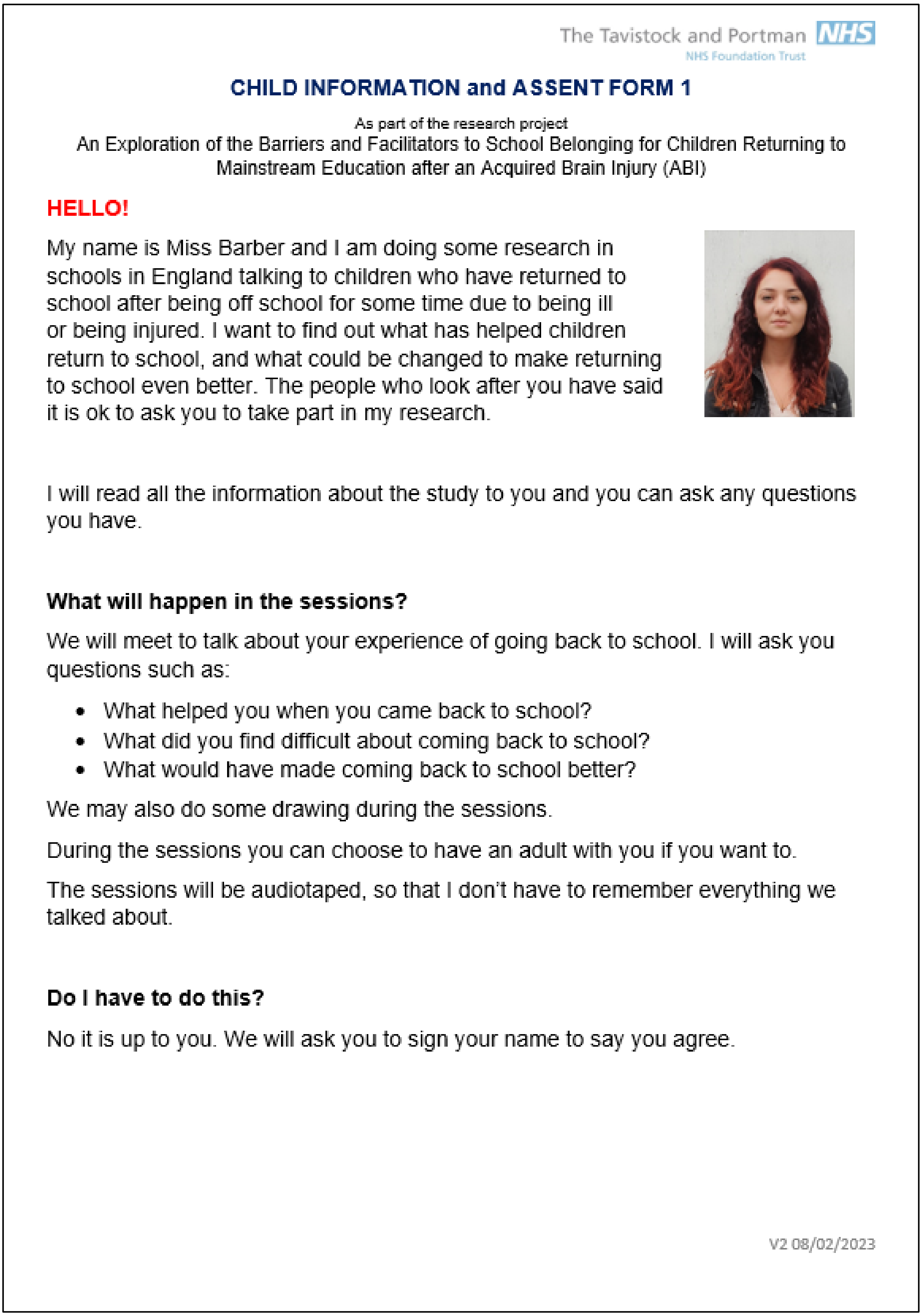
FOR THE RESEARCHER TO FILL IN

Investigator's Name (BLOCK CAPITALS):	
Investigator's Signature:	
Date:	

If you have any queries regarding the conduct of the programme in which you are being asked to participate, please contact: Simon Carrington, Head of Academic Governance & Quality Assurance: academicquality@tavi-port.nhs.uk

Child Information and consent form (for parents/carers to complete) - V2 08/02/2023

7.7 Appendix G: Child Information Sheet and Assent



The Tavistock and Portman NHS
NHS Foundation Trust

CHILD INFORMATION and ASSENT FORM 1

As part of the research project
An Exploration of the Barriers and Facilitators to School Belonging for Children Returning to Mainstream Education after an Acquired Brain Injury (ABI)

HELLO!

My name is Miss Barber and I am doing some research in schools in England talking to children who have returned to school after being off school for some time due to being ill or being injured. I want to find out what has helped children return to school, and what could be changed to make returning to school even better. The people who look after you have said it is ok to ask you to take part in my research.

I will read all the information about the study to you and you can ask any questions you have.

What will happen in the sessions?

We will meet to talk about your experience of going back to school. I will ask you questions such as:

- What helped you when you came back to school?
- What did you find difficult about coming back to school?
- What would have made coming back to school better?

We may also do some drawing during the sessions.

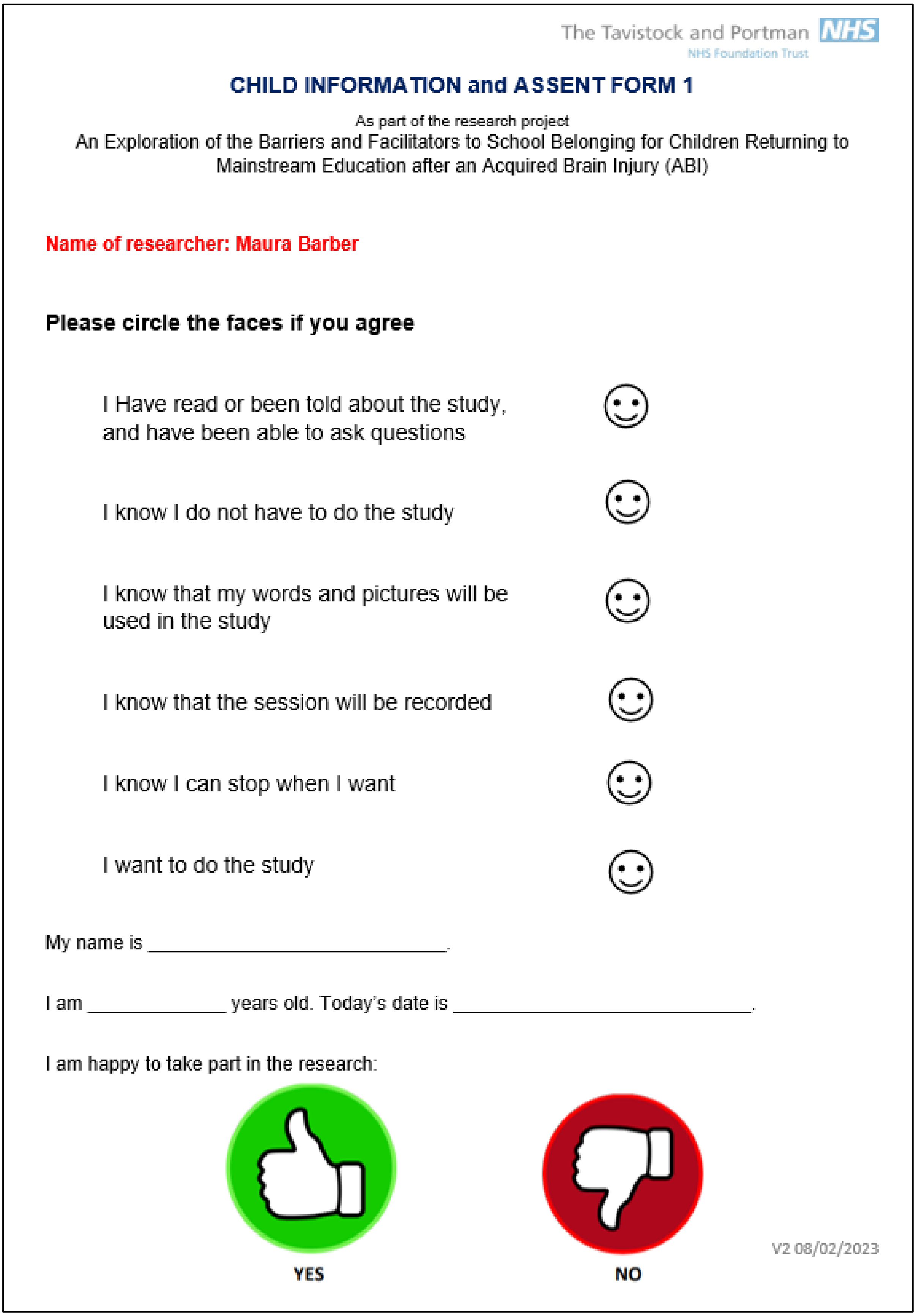
During the sessions you can choose to have an adult with you if you want to.

The sessions will be audiotaped, so that I don't have to remember everything we talked about.

Do I have to do this?

No it is up to you. We will ask you to sign your name to say you agree.

V2 08/02/2023



The Tavistock and Portman NHS
NHS Foundation Trust

CHILD INFORMATION and ASSENT FORM 1

As part of the research project
An Exploration of the Barriers and Facilitators to School Belonging for Children Returning to Mainstream Education after an Acquired Brain Injury (ABI)

Name of researcher: Maura Barber

Please circle the faces if you agree

I Have read or been told about the study, and have been able to ask questions	☺
I know I do not have to do the study	☺
I know that my words and pictures will be used in the study	☺
I know that the session will be recorded	☺
I know I can stop when I want	☺
I want to do the study	☺

My name is ______________________________.

I am ______________ years old. Today's date is ______________________________.

I am happy to take part in the research:

👍 YES

👎 NO

V2 08/02/2023

The Tavistock and Portman NHS
NHS Foundation Trust

CHILD INFORMATION and ASSENT FORM 2

As part of the research project
An Exploration of the Barriers and Facilitators to School Belonging for Children Returning to Mainstream Education after an Acquired Brain Injury (ABI)

My

name

is Maura

I am

finding out about

children who

have gone back

to school

After being away from school

because of an illness or injury

What

was good

and

+

what

was difficult

at school

In the sessions

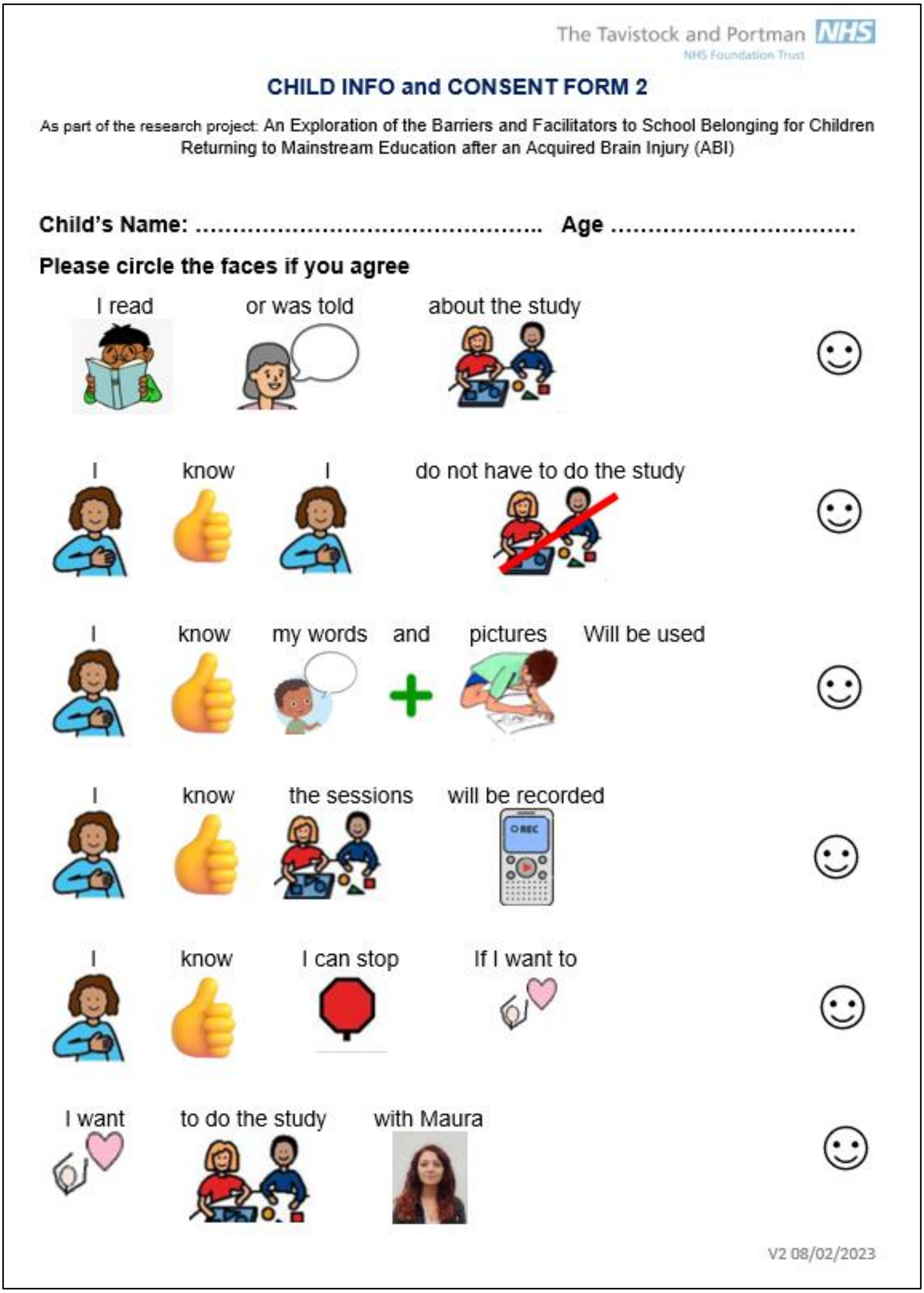
we will talk

and

+

draw pictures

V2 08/02/2023



The Tavistock and Portman NHS
NHS Foundation Trust

CHILD INFO and CONSENT FORM 2

As part of the research project: An Exploration of the Barriers and Facilitators to School Belonging for Children Returning to Mainstream Education after an Acquired Brain Injury (ABI)

Child's Name: .... **Age** ....

Please circle the faces if you agree

I read or was told about the study ☺

I know I do not have to do the study ☺

I know my words and pictures Will be used ☺

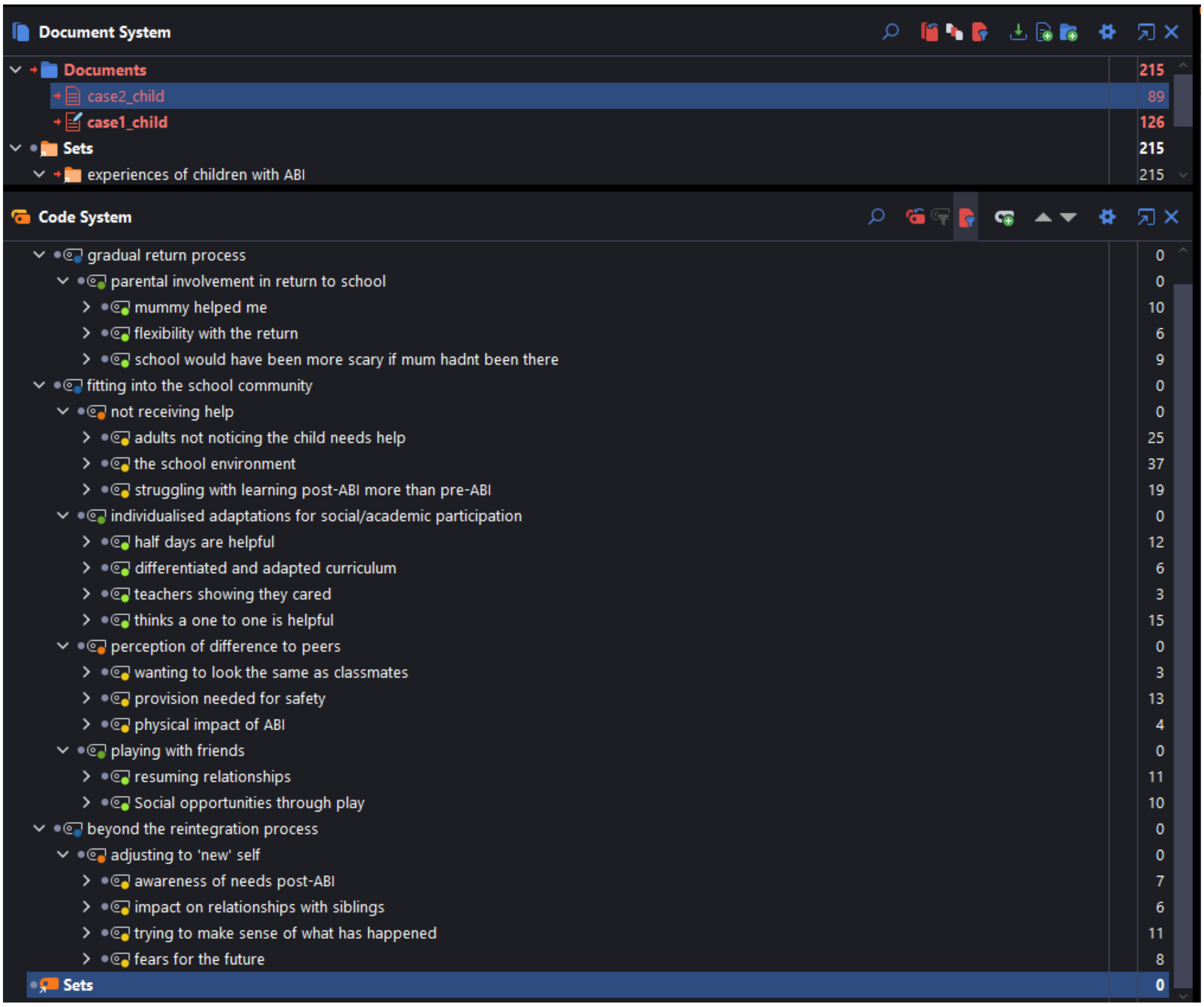
I know the sessions will be recorded ☺

I know I can stop If I want to ☺

I want to do the study with Maura ☺

V2 08/02/2023

7.8 Appendix H: MAXQDA Coding Extract

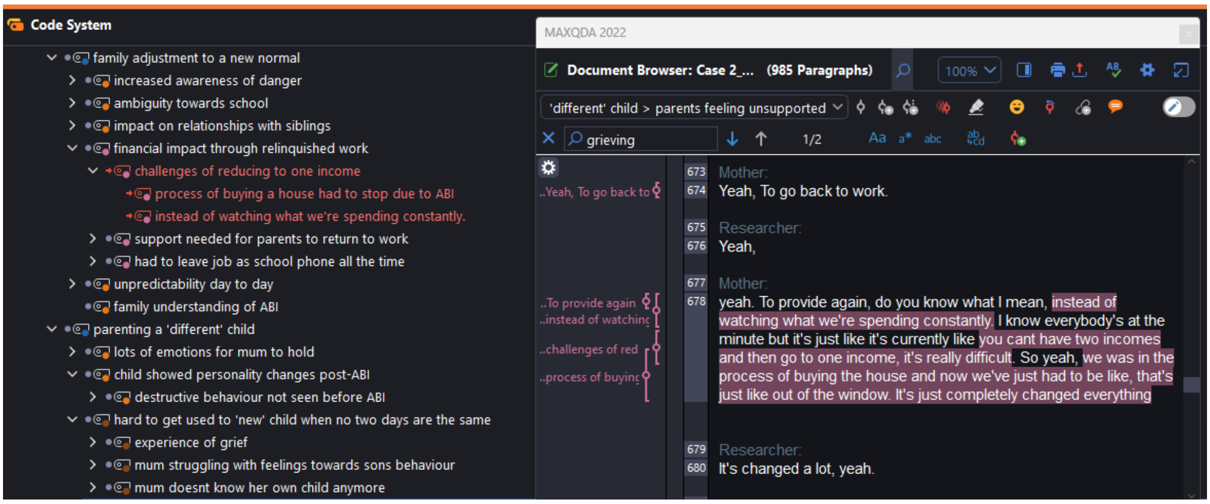


Document System

Documents	215
case2_child	89
case1_child	126
Sets	215
experiences of children with ABI	215

Code System

gradual return process	0
parental involvement in return to school	0
mummy helped me	10
flexibility with the return	6
school would have been more scary if mum hadnt been there	9
fitting into the school community	0
not receiving help	0
adults not noticing the child needs help	25
the school environment	37
struggling with learning post-ABI more than pre-ABI	19
individualised adaptations for social/academic participation	0
half days are helpful	12
differentiated and adapted curriculum	6
teachers showing they cared	3
thinks a one to one is helpful	15
perception of difference to peers	0
wanting to look the same as classmates	3
provision needed for safety	13
physical impact of ABI	4
playing with friends	0
resuming relationships	11
Social opportunities through play	10
beyond the reintegration process	0
adjusting to 'new' self	0
awareness of needs post-ABI	7
impact on relationships with siblings	6
trying to make sense of what has happened	11
fears for the future	8
Sets	0



Code System

- family adjustment to a new normal
  - increased awareness of danger
  - ambiguity towards school
  - impact on relationships with siblings
  - financial impact through relinquished work
    - challenges of reducing to one income
      - process of buying a house had to stop due to ABI
      - instead of watching what we're spending constantly.
    - support needed for parents to return to work
    - had to leave job as school phone all the time
  - unpredictability day to day
  - family understanding of ABI
- parenting a 'different' child
  - lots of emotions for mum to hold
  - child showed personality changes post-ABI
    - destructive behaviour not seen before ABI
  - hard to get used to 'new' child when no two days are the same
    - experience of grief
    - mum struggling with feelings towards sons behaviour
    - mum doesnt know her own child anymore

MAXQDA 2022

Document Browser: Case 2_... (985 Paragraphs)

'different' child > parents feeling unsupported

grieving 1/2

..Yeah, To go back to
..To provide again
..instead of watching
..challenges of red
..process of buying

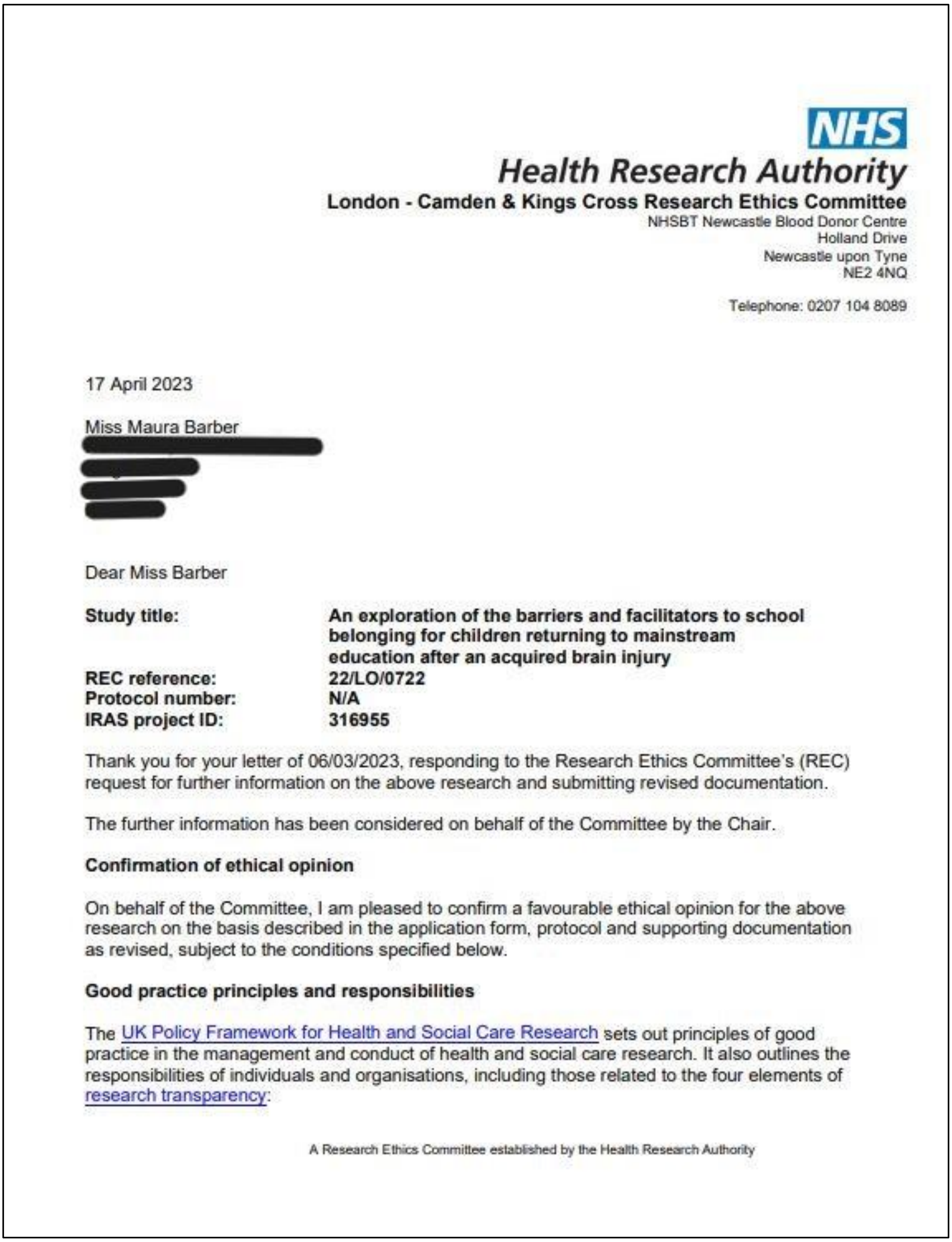
673 Mother:
674 Yeah, To go back to work.

675 Researcher:
676 Yeah,

677 Mother:
678 yeah. To provide again, do you know what I mean, instead of watching what we're spending constantly. I know everybody's at the minute but it's just like it's currently like you cant have two incomes and then go to one income, it's really difficult. So yeah, we was in the process of buying the house and now we've just had to be like, that's just like out of the window. It's just completely changed everything

679 Researcher:
680 It's changed a lot, yeah.

7.9 Appendix I: Research Ethics Approval



NHS
Health Research Authority
London - Camden & Kings Cross Research Ethics Committee
NHSBT Newcastle Blood Donor Centre
Holland Drive
Newcastle upon Tyne
NE2 4NQ

Telephone: 0207 104 8089

17 April 2023

Miss Maura Barber
[redacted]

Dear Miss Barber

Study title:	**An exploration of the barriers and facilitators to school belonging for children returning to mainstream education after an acquired brain injury**
REC reference:	**22/LO/0722**
Protocol number:	**N/A**
IRAS project ID:	**316955**

Thank you for your letter of 06/03/2023, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

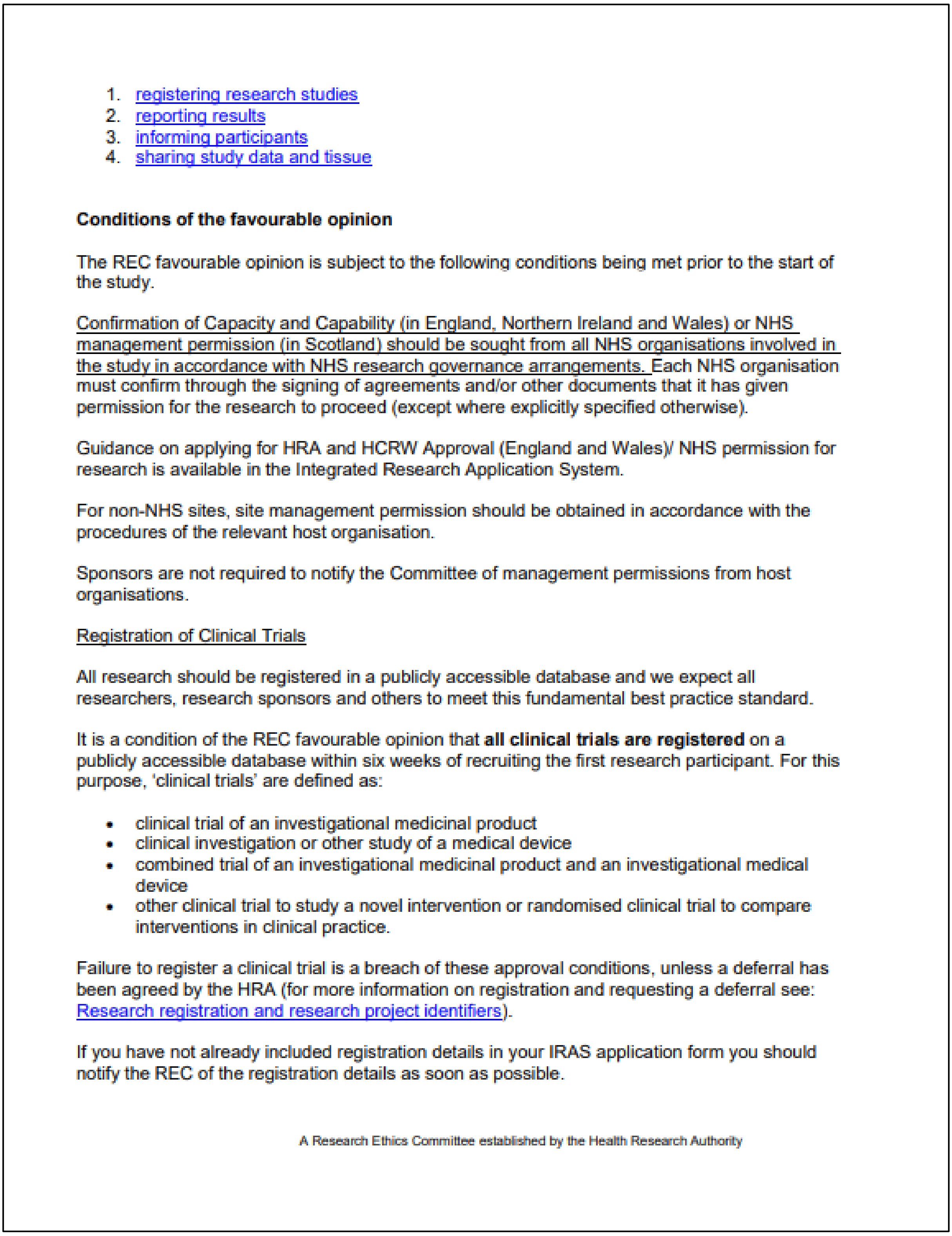
Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

A Research Ethics Committee established by the Health Research Authority



1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

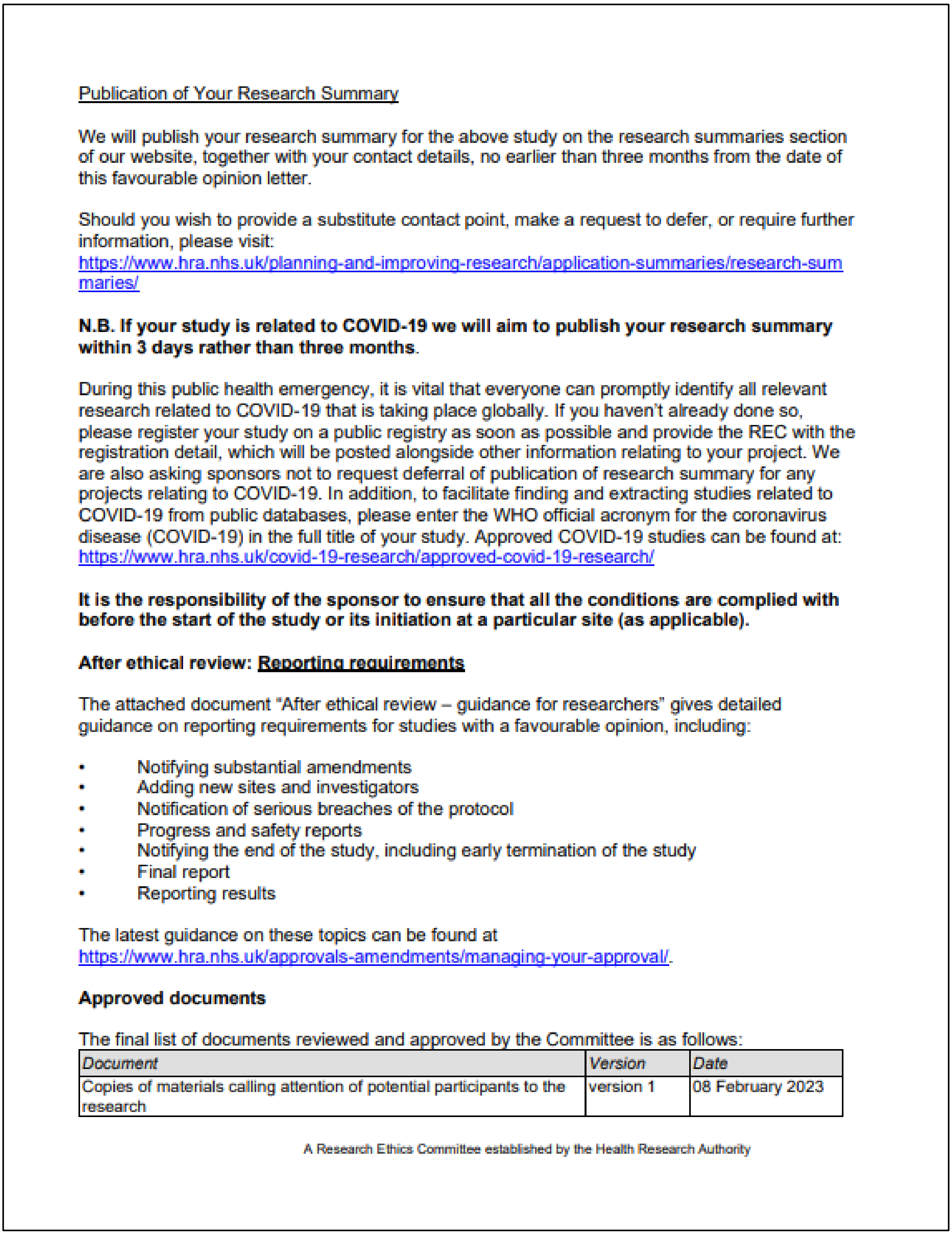
All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device
- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.



Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:
https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

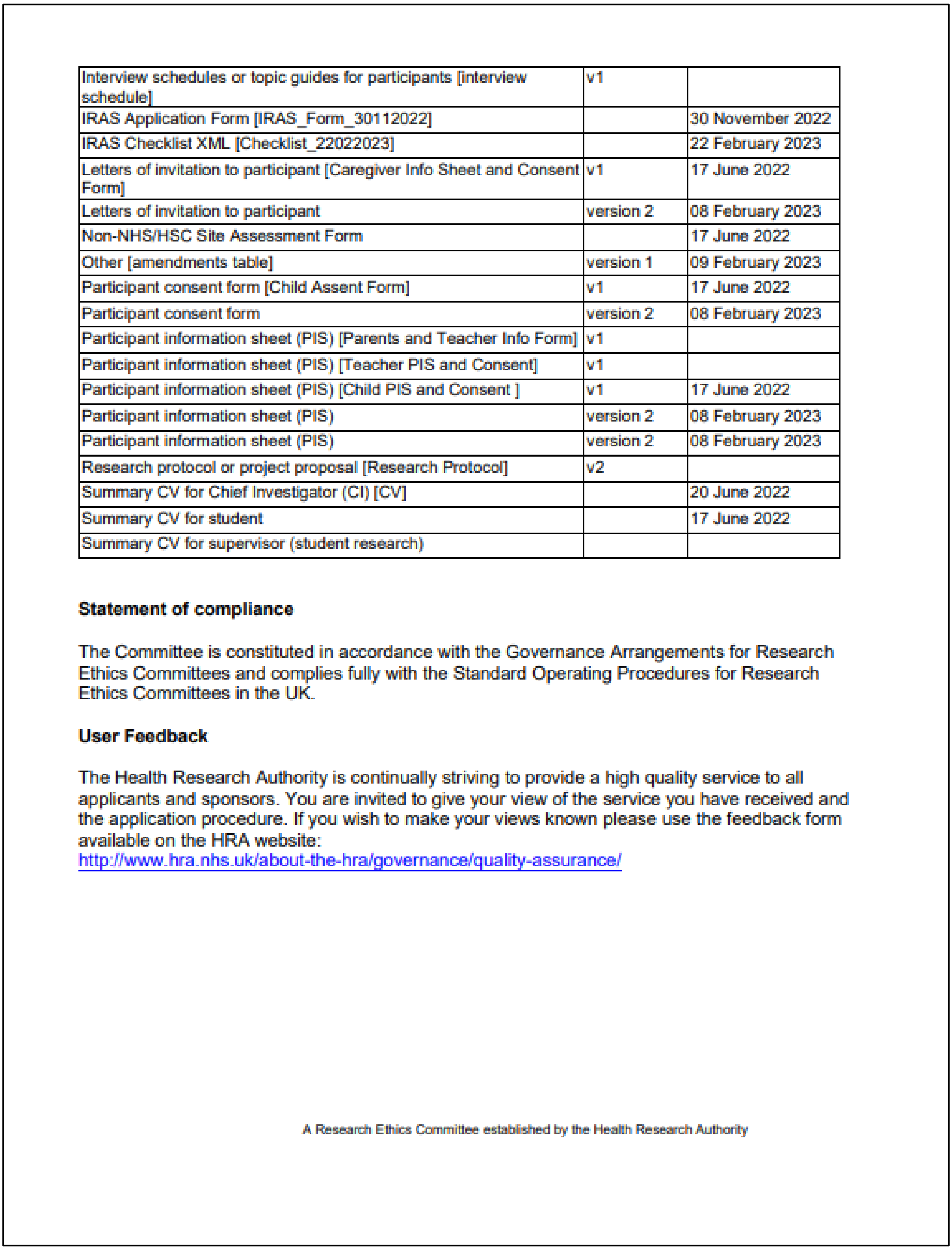
- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study
- Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research	version 1	08 February 2023



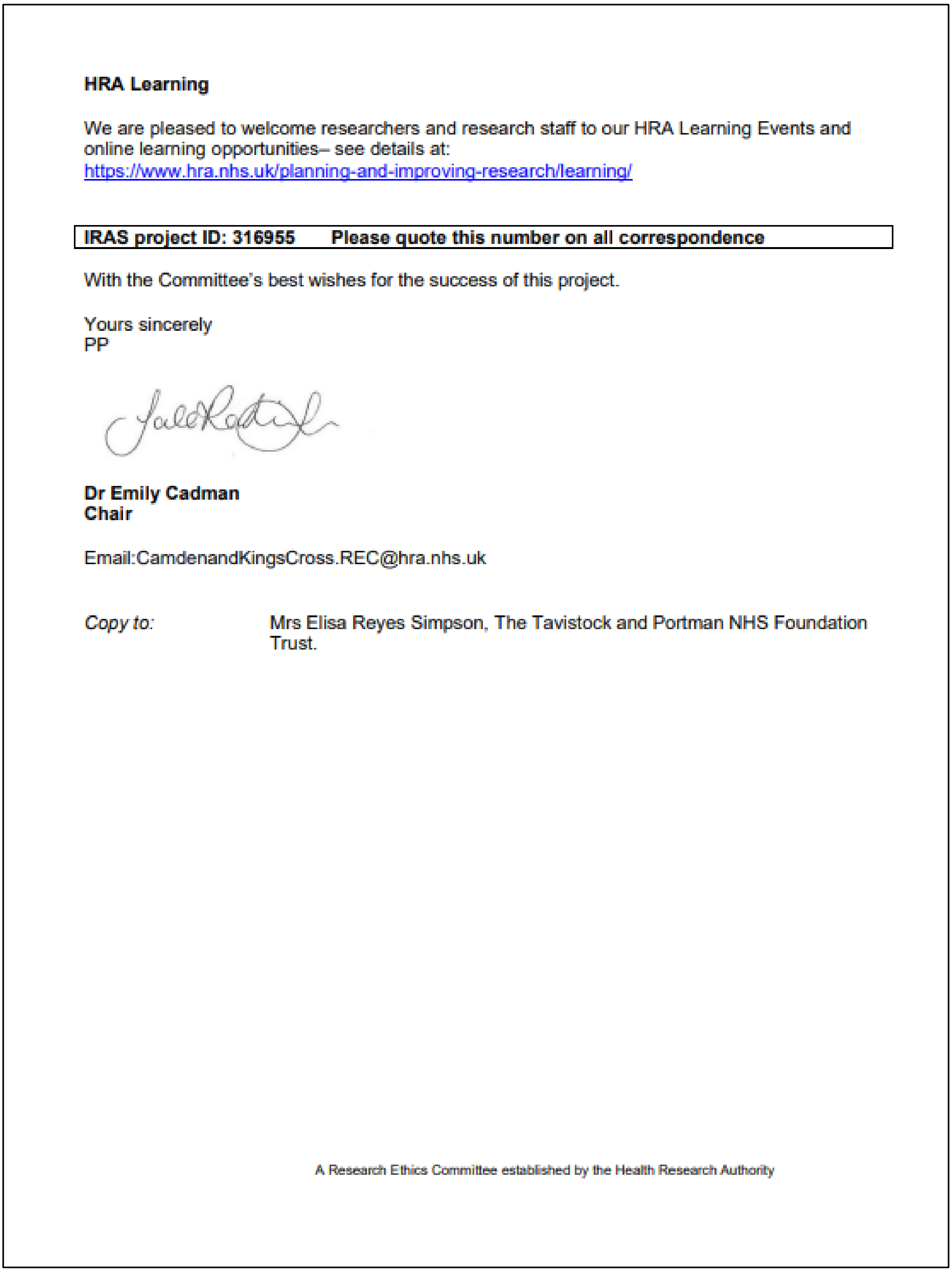
Interview schedules or topic guides for participants [interview schedule]	v1	
IRAS Application Form [IRAS_Form_30112022]		30 November 2022
IRAS Checklist XML [Checklist_22022023]		22 February 2023
Letters of invitation to participant [Caregiver Info Sheet and Consent Form]	v1	17 June 2022
Letters of invitation to participant	version 2	08 February 2023
Non-NHS/HSC Site Assessment Form		17 June 2022
Other [amendments table]	version 1	09 February 2023
Participant consent form [Child Assent Form]	v1	17 June 2022
Participant consent form	version 2	08 February 2023
Participant information sheet (PIS) [Parents and Teacher Info Form]	v1	
Participant information sheet (PIS) [Teacher PIS and Consent]	v1	
Participant information sheet (PIS) [Child PIS and Consent]	v1	17 June 2022
Participant information sheet (PIS)	version 2	08 February 2023
Participant information sheet (PIS)	version 2	08 February 2023
Research protocol or project proposal [Research Protocol]	v2	
Summary CV for Chief Investigator (CI) [CV]		20 June 2022
Summary CV for student		17 June 2022
Summary CV for supervisor (student research)		

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/



HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:
https://www.hra.nhs.uk/planning-and-improving-research/learning/

IRAS project ID: 316955 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

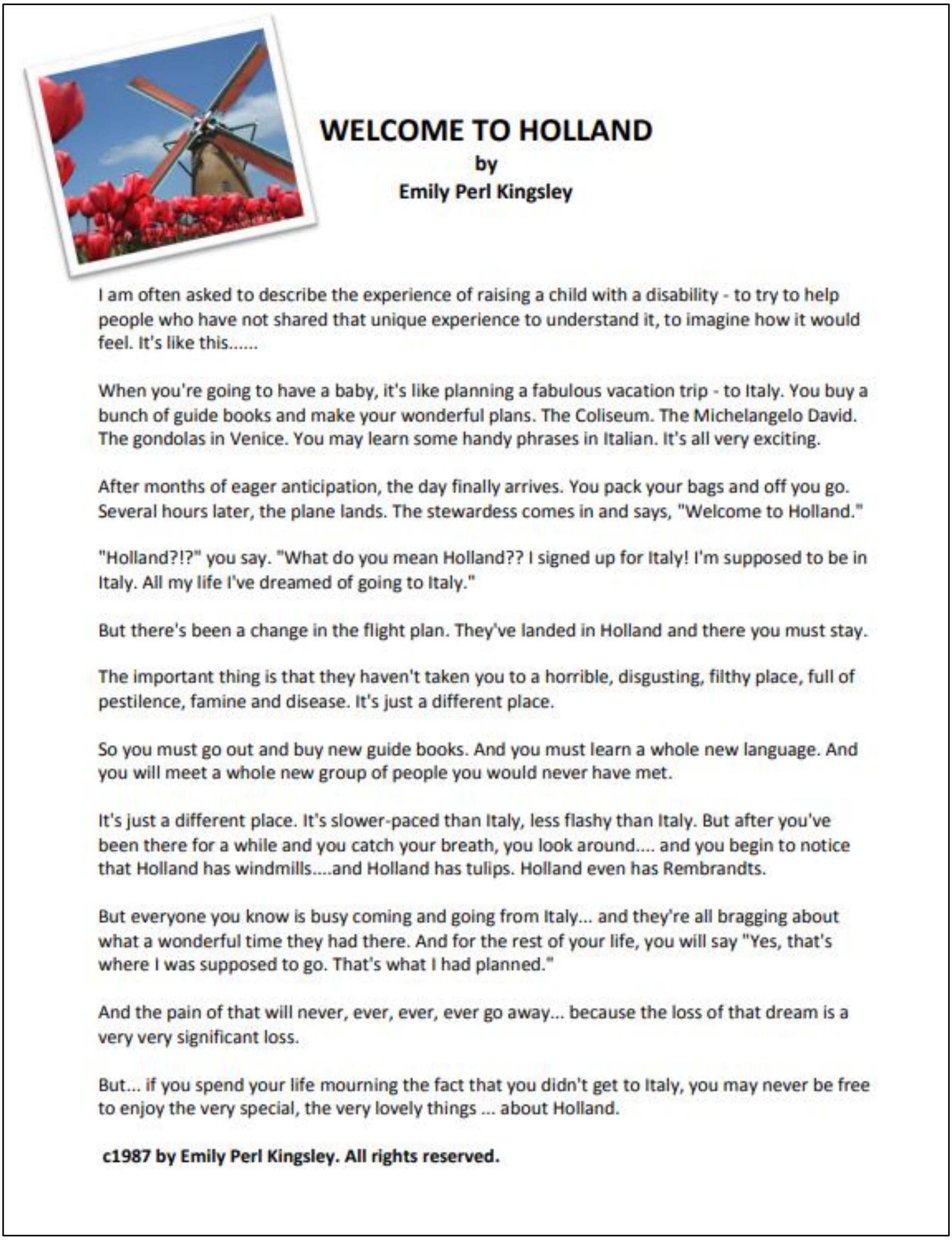
Yours sincerely
PP

Dr Emily Cadman
Chair

Email:CamdenandKingsCross.REC@hra.nhs.uk

Copy to: Mrs Elisa Reyes Simpson, The Tavistock and Portman NHS Foundation Trust.

7.10 Appendix J: ‘Welcome to Holland’ by Emily Perl Kingsley



WELCOME TO HOLLAND

by

Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability - to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this......

When you're going to have a baby, it's like planning a fabulous vacation trip - to Italy. You buy a bunch of guide books and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The stewardess comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland?? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place.

So you must go out and buy new guide books. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower-paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around.... and you begin to notice that Holland has windmills....and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy... and they're all bragging about what a wonderful time they had there. And for the rest of your life, you will say "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But... if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland.