

**“The Lobe Family”:  
Collaborative Development of a Psychoeducational Resource for Children  
who have Experienced an Acquired Brain Injury**

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## **ABSTRACT**

**Background:** This thesis describes the collaborative development and preliminary evaluation of a new psychoeducational resource for children and young people (CYP) who have experienced an acquired brain injury (ABI). Despite being acknowledged as a key aspect of neurorehabilitation associated with improved outcomes, the informational needs of CYP and their families are often not met (Danzi, Etter, Andretta & Kitzman, 2012; Forsyth et al., 2017). Whilst a number of informational resources are currently available, these are primarily developed for younger audiences, or those with milder forms of ABI that do not result in enduring neurocognitive impairment such as for concussion. A new psychoeducational resource may have the potential to meet these needs, particularly if grounded in theoretical and therapeutic research and theory, and delivered in a developmentally and pedagogically coherent manner.

**Methods:** Researcher generated ideas derived from a review of the literature were integrated with the views of three CYP who have experienced an ABI via interviews to develop a prototype resource, and acceptability of this was addressed via a bespoke feedback form.

**Results:** After identifying key neuropsychological concepts, the narrative framework was chosen as the therapeutic base for a new resource. This led to the development of a prototype for 'The Lobe Family', a new strengths-based psychoeducational resource. It was envisaged that 'The Lobe Family' would be presented as books for younger audiences, comics for adolescent audiences, and an interactive and personalisable web-based app. Preliminary evaluation suggests that 'The Lobe Family' may be acceptable to CYP, although further validation of this is required.

**Conclusions:** Whilst methodological limitations relating to the sample necessitate further exploration of how best to meet the informational needs of the diverse ABI population, 'The Lobe Family' may have the potential to meet the needs of CYP who are not catered for by the existing resources, particularly adolescents experiencing enduring neurocognitive impacts.

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## **1. INTRODUCTION**

This chapter provides an evidence-based rationale for the development of a psychoeducational resource for children and young people (CYP) who have experienced an acquired brain injury (ABI). ABI is an extremely heterogeneous term and therefore this chapter will begin by summarising the range of difficulties it encapsulates, including epidemiology and severity. Following an overview of the key principles of paediatric neuropsychology, the wide-ranging impacts and consequences of ABI will be summarised. This chapter will proceed to define and explore the range of approaches to neurorehabilitation that CYP may benefit from. Despite there being a plethora of evidence-based approaches for meeting the physical (i.e. managing physical health difficulties), cognitive (i.e. compensatory strategies for neurocognitive impairments), and psychosocial (i.e. supporting emotional wellbeing) needs of CYP following ABI, it will be argued that there is a gap in the literature around meeting their established informational needs (i.e. supporting CYP's understanding of ABI and what it means for them). Psychoeducation will then be introduced and proposed as a mechanism for the therapeutic provision of theoretically grounded information in a developmentally and pedagogically appropriate manner. This will be followed by a review of existing psychoeducational resources, from which it will be argued that there is significant scope for the collaborative development of a novel resource. In light of this, the research questions for the present study will be detailed.

### **1.1. Literature review**

During the project development phase, literature searches were conducted across Science Direct, ERIC, Scopus, and EBSCO databases (Academic Search Complete, CINAHL-Plus, PsychInfo). The purpose of this literature review was to identify research and evidence around psychoeducation for CYP who have experienced an ABI. Search terms therefore centred on three broad areas; Children and Young People (e.g. "child", "young person" and "CYP"), brain injuries (e.g. "acquired brain injury", "ABI" and "Traumatic Brain Injury", and psychoeducational approaches (e.g. "psychoeducation", "information" and "resource". Books, unpublished works and duplicates were excluded, and remaining search results were screened manually. Literature that related to

adults, non-brain injury presentations, and non-psychoeducational interventions were also excluded. Literature relating to traumatic and non-traumatic ABI was included. An additional description of the search procedure, inclusion and exclusion criteria, and results can be found in Appendix A. This literature review was complemented by a review of existing resources published outside of an academic framework, from which further published resources were identified.

## **1.2. Paediatric Acquired Brain Injury (ABI)**

### **1.2.1. Definition(s) and terminology**

ABI has been defined as neurological damage sustained after a period of typical development (Forsyth & Kirkham, 2012), or alternatively a non-degenerative injury to the brain after birth that is not the result of a developmental or congenital disorder (Appleton, 1998). ABI is therefore an inclusive category referring to neurological damage from a diverse range of injuries (Royal College of Physicians, 2003; British Society of Rehabilitation Medicine, 2003). ABI is widely recognised to be the modal cause of childhood neurological disability (Cassidy et al., 2004; Shah, 2016).

ABI describes an extremely heterogeneous population, which has resulted in a highly fragmented literature base that can be challenging to navigate. In addition to the emergence of aetiology-specific evidence bases, terms such as head injury and traumatic brain injury (TBI) are often used interchangeably in research. For the purposes of inclusivity, the term ABI will be adopted throughout this thesis to refer to both traumatic (e.g. head injury) and non-traumatic (e.g. stroke, meningitis, encephalitis) brain injuries unless it is in the context of a specific piece of research reviewed.

### **1.2.2. Epidemiology**

Despite being acknowledged as the dominant cause of neurological disability amongst CYP, there are few prevalence or epidemiological studies of this population (Anderson & Yeates, 2010; Hawley et al., 2003; World Health Organisation, 2009). This is primarily due to the heterogeneity of conditions that fall under the ABI umbrella, and the fragmentation of the evidence base to understand specific types of ABI (National Institute for Health and Clinical

Excellence, 2007). It is therefore difficult to report accurately on the prevalence of paediatric ABI, however it is estimated that 40,000 children present in emergency departments with a suspected ABI in the UK each year, around 10% of which may be categorised as 'severe' (NHS England, 2013).

More accurate data on prevalence has been reported in the aetiology-specific literature bases. TBI is the most common form of ABI with an estimated incidence rate of 280 cases per 100,000 children (Crowe, Anderson, Catroppa & Babi, 2010; Hawley et al., 2003; Langlois, Rutland-Brown & Thomas, 2006). Research suggests higher TBI incidence rates amongst boys, those from urban and/or deprived areas, and amongst those with pre-existing behavioural and cognitive problems (Colantonio et al., 2011; Parslow et al., 2005; Rivara, 1994; Schwartz et al., 2003). Higher TBI incidence rates have also been observed in two age brackets; those under five and between 15-25 years old (Kraus, Fife & Conroy, 1987; Yates et al., 2006). Non-traumatic brain injuries occur less frequently, but can have an equally devastating impact on an individual's life. In a prevalence study by Chan et al., (2006); substance toxicity (22.7 per 100,000) was found to have the highest incidence rate of non-traumatic ABI's, followed by brain tumour (18.4 per 100,000), meningitis (15.4 per 100,000) anoxia (9.5 per 100,000) and encephalopathy (3.2 per 100,000). ABI as a consequence of stroke during childhood has been estimated to have an incidence rate of 2-3 cases per 100,000 (deVeber, Roach, Reila & Wiznitzer, 2000), brain tumours 5 per 100,000 (Cancer Research UK, 2005), and encephalitis 3 per 100,000 (Johnson, 1996).

### 1.2.3. Severity

Severity of paediatric ABI is typically classified on a three-point scale of mild, moderate or severe, although the methodology for assessing this varies depending on aetiology. Severity of TBI is most commonly assessed using scores on the Paediatric Glasgow Coma Scale (Reilly, Simpson, Sprod & Thomas, 1988), with reference to the length of post-traumatic amnesia and duration of loss of consciousness (Eastvold et al., 2013). Whilst limited data is available on the proportion of the population in each severity classification, it has been estimated that 6% of children who experience a TBI fall within the severe range (Hawley et al., 2003). Whilst some measures of non-traumatic brain injury

exist (e.g. Paediatric National Institute of Health Stroke Scale; Ichord et al., 2011), the modified Rankin scale (mRS; Rankin, 1957) is typically used in clinical practice. The mRS requires a trained clinician to categorise patients on an ordinal scale of 0 (no symptoms) to six (dead), based on their assessment of disability severity and functional ability. It has become the most widely used outcome measure used in clinical practice and research (Sayer et al., 2010), overcoming criticisms of subjectivity through the introduction of structured assessment interviews (Wilson et al., 2002).

#### 1.2.4. Neuropathology and neuropsychology

Until relatively recently, understanding of paediatric ABI was transposed directly from research with adults. Research involving adult participants assumes that the brain is static, and that anatomical structures are modularised and specialised in function (Wabar et al., 2007). Emphasis is therefore placed on mapping cognitive functions against neurological regions through lesion and neuroimaging studies. Whilst these studies remain relevant they neglect to account for the impact of ABI on a dynamically developing brain (Neville, 2006). The purpose of this section is to outline key principles of paediatric neuropsychology in order to provide the foundations for exploring impacts and consequences of paediatric ABI.

##### 1.2.4.1. *Focal and diffuse neurological damage*

ABI may result in focal (i.e. to a specific location) or diffuse (i.e. across a broader region) neurological damage. Focal damage may be the result of trauma from an external force such as a head injury, or stroke caused by internal haemorrhage or ischemia (Bigler et al., 2016). Focal damage typically results in impairment in functions associated with the specific location that is damaged, whereas diffuse damage may be the result of infection or inflammation of brain tissue and the impacts more widespread. Most children who experience an ABI suffer both focal and diffuse neurological damage (Boll, 1983). It is therefore not necessarily helpful to conceptualise the neuropathology of paediatric ABI purely in terms of specific neurological locations that have experienced damage.

#### 1.2.4.2. *Context of the developing brain*

Despite being widely accepted, it was not until relatively recently that research and theory acknowledged that children are born with highly interconnected brains that develop with exposure to stimuli and processing (Meunier, Achard, Morcom & Bullmore, 2009). Children's brains dynamically develop in spurts, becoming increasingly modularised and specialised in functioning over the course of childhood and young adulthood (Evans, 2006). Neurologically this process involves brain growth and increases in synaptic activity, followed by a period of pruning and refinement, finally culminating in the relatively static adult state (Stiles & Jamigan, 2010). Advances in neuroimaging technology have enabled researchers to map developmental milestones in neurological terms. Broadly, research has indicated that the first structures to develop are those in the lower brain stem, followed by regions posterior to the central sulcus, and finally regions anterior to the central sulcus (Anderson, Northam, Hendy & Wrenall, 2014). This has validated much of the work of Luria (1963; 1966; 1973), who hypothesised five phases of neurodevelopment occurring through an interaction between genetic and environmental factors.

This has profound implications for understanding paediatric ABI. Cognitive impacts need to be understood both in terms of the neurological location, and the impact on subsequent neurological development. Chapman (2007) refers to this phenomena as 'neurocognitive stalling', the cascading impact of delayed neurological impairment post-injury. This means that the full impact of ABI during childhood may only be realised later in life and in comparison to peers (Ewing-Cobbs, Barnes & Fletcher, 2011). These impacts often only become apparent during adolescence, a period typically associated with rapid neurological and psychosocial development in which the discrepancy between CYP who have experienced ABI and their peers can widen (Spear, 2014). Developmental trajectories are therefore key to idiosyncratically understanding the full range of impacts of paediatric ABI (Neville, 2006).

#### 1.2.4.3. *Neuroplasticity: protection versus vulnerability*

Neuroplasticity is a broad term that refers to the flexibility of neural development and the brain's ability to remodel its synaptic connections on both a structural and functional level (Macher & Olie, 2009). Evidence for neuroplasticity has been uncovered in both child and adult populations, challenging the view that fully developed brains are static (Mayer et al., 2015). In the context of paediatric ABI, neuroplasticity has historically been viewed as being a protective factor that enables recovery (Kennard, 1938). This view has been challenged by longitudinal research tracking the long-term outcomes of CYP who have experienced an ABI (Anderson, Brown, Newitt & Holie, 2011; Anderson, Spencer-Smith & Wood, 2011; Kennard, 1938; Smith, 1983; Pickard & Stewart, 2007; Vargha-Khadem, Issaacs & Muter, 1994). This has led to many theorising that the developing brain is more vulnerable to damage, particularly during critical periods of neurological development (Giza & Hovda, 2017). Research tracking developmental trajectories of CYP post-injury typically shows initial recovery followed by developmental plateauing, resulting in increasing impairment in comparison to typically developing peers, and it is therefore likely that the truth lies somewhere between these positions (Savage, DePompei, Tyler & Lash, 2005).

### **1.3. *Impacts and consequences of ABI***

ABI can be a life-changing event for many young people, although its impact and consequences vary significantly (Byard, Fine & Reed, 2011). It is important to remember that ABI is an extremely heterogeneous term and therefore individual CYP's difficulties should be understood through idiosyncratic formulation that takes into account injury aetiology, severity, environmental factors and developmental trajectories pre and post injury. The range of possible impacts and consequences CYP and their families may experience after an ABI may be summarised in terms of physical, cognitive, psychosocial and systemic difficulties.

### 1.3.1. *Physical*

Physical disability and/or motor difficulty is often reported as a consequence of paediatric ABI, although severity varies widely. Whilst many young people do not experience physical or motor impairments, others may experience difficulties ranging from poor fine motor skills to full paralysis (Katz-Leurer, Rotem, Keren & Meyer, 2010). Commonly expressed complaints include difficulty with motor planning, gross motor skills such as balance and gait, reduced strength, and co-ordinating bodily movements (Ahlaner, Persson & Emanuelson, 2013; Davis, Moore, Rice & Scott, 2015; Hackman, LaVecchia & Kamen, 2014; Sakzewski et al., 2016). Some young people also experience hypertension, muscle contracture or tremors, whilst others experience frequent or constant headaches and tinnitus after experiencing an ABI (Chathurgangana et al., 2017; Synnot et al., 2017; Winkler & Taylor, 2015). Additional physical impairments may include sensory impairment, epilepsy and non-epileptic seizures, hormonal and movement disorders (Annerggers, Hauser, Coan & Rocca, 1998; Englander, 2014; Kahulik et al., 2017; Killington et al, 2013; Kriel et al., 1994; Matsumoto et al, 2013; Thornhill et al., 2000). High levels of fatigue are reported to be the most frequently observed physical impact of paediatric ABI (Doornsbosch et al., 2016).

### 1.3.2. *Cognitive*

Given the challenges defining the impact of neurological damage in terms of focal damage in the context of the developing brain, it is helpful to use a broader conceptual framework to link neurology and cognitive function at a lobal level. Whilst it is acknowledged that such an approach may be accused of both lacking in specificity, or of being reductionist given the interconnectivity and plasticity of cognitive pathways across lobes, it is argued that this provides a meaningful and accessible framework for summarising the range of impairments that may follow paediatric ABI.

#### 1.3.2.1. *Impairments associated with frontal lobe damage*

The frontal lobes are located at the front of the brain and include a number of major neurological regions including the anterior cingulate cortex, dorsolateral

and ventromedial prefrontal cortex. It is vulnerable to injury due to its relative size and exposed position at the front of the brain, and is susceptible to both coup (injury on the site of impact) and contrecoup (injury on the side opposite the site of impact) damage (Lury & Castili, 2004). These brain regions are associated with higher-order executive functions such as planning, evaluating potential outcomes and consequences, regulation of emotion, impulse control and inhibition as well as mentalisation, reasoning and problem-solving abilities (Baddeley, 1996; Elliott, 2003; Stuss & Benson, 1986). The left and right hemispheres of the frontal lobe are associated with specialised functions involving language and memory abilities respectively (Ellis & Freeman, 2008; Neulinger et al., 2016). Furthermore, the frontal lobes are implicated in arousal, motivation, social cognition and personality (Rowe, Bulluck, Polkey & Morris, 2001). Consequentially, damage to the frontal lobes can result in dysexecutive functioning, impulsivity, emotional instability, poor decision making, reduced cognitive flexibility, and theory of mind difficulties (Denmark et al., 2017; Funahashi, 2001; Schneider & Koenigs, 2017; Zai-Ting et al., 2017). It may also result in personality change, increases in risk taking behaviour, and reduced affect (Floden et al., 2008; Gaines & Spencer, 2018).

#### 1.3.2.2. *Impairments associated with parietal lobe damage*

The parietal lobes are bi-laterally positioned anterior to the frontal lobes and are associated with two key functions. The first involves the integration and processing of incoming sensory information to transform this into perception (cognition), whilst the second involves the formation of a representative system of spatial orientation (Gorman et al., 2012). Damage to the left parietal lobe is associated with language and mathematics difficulties, agnosia, and right-left confusion (Hjelmervik & Hausmann, 2015; Wendelken, 2015), as well as verbal memory abilities (Warrington & Weiskrantz, 1977). Damage to the right parietal lobe is associated with hemispheric neglect, apraxia, and awareness of one's own impairments (Joao, Filgueiras, Mussi & de Barros, 2017), as well as non-verbal memory (Warrington & Weiskrantz, 1977). Damage to the parietal lobes can therefore cause specific difficulties in these domains, in addition to difficulties with

spatial awareness, construction, body image, and dyspraxia (Fuelscher et al., 2018; Kandal, Schwatz & Jessel, 1991).

#### *1.3.2.3. Impairments associated with temporal lobe damage*

The temporal lobes are located bi-laterally anterior and inferior to the frontal lobe and parietal lobes. Damage to the temporal lobes is highly associated with impairment in attention and working memory difficulties (Catroppa et al., 2007; 2014), with the severity of this being mediated by processing speed difficulties (Babikian & Assarnow, 2009; Gorman et al., 2007). Damage to the temporal lobe is also associated with other forms of memory difficulty such as declarative, retrospective and prospective memory abilities (Catroppa & Anderson, 2002; Edrodi & Bigler, 2010; Ellis & Freeman, 2008; Lajiness-O'Neill; Rous, 2011; Squire, 1994). Left hemispheric damage is more associated with verbal memory difficulties, whilst right hemispheric damage with non-verbal memory. Temporal lobe damage is also associated with language comprehension and speech production. Whilst aphasia is relatively uncommon, many children experience difficulties with lexical comprehension and speech production (Alyahya & Ralph, 2018). More subtle difficulties with non-literal and advanced use of language, such as understanding of metaphor and drawing inferences are more commonly experienced (Dennis et al., 2001; Dennis, Barnes, Wilkinson & Humphries, 1998). Other challenges associated with temporal lobe damage include emotional and facial recognition difficulties and paranoia (Monti & Meltti, 2015; Thorsness & Nelson, 2015).

#### *1.3.2.4. Impairments associated with occipital lobe damage*

The occipital lobe is located at the posterior of the cortex and, alike the frontal lobe, is vulnerable to injury given its exposed position. The occipital lobe is primarily associated with perceptive abilities and houses the primary visual cortex. Damage to the occipital lobe can result in a range of altered visual experiences including difficulty discriminating movement, or with colour discrimination (Mundinano et al., 2017). At the most severe end of the spectrum, damage to the occipital lobe may result in cortical blindness, however more subtle changes to perceptual systems are more frequently reported following

paediatric ABI (Tirado, Jimenez-Rolondo & Bermejo, 2017). Damage to the occipital lobe may also cause difficulties including hallucinations and distorted visual experiences, or blindness to specific forms of stimuli (Appel et al., 2015).

### 1.3.3. Behavioural and neurodevelopmental impacts

In the context of the range of cognitive impairments that may be experienced following ABI, and given that all behaviour may be considered as functional, behavioural difficulties post-injury may not be unanticipated (Taylor et al., 2017). For example; should a child experience an ABI which results in difficulties in expressive communication, problem solving and impulse control, then it may be unsurprising that they engage in behaviour that challenges in an attempt to get their needs met by a caregiver (Gresham et al., 2004). Research has indicated that CYP who experience ABI are more likely to show behavioural changes post-injury including showing aggression, non-compliance with caregivers, heightened irritability (Andrews, Rose & Johnson, 1998; Cole et al., 2008), poor self-regulation (Ganasalignham, Sanson, Anderson & Yeates, 2006), and inappropriate behaviour in social settings (Rutter, Chadwick & Shaffer, 1983; Rosema, Crowe & Anderson, 2012). Schwatz et al., (2003) estimates that as many as 36% of CYP who have experienced a severe TBI, and 22% of those with moderate, engage in behaviour that challenges. Nevertheless, injury severity is a poor predictor of behavioural difficulties (Catroppe et al., 2012), although there is some evidence that behavioural difficulties are more prevalent in those with traumatic rather than non-traumatic ABI (Poggi et al., 2005). It is estimated that the incidence rate of behavioural disorders amongst CYP who have experienced an ABI is between 35% and 70% (Max et al., 1997).

Increased prevalence rates of neurodevelopmental disorders, such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorders (ASD), have been observed amongst CYP who have experienced an ABI (Compton et al., 2017; Rutter, Chadwick, Shaffer & Brown, 1980). It may however be argued that this is a product of a lack of diagnostic validity, as there is significant overlap between the criteria for neurodevelopmental disorders and the neurocognitive impacts of ABI (Silberman, 2015).

#### 1.3.4. Psychosocial impacts

ABI can have a profound impact on children's wellbeing, sense of self and identity (Myles, 2004; Rittman et al., 2007; Wilson et al., 2015), regardless of injury severity (Limmond, Dorris & McMillan, 2010). Transitioning from being healthy to suddenly disabled with associated loss of abilities is likely to result in feelings of frustration, aggression or depression as CYP begin discovering the impacts of their injury (Hart et al., 2017). Having to spend time away from home, school and friends during hospital admission, or whilst attending neurorehabilitation services, can be difficult for many young children (Heary et al., 2003). Even returning to typical daily routines and friendship groups after a period of absence can be anxiety-provoking for many young people (Catroppa et al., 2015). For many CYP, the circumstances around their ABI may be experienced as traumatic, particularly if it occurred as a result of an accident, or was sudden and unexpected. (Middleton, 2001). In some cases the circumstances around their ABI may have involved others being hurt or killed, and feelings of guilt and grief may be experienced (Jordan & Linden, 2013). Given this context, it may be unsurprising that CYP who have experienced an ABI often present with a range of psychosocial difficulties including low self-esteem, social rejection, and poor emotional wellbeing (Carrol & Coetzer, 2011; Hawley, 2012; Mealings & Douglas, 2010). This is reflected in research identifying increased prevalence of mental health difficulties amongst CYP who have experienced an ABI (Ylvisaker et al., 2007).

#### 1.3.5. Systemic impacts

Paediatric ABI can also have a profound impact on the multiple systems in which children exist (Brown, Whittingham, Boyd & McKinlay, 2015). ABI is associated with increased parental stress, social isolation, loss of income and psychological distress (Cole, Paulos, Cole & Tankard, 2009; Gan et al., 2006; Wade, Wolfe, Brown & Pestian, 2005). This is reflected in research observing clinically significant levels of stress in 40-45% of parents of CYP who had experienced an ABI (Wade et al., 1996). Whilst familial and social support has been found to be associated with decreased parental stress, research has identified that many families experience the diminishment of these relationships following their child's

ABI (Gill et al., 2011). It is also important to acknowledge the impact of ABI on siblings, particularly as research indicates that they report being required to take on increased responsibility, and a sense of parental neglect (Butera-Prinzi & Perlez, 2004; Gill & Wells, 2000). Furthermore, increased rates of behavioural and emotional difficulties have also been identified amongst siblings of ABI survivors (Li & Liu, 2013).

#### **1.4. Neurorehabilitation**

##### **1.4.1. Definition(s)**

Given the wide ranging impacts and consequences that evolve over time in line with developmental trajectories, it is important that CYP who have experienced an ABI are offered a package of support that meets their varied needs (Falk, 2007; Greenspan & MacKenzie, 2000). Neurorehabilitation refers to the interdisciplinary process of holistically meeting the needs of CYP who have experienced an ABI (Dietz & Ward, 2015). It is described as a goal-based process that seeks to reduce the impact of neurological damage on everyday life (NHS England, 2013). However, research has indicated that only a small proportion of children receive appropriate neurorehabilitation services (Emanuelson & von Welt; Javouhey et al., 2006), particularly for those with the most complex familial circumstances (Slomine et al., 2006).

There are a number of key policy drivers for the provision of Neurorehabilitation services in the UK<sup>1</sup>. These policies typically recommend that integrated interdisciplinary care begins as soon as possible after a brain injury. This process begins when a child or young person attends an emergency department, or is seen within neurology, neurosurgery or specialist paediatric services immediately after experiencing an ABI. Following assessment and depending on injury severity, CYP may be referred on to either a specialist inpatient or outpatient neurorehabilitation team for ongoing support and intervention (NHS England, 2013).

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<sup>1</sup> See NHS England (2013) for a full review of neurorehabilitation policy drivers in the UK.

#### 1.4.2. Key components of neurorehabilitation

Whilst approaches to neurorehabilitation for adults who have experienced an ABI have been described and evaluated (e.g. Heinemann, 2007), few models of care have been reported for paediatric populations. Those that have been reported (e.g. Braga et al., 2005; Chavignard et al., 2009; Gregg & Appleton, 1999; McDougall et al., 2006) share commonalities in structure (i.e. beginning in acute care before transfer to community services), delivery (i.e. from a multi-disciplinary and inter-agency team), and content (i.e. incorporating physical, cognitive and psycho-social intervention) Approaches to neurorehabilitation may be said to share the common aims of understanding and managing behaviour, and facilitating participation and empowerment through advocacy and consultancy (Hibbard, Layman & Stewart, 2011).

In developing an instrument to quantitatively assess the neurorehabilitation needs of CYP who have experienced an ABI, Forsyth et al., (2017) identified five key ingredients of effective neurorehabilitation. The first of these involves the management of body structure and function, which can broadly be understood as the meeting of physical needs, and the second involves skill acquisition, which can broadly be understood as the meeting of cognitive needs. The third and fourth ingredients involve emotional health support and adaptation, which can broadly be understood as the meeting of psychosocial needs. The fifth key ingredient involves knowledge acquisition, and is concerned with meeting the informational needs of CYP who have experienced an ABI and their families. The purpose of this section is to summarise neurorehabilitation practices in these domains.

##### 1.4.2.1. *Meeting physical needs*

Teams of physicians, physiotherapists, occupational therapists and clinical nurse specialists typically coordinate interventions aimed at meeting the physical needs of CYP following ABI. Whilst a full review of physical interventions is beyond the scope of this paper, a significant body of evidence has established efficacy in improving a range of outcomes including improved balance and gait, motor skills, strength and muscle tone (Baque, Sakzewski, Barber & Boyd, 2016; Tatla et al.,

2012), as well as for managing associated conditions such as sensory impairments and epilepsy (Karin, Behr & Rask-Anderson, 2017). The ultimate aim of these approaches is to promote participation.

#### 1.4.2.2. *Meeting cognitive needs*

Cognitive rehabilitation has been defined as interventions that are designed to compensate or ameliorate the impact of cognitive difficulties following brain injury (Ylvisaker et al., 2008). Whilst a full review of approaches to cognitive rehabilitation is beyond the scope of this paper<sup>2</sup>, a significant body of evidence has established efficacy in the domains of attention and working memory (Butler et al., 2008; van Hooft et al., 2005), memory (Franzen et al., 1996; Wilson et al., 2001), spatial neglect (Chevignard et al., 2008), speech and language (Morgan & Skeat, 2011), and executive functioning (Feeney & Ylvisaker, 2003; 2006).

#### 1.4.2.3. *Meeting psychosocial needs*

Interventions aimed at meeting the psychosocial needs of CYP following ABI are diverse and may be targeted at the level of the individual, family or wider system. Parenting programmes, such as Triple P and Stepping Stones (Brown et al., 2014) are amongst the most evidenced approaches, as are computerised cognitive-behavioural approaches for both parent and child (Wade et al., 2005; 2006). Research has also demonstrated that targeted interventions to enable CYP to engage in social interaction can be helpful in facilitating reintegration into mainstream schools, which is presumed to improve psychological wellbeing (Wiseman-Hakes, MacDonald & Keightley, 2010).

Psychologists working in paediatric neurorehabilitation services often also work directly with CYP who have experienced an ABI and who are experiencing emotional distress. Psychological interventions are informed by idiosyncratic formulation and may be framed within a range of therapeutic modalities such as cognitive-behavioural, systemic, and narrative frameworks. The aims of

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<sup>2</sup> For a full review of the evidence base for cognitive rehabilitation following paediatric ABI, please refer to systematic reviews conducted by Laatsch et al., (2007), Limond and Leeke (2005) and Slomine and Locascio (2009).

psychosocial interventions are often to facilitate gains in a range of areas known to be mediators of psychological wellbeing amongst CYP who have experienced an ABI such as empowerment, positive identity, and participation (Di Battista et al., 2014; Yeates & Taylor, 2005).

#### **1.4.2.4. Meeting informational needs**

Information has been identified as a key need for CYP following ABI (Sweeney, Vilner, Booy & Christie, 2013), however little research has centred on the fifth key ingredient of neurorehabilitation described by Forsyth et al., (2017) – knowledge acquisition. This is despite contemporary western healthcare emphasising the importance of self-management (Donker, Griffiths, Cuijpers & Christensen, 2009; Ocloo & Matthews, 2016; Tritter, 2009; Wait & Nolte, 2006), and best practice guidelines making clear the need for information to be provided to CYP about their conditions (Kirkwood et al., 2008; NICE, 2014).

Providing information to CYP who have experienced an ABI and their families is likely to be of particular interest as an understanding of one's condition has been identified as a mediating factor in the efficacy of physical, cognitive and psychosocial neurorehabilitation (Danzi, Etter, Andretta & Kitzman, 2012). One possible explanation for this is that an understanding of one's difficulties and of the recovery journey increases engagement in the neurorehabilitation process (Bains, Powell & Lorenc, 2007; Cunningham, 2009). Information is therefore a key need for CYP and their families following an ABI (Murray, Maslany & Jeffery, 2006). Meeting the information needs of CYP who have experienced an ABI is therefore an area worthy of further exploration.

#### **1.5. Review of existing Informational resources**

The purpose of this section is to provide an overview of the existing resources available to CYP who have experienced an ABI and their families. This has been based on a review of the academic literature (see section 1.2), which has been complemented by a less formalised review of published resources and packages available online and in print.

### 1.5.1. Informational resources for parents, guardians and teachers

The majority of informational resources currently available regarding paediatric ABI are targeted at parents, carers, guardians and teachers (Roos et al., 2015). These have primarily been developed by clinicians working in third sector organisations, made available online or in print, and have not been formally evaluated in the academic literature. One such resource is the Brain Injury Hub (The Children's Trust, 2018), an online web resource that provides information about ABI for families, carers and teachers. This provides information regarding ABI and its effects, neurorehabilitation and the recovery journey, negotiating transitions between settings and towards adulthood, and practical advice for carers. Whilst the majority of content on the Brain Injury Hub has been written by clinicians, the website also contains a forum where parents and carers can share information. Furthermore; The Child Brain Injury Trust (CBIT, 2018) provide a series of web-based e-learning sessions aimed at understanding the ABI and the range of impacts it can have on the cognitive abilities of CYP. This is complemented by a series of factsheets relating to specific potential areas of difficulty CYP may encounter during their recovery such as feeling sad, worry and anxiety, self-care, sleep difficulties, and transitions. Whilst these informational resources are presumed to be valuable, they have not been extensively evaluated.

A review of the academic literature identified only one evaluated informational resource for parents of, and teachers working with, CYP who have experienced an ABI. The 'Heads Up' informational package for mild TBI (Centers for Disease Control and Prevention, 2010a, 2010b) is a preventative programme aimed at preventing concussion symptoms amongst student athletes. The package provides multimedia resources complemented by an online training course, seeking to enable quick identification of concussion injuries. Evaluation indicated improvements in sports coaches' and parents' knowledge, attitudes and practices towards the prevention and management of concussion symptoms in a mixed-methods evaluation study (Sarmiento, Mitchko, Klein & Wong, 2010). Whilst a number of further parental resources provide information around ABI, these are in the context of a wider discussion around meeting the needs of CYP with

developmental delay and therefore lack specificity. An example of this is the Nurturing Programme (Burton et al., 2017), a twelve session informational curriculum delivered to parents that provides information on how to manage behavioural concerns. The scarcity of evidence is highlighted in Roos et al's (2015) critical examination of TBI management literature distributed to parents. This review identified confusion in the diverse terminologies to describe ABI (Coghlin, Myles & Howitt, 2009), and in the differential manner in which information frames the probability of full recovery (Tavender et al., 2011).

#### 1.5.2. Informational resources for CYP

Whilst resources developed for adult audiences may be shared with CYP who have experienced an ABI, they are often not made available, understood or able to meet their informational needs (Falk, von Wendt & Soderkvist, 2009; Grootens-Wiegers et al., 2015). Despite this, research has indicated that CYP who have experienced an ABI are often able to comprehend medical concepts (Redding, 1993) and express a wish to be informed (Baker et al., 2013), highlighting the necessity for resources to be developed specifically for CYP.

The majority of informational resources have been developed by clinicians working in third sector organisations, and have not been formally evaluated in the academic literature. These primarily take the form of physical resources such as illustrated books and comics, and tell the story of characters who experience a specific form of ABI, and use literary techniques to demonstrate physical and cognitive difficulties that are commonly experienced subsequently. Examples include 'Gilley the Giraffe... Who changed' (Channa, 2006), which tells the story of a character who experienced an ABI after contracting encephalitis, 'Hands up for Andie' (Palmer, 1998), which tells the story of an eight year old with hemiplegia, and 'Benny the bear' (Batchelor & Mayer-Hall, 2005), which tells the story of a character with hydrocephalus. Other resources use metaphorical techniques to communicate the potential impacts of ABI to help CYP understand the symptoms they are experiencing. Examples of this include 'Heads up, Tim Tron' (Ray & Parsons, 2013), which uses a mechanical circuit metaphor to explore neurocognitive impacts, and 'Medikidz', which uses a planet metaphor to describe the physical impacts of ABI (Chilman-Blair, 2014). Whilst these

resources can be extremely valuable, they are primarily targeted at younger audiences (between five to eleven years) and do not attempt to communicate more complex and nuanced aspects of ABI such as neurocognitive stalling and neuroplasticity. Informational resources for adolescents are closer in content to that provided to adults, for example 'Me and my brain' (The Children's Trust, 2018), a handbook summarising the range of possible impacts of ABI. Resources such as 'Horrible science: Bulging brains' (Arnold, 2008), which have been designed as educational resources for CYP, may also have utility in helping explain ABI, although this is not their primary function. CYP are increasingly technologically aware, which has led to the development of interactive resources available online such as peer-to-peer forums (e.g. Brain Injury Network, 2018). Furthermore; the consensus around the importance of learning from the experiences of CYP has led to the collaborative development of leaflets and videos, in which CYP who have experienced an ABI share their personal experiences, such as 'As easy as ABI' (The Encephalitis Society, 2018) and 'Hot topics for young people' (CBIT, 2018).

A review of the academic literature identified a limited number of informational resources relating to ABI that have been developed for CYP and evaluated for their efficacy in improving knowledge. Two of the identified studies discuss a preventative informational video targeted at athletes in the United States of America who are considered at risk of concussion. These found that the presentation of a video resource improved knowledge and attitudes towards the symptoms and signs of concussion (Cuisimano, Chiman, Donnelly & Hutchinson; 2014; Hunt, 2015). A third study built on these findings with the creation of the Sports Legacy Initiative Community Educators (SLICE) curriculum comprising of a multifaceted educational programme, which was found to facilitate knowledge around concussion amongst student athletes at risk of injury (Bagley et al., 2012). Whilst these resources have proven preventative value, they are less relevant for CYP who have already experienced an ABI, particularly those with enduring symptoms caused by injuries of greater severity.

Nevertheless a small number of informational resources for CYP who have experienced an ABI have been described in the academic literature. Ponsford et

al., (2001) describe and evaluate an informational booklet distributed to CYP within a week of experiencing mild-TBI. This resource summarises possible symptoms of TBI, and suggests coping strategies that may be helpful for managing these. In a pre-post intervention experimental design, CYP who were provided with the booklet reported fewer unmanageable symptoms and reduced stress levels relating to their TBI compared to those who were not. It was however noted that CYP who had previously incurred a head injury, or had a history of learning or behavioural difficulties, reported ongoing difficulties, suggesting that this resource may not be appropriate for those with enduring difficulties.

Olsson et al., (2015) describe and evaluate the efficacy of an informational resource in reducing post-concussion symptoms (PCS) and psychosocial difficulties in children who had experienced a mild ABI. This resource, which was developed collaboratively with a group of CYP who had experienced PCS, comprised of a website and booklet that provided information about common emotional reactions to PCS. In an experimental design, CYP were randomly allocated to either a group that were provided with the resources or to continue to usual care. Whilst no differences were observed between the groups on a measures of PCS symptomology nor health-related quality of life, the studies small sample size and methodological issues such as the absence of baseline measures of participant knowledge may have contributed to reduced effect sizes.

Renaud et al. (2016) describe the 'Brains ahead' programme, which seeks to provide symptom management information to CYP aged six to eighteen who have experienced a mild TBI during the first two weeks of injury occurrence. This program involves a clinician verbally providing information first in person and later by telephone, and is complemented by three informational booklets varying in terms of the age group they are designed for. Evaluation of the 'Brains ahead' programme is currently ongoing via a randomised controlled trial, however is similar to the aforementioned resources in that it may not be as helpful for CYP who have experienced ABI of moderate and severe resulting in enduring difficulties.

Only one further article was identified in the review of the literature although this was neither available in print nor online as the relevant journal ceased publication. A brief synopsis however describes this resource explaining brain injury to CYP as “a bruise to the brain” (Hendrickson & Becker, 1996).

## **1.6. *Psychoeducation***

The purpose of this section of the report is to outline the potential of psychoeducation as a mechanism for meeting the outstanding informational needs of CYP who have experienced an ABI.

### **1.6.1. Definition(s)**

Psychoeducation is a therapeutic approach seeking to convey theoretically grounded information regarding their area of concern in the aim of providing individuals with the tools to regain control of their lives (Goldman, 1988; Vermuelen, 2013). The term originates in the development of psychoeducational clinics in the US from which the Educational Psychology profession evolved (Smith, 1914; Wallin, 1914; Witty & Theman, 1934). As attitudes in healthcare moved progressively towards patient involvement in their care, modern conceptualisations of psychoeducation as a means of explaining the symptoms and processes of health conditions emerged (Anderson, Hogarty & Reiss, 1980). Psychoeducation differs from purely informational resources due to its integration of therapeutic and educational material, and its aim of improving individual’s health-related quality of life (Solomon, 1996). Cummings and Cummings (2008) define psychoeducation as a health psychology comprising of four components; treatment of the condition, management of the condition, compliance with medical or psychological regime, and prevention of progression or deterioration.

Today, psychoeducation refers to a diverse range of approaches, which are typically delivered by health and social care professionals, with content varying depending on contemporary research and theory within specialities. It may be delivered in a range of formats (e.g. individual and group) and modalities (e.g. in person, on paper, via books, video, online or through interactive media).

Psychoeducation may be targeted either directly to patients themselves, or to parents, teachers or other professional audiences. Peer-to-peer sharing of

information and resources may also be considered as a psychoeducational approach, particularly if facilitated by professionals (Dixon et al., 2001).

Psychoeducation is recommended as a first line intervention in clinical guidelines for a range of physical and mental health conditions, and has become an integral component of a variety of psychotherapeutic interventions such as cognitive-behavioural therapy (CBT; Beck, 2011) and acceptance and commitment therapy (ACT; Hayes et al., 1999).

#### 1.6.2. Benefits of psychoeducation

Despite being under-researched in the context of ABI, psychoeducational approaches have been shown to be efficacious in improving children's knowledge, attitudes and ability to self-manage in the context of neurodevelopmental, mental and physical health conditions (Bilxen et al., 2016; Nussey, Pistrang & Murphy, 2013). When delivered directly to CYP; psychoeducation has been found to be effective in increasing knowledge and mastery over one's condition, in addition to a reduced sense of fear and anxiety related to their diagnosis and treatment (Gordon et al., 2014; Shahmansouri et al., 2013). Psychoeducation has been found to support the development of positive identity and foster a sense of community (Im et al., 2017), resulting in subsequent increases in quality of life and emotional wellbeing (Kohrt, Jordans, Koirala & Worthman, 2015; Lucksted et al., 2012). Psychoeducation delivered to parents and carers has also been found to increase knowledge of health conditions, as well as increasing understanding of and ability to manage behavioural difficulties (Ferrin et al., 2013). Psychoeducation for parents is also associated with reduced parental stress, and often leads to increases in social support (Lau, Rapee & Coplan, 2017).

Psychoeducation has also been reported to increase gains in other interventions that CYP may be undergoing related to their conditions (Martinez et al., 2017). This is consistent with the view that the provision of information increases engagement in the recovery process, which is associated with positive outcomes (Cunningham, 2009). Psychoeducation may therefore be considered integral to the neurorehabilitation process for CYP who have experienced an ABI.

### 1.6.3. What makes psychoeducation effective for CYP?

Whilst there is a wealth of evidence as to the potential benefits of psychoeducation, little research has been conducted on understanding the mechanisms that make psychoeducation effective for CYP (Modaresi & Moradi, 2016). It may however be argued that effective psychoeducation sustains a pedagogical position that enables the acquisition of knowledge, and is pitched at a developmentally appropriate level. It may also be argued that effective psychoeducation should accessibly provide information consistent with contemporary research and theory, as well as be underpinned by an established therapeutic mechanism to facilitate psychosocial benefits.

#### 1.6.3.1. *Pedagogy*

There are differing perspectives on how best to provide information to CYP, however it has been argued that effective teachers plan and implement appropriate pedagogy (McLaren, 2015). Pedagogy refers to the interactions between teachers, students, the learning environment and the learning tasks (Murphy, 2008). Whilst there are a wide range of pedagogical approaches<sup>3</sup>, these may be conceptualised as being on a spectrum from teacher-centred to learning-centred approaches (Waring & Evans, 2015).

Teacher-centred pedagogy places emphasis on the teacher's role in the learning process. It is assumed that as the teacher commands greater expertise than the learner, they are best placed to determine content and structure (Hancock, Bray & Nason, 2003). In such approaches the teacher provides knowledge to the learner through techniques such as lectures and rote learning (Cicchelli, 1983). Adopting a teacher-centred pedagogy in psychoeducation may therefore involve didactic information giving from health professionals, or resources made purely by those in expert positions. Teacher-centred approaches are criticised for neglecting experiential aspects of knowledge acquisition (e.g. Masculo, 2009; Westbrook et al., 2013). Conversely; learning-centred pedagogy draws on constructivist developmental theories suggesting that learners need to be active

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<sup>3</sup> For a full review of pedagogical approaches, please refer to Waring and Evans (2015)

participants in the learning process (e.g. DeVries & Kohlberg, 1997; Piaget, 1973; Vygotsky, 1987). In such approaches, teachers take on the role of a facilitator to enable the learner to use their existing knowledge and new experiences to develop their own knowledge (Hancock, Bray & Nelcon, 2003). Adopting a learning-centred pedagogy in psychoeducation may therefore involve collaboration between teacher and learner in exploratory discovery.

It has however been argued that neither of these pedagogical approaches are alone sufficient, and that a more integrated learner-centred pedagogical approach would be more helpful (O'Sullivan, 2004). Learner-centred pedagogy may be understood as guided participation (Rogoff, 1990). Learner-centred approaches combine the exploratory and active participatory element of learning-centred approaches, with the expertise of teacher-centred approaches (Mascalo, 2009). Adopting a learner-centred pedagogy in psychoeducation may therefore involve collaboration between teacher and learner in the creation of knowledge.

#### *1.6.3.2. Developmentally appropriate*

CYP and adults have different informational needs (Turkstra et al., 2016), and therefore information should be tailored to a developmentally appropriate level suitable for intended recipients (Gagnon, Swaine, Champagne & Lefebvre, 2008; Falk, von Wendt & Klang, 2008). For example; factors influencing children's comprehension, retention and ability to flexibly employ information include readability, length, concreteness, layout and visual supports (Kass et al., 2011; Mayer & Moreno, 2003; Tait et al., 2007). It has been suggested that utilising children's preferred technologies and an interactive element also facilitate CYPs ability to understand and use psychoeducational resources (Ann, McCall, Hee & Kim, 2015). Psychoeducational resources may either be made developmentally appropriate by tailoring the content, or by entrusting an agent (i.e. a parent, teacher or health professional) to deliver it in an understandable way. Whilst tailoring the content may be considered preferable it presents a challenge for the mass production of psychoeducational resources, however entrusting an agent to facilitate access may detract from the self-discovery element of learner-centred pedagogy and the ability of CYP to independently access resources.

It is helpful to draw on theories of cognitive and social development to ensure that psychoeducational resources are pitched at an appropriate level for individual's needs. Piaget's (1936) theory of cognitive development posits the CYP develop cognitive abilities in four phases through processes of assimilation and accommodation. It is hypothesised that between birth and two years of age children are at the sensorimotor stage, in which object permanence and the ability to form mental representations of the world. This is followed by the pre (two to seven years) and concrete (seven to eleven years) operational stages in which children develop symbolic thinking and logical thought abilities. Finally, children are thought to enter the formal operational stage where they develop abstract thinking abilities and begin to test hypotheses about the world. Whilst this may be a useful framework to consider, it is important to note that most theorists view development as continual rather than in stages (Keating, 1979), and age is a poor predictor of ability amongst children who have experienced an ABI (Gordon, 2014). It may also be helpful to draw Vygotsky's (1934; 1978) works, which highlights the role of interaction and sociocultural context in cognitive development. Vygotsky argues that optimum learning occurs in the 'zone of proximal development', which falls between the known and the unknown where CYP require guidance and encouragement to understand new information, concepts and skills. Finally, consideration should be given to the wider context of psychosocial development, and therefore Erikson's (1950; 1963) stage theory, is likely to be highly relevant. In the context of psychoeducation for CYP the stages of industry versus inferiority, in which a sense of competence in one's own abilities is the desired end product, and identity versus role confusion, in which a sense of self is sought, are likely to be particularly relevant. This is because the theorised ages at which these stages of development occur encompass childhood and adolescence.

#### 1.6.3.3. *Theoretically grounded*

Whilst it is important to acknowledge the fallacy that theory is equivalent to fact, it is important that psychoeducation conveys theoretically grounded information that is consistent with contemporary research. This is particularly true in the modern era in which vast quantities of information is available online with varying

degrees of accuracy and vested interests (LaValley, Kiviniemi & Gage-Bouchard, 2017). In the context of this thesis, neuropsychological research and theory is likely to be of particular relevance.

#### 1.6.3.4. *Therapeutically meaningful*

Whilst psychoeducation may be considered a therapeutic approach in its own right, it is often set within a wider framework when working with mental health, neurodevelopmental and neuropsychological presentations. Psychoeducational resources may be rooted within the behaviourist (Bandura, 1976; Skinner, 1971; Watson, 1913) or cognitive-behavioural framework (Beck, 2011). These approaches typically seek to support parents to use information about conditions to understand, manage and change behaviour to establish healthier patterns of being, such as the ASCEND programme for children with a diagnosis of an autism spectrum disorder (Pillay et al., 2010). Other psychoeducational approaches have incorporated principles from third-wave behavioural approaches (e.g. ACT; Hayes et al., 1999). An example of this is comes from Brown et al., (2015) who incorporated the principles of accepting one's circumstance and committing to values-driven behaviour into the Triple P programme for parents of children with a diagnosis of ADHD.

The narrative framework (White & Epstein, 1990) may represent an alternative approach for a psychoeducational resource. This approach exemplifies an ideological shift towards a post-modernist social constructionist epistemology, in which 'problems' are viewed as a construct of social processes rather than located within individuals (White, 2007). The narrative framework theorises that psychosocial difficulties are the result of the dominant discourses around a person being problem-saturated, and the strengths-based stories of strength and resilience being subjugated (Payne 2000). Narrative approaches therefore seek to explore subjugated narratives to enable change within systems and contexts (Kurri, 2015). Externalisation-based approaches have been shown to reduce distress in children experiencing psychological distress arising from neurodevelopmental, mental and physical health difficulties (Ullman, 2016). Narrative approaches in general have been shown to be helpful in supporting CYP with issues around identity and adjustment, particularly after they have

experienced significant or traumatic life events (Segal, 2018). Narrative approaches may be of particular relevance given the consistency between this and the psychosocial impacts associated with paediatric ABI (Perkins, 2015).

### **1.7. Project rationale**

Paediatric ABI is associated with a wide ranging of physical, cognitive and psychosocial difficulties (Byard, Fine & Reed, 2011). Whilst comprehensive neurorehabilitation approaches have been developed to meet CYP's physical, cognitive and psychosocial needs (Forsyth et al., 2017), the informational needs of CYP and their families are often not met (Murray, Maslany & Jeffery, 2006). This is despite the provision of information being emphasised in best practice guidelines (Kirkwood et al., 2008; NICE, 2014), particularly given that this is a mediating factor in the efficacy of physical, cognitive and psychosocial neurorehabilitation (Danzi, Etter, Andretta & Kitzman, 2012).

Existing informational resources are primarily aimed at parents, carers and teachers (Roos et al., 2015). Whilst these may be made available to CYP who have experienced an ABI they are often not made available, understood or able to meet their informational needs (Falk, von Wendt and Soderkvist, 2009; Grootens-Wiegers et al., 2015). Whilst there are some resources developed specifically for CYP who have experienced an ABI, they tend to be purely informational, targeted at those with milder forms of ABI, or have not been formally evaluated.

Psychoeducation, a therapeutic approach seeking to convey theoretically grounded information with the aim of providing individuals with the tools to regain control of their lives (Goldman, 1988; Vermuelen, 2013), has been shown to be effective in increasing knowledge and achieving a wide range of psychosocial outcomes amongst those with a variety of physical and mental health difficulties (Bilxen et al., 2016; Nussey, Pistrang & Murphy, 2013). Given the potential benefits of psychoeducation and the limitations of the currently available resources, it is argued that there is scope for the development of a new psychoeducational resource to meet the informational needs of CYP and support their neurorehabilitation.

Whilst the mechanisms underpinning effective psychoeducation are under-researched (Modaresi & Moradi, 2016), it is argued that effective psychoeducation is grounded in contemporary neuropsychological research and theory, is delivered in a developmentally appropriate way consistent with a learner-centred pedagogy (Mascalo, 2009). Furthermore; it is argued that effective psychoeducation is grounded in a therapeutic framework, and that the narrative framework is most appropriate due to its benefits in addressing the psychosocial needs of CYP who have experienced an ABI (Perkins, 2015; Segal, 2018; White & Epstein, 1990). It is also argued that collaborating with CYP in resource development is likely to help ensure that it meets their informational needs. The purpose of this thesis is therefore to draw on the theoretical and research evidence base and the views of CYP who have experienced an ABI to collaboratively develop a new psychoeducational resource that meets their informational needs.

### **1.8. Research questions**

Four research questions are therefore proposed;

1. How could a new psychoeducational resource help address the informational needs of CYP who have experienced an ABI?
2. What do CYP who have experienced an ABI think is important in a new psychoeducational resource?
3. How can the views of CYP who have experienced an ABI be integrated with the existing theoretical and empirical literature to develop a new psychoeducational resource?
4. What do the views of CYP who have experienced an ABI tell us about the acceptability of a newly developed psychoeducational resource?

## **2. Methodology**

This chapter provides a philosophical and theoretical explanation for the epistemological positioning of the study, including its relevance for the chosen mixed-methods approach. This is followed by an overview of how the three methods that are integrated in this thesis; the researcher's knowledge and theory derived from a review of the literature (i.e. a 'top-down' approach), and both qualitative and quantitative data collected via interviews and a feedback form from CYP who have experienced an ABI (i.e. a 'bottom-up' approach), in a four-phased research process. Details of the service context, recruitment, data collection and analytic processes are described. Consideration is given to how key ethical issues inherent within the research process have been addressed.

### **2.1. *Ontological and epistemological position***

Epistemology, referring to the theory of knowledge, seeks to address the question of "how, and what, can we know?" (Willig, 2013). In the context of research, epistemological positions provide parameters for the claims about reality that can be made from data (Scotland, 2012). It is particularly important for researchers collecting qualitative data to state the adopted epistemological position to allow claims made to be evaluated (Harper, 2011).

This thesis adopts a pragmatist epistemology (Dewey, 1958). Pragmatism questions the utility of debates around the relative benefits of the apparently opposing realist/positivist and subjectivist/constructivist ontological and epistemological positions (Cresswell & Plano-Clark, 2007), on the basis that these positions are not as opposite as they first appear as both seek to uncover 'the truth', whether objective or relative (Dewey, 1925; Hanson, 2008). Pragmatists believe that 'reality' is in a constantly renegotiated perpetual state of flux, and research is therefore no different to forms of inquiry used in daily life (Feilzer, 2010). Pragmatism is therefore a process-based approach to knowledge, whereby experience is a consequence of a cyclical process of reflecting on actions to choose beliefs, and beliefs to choose actions. Systematic inquiry is central to this process and involves recognising problematic situations, considering the differences between different ways of defining the problem,

developing actions to respond to the problem, evaluating potential actions, and taking action to address the situation (Strubing, 2007). Through this framework, research may be understood as a self-conscious approach to solving problems in the 'real world' (Morgan, 2013). It therefore follows that the best research methodology to adopt is whatever best answers the research question (Rorty, 1999).

## **2.2. Methodological approach**

This thesis adopted a mixed-methods approach in which three methods are integrated. Firstly, the researcher adopted an active (top-down) role in drawing on knowledge and theory derived from a review of the literature to develop initial ideas for a new psychoeducational resource. Secondly, qualitative data is collected from CYP who have experienced an ABI to understand what they feel is important in a new resource. Thirdly; quantitative data is collected from CYP who have experienced an ABI to assess the acceptability of a prototype resource developed through the course of this thesis, which will be supplemented by a limited amount of qualitative data.

Pragmatist epistemology is highly associated with mixed-methods research due to its flexibility and philosophical acceptance of the integration of data from multiple sources with the aim of solving 'real-world' problems (Teddlie & Tashakkori, 2009). Pragmatism not only enables the integration of objective and subjective inquiry through the collection of qualitative and quantitative data (Rorty, 1999), but also provides scope for combining 'top-down' and 'bottom-up' processes if they are beneficial to achieving the desired outcome (Johnson and Stefurak, 2013). Consequentially It was felt felt that a mixed-methods methodology was ontologically and epistemologically coherent, and held the greatest utility for the present study. This decision was made after considering alternative methodologies that may have also answered the research questions. A purely 'top-down' approach drawing solely on secondary sources was rejected as this would risk the resource not communicating issues of importance to CYP who had experienced an ABI. However, a purely 'bottom-up' approach drawing solely on the views of CYP who have experienced an ABI was also rejected as it was considered important to set development parameters based on

neuropsychological, therapeutic, developmental and pedagogical research and theory. Within the 'bottom-up' aspects of this study, both quantitative and qualitative data have been collected. This approach was chosen over a purely quantitative approach as it was felt this would restrict the depth of knowledge generated and restrict the ability of the research to inform resource development. It was also chosen over a purely qualitative approach as it was felt that some CYP, particularly those with more moderate and severe impairments, might require the concrete scaffolding quantitative methods can provide to facilitate their participation. Furthermore; an alternative approach to this research would have been to adopt an action research framework influenced by participatory action research (PAR; Kemmis & McTaggart, 2005), and community-based participatory research (CBPR; Stoecker, 2003). Action research is not technically a methodology but rather an orientation that seeks to equalise power relationships in research relationships (Khanlou & Peter, 2005). This approach would not have specified research questions, and would have recruited co-researchers (i.e. CYP who have experienced an ABI) to design, plan and conduct the research. Whilst such an approach would be consistent with a pragmatist epistemology, adopting an action research framework was rejected as it would have required the researcher to relinquish control over the parameters for resource development, risking the possibility of developing a resource that was not pedagogically, theoretically or therapeutically grounded.

### **2.3. *Methods and data sources***

In order to address the first research question relating to how a new psychoeducational resource could help address the informational needs of CYP who have experienced an ABI, a top-down methodological approach has been adopted. This encompasses the first phase of the research process, and involved the researcher taking an active role to draw on the theoretical and research evidence gained through the literature review to develop initial ideas for a new psychoeducational resource. This method has been adopted because the efficacy of psychoeducational approaches is hypothesised to be associated with its consistency with contemporary neuropsychological, developmental,

therapeutic and pedagogical research and theory, which participants alone cannot be expected to have comprehensive knowledge of.

A second phase involved qualitative data being collected via interviews with CYP who have experienced an ABI. This phase intended to address the second research question relating to what CYP who have experienced an ABI think is important in a new psychoeducational resource. Interviews were considered more appropriate than other forms of qualitative data collection, such as focus groups, as it enabled the researcher to tailor their language and style to idiosyncratically take account of their developmental level and nature of their impairment. Whilst it was acknowledged that the debate generated from focus groups could be advantageous in enabling discussion (Fusch & Ness, 2015), it was felt that individual interviews would allow for the collection of data of sufficient depth for analysis.

In order to address the third research question, relating to how the views of CYP can be incorporated with the key findings from the literature review, the researcher adopted an active role in synthesising the results from the first two phases of the research to develop a prototype for a new psychoeducational resource. This method has been chosen as it was considered the approach with the greatest utility for answering the research question, which is consistent with the pragmatist epistemology of this thesis.

A fourth phase involved the collection of both qualitative and quantitative data via a bespoke feedback form completed by CYP who have experienced an ABI. This phase intended to address the final research question relating to the acceptability of the prototype resource. Feedback form consisted of items designed to collect feedback on specific aspects of the prototype resource through participants responses on a five-point rating scale and comment boxes. Collecting mixed methods data was chosen over the purely qualitative or quantitative approaches, such as solely interviews or ratings scales, as it was felt that a combination held greater utility in answering the research question and was therefore more consistent with a pragmatist epistemology. The decision to develop a bespoke feedback form was made due to the absence of existing tools appropriate to the research question, and the flexibility it provided in tailoring items to maximise

relevance. It was felt that the scaffolding provided by feedback forms would be beneficial in enabling the participation of CYP with more moderate and severe impairments.

## **2.4. Context and participants**

### **2.4.1. The service context**

This research has been conducted in collaboration with a national tertiary-level third-sector organisation<sup>4</sup>. This organisation offers residential and community-based rehabilitation services for CYP who have experienced an ABI, as well as educational services aimed at facilitating return to mainstream education. The organisation also contains an ambitious research team that seek to become an internationally recognised centre for research into paediatric ABI. This thesis fits with a number of the organisation's identified research priorities, most especially in the domain of developing comprehensive informational resources specialising in brain injury. It has been partially supervised by two members of the organisation's clinical and research teams, and has been designed to complement their, as yet unpublished, co-occurring research strands. The role of the organisation in this research has primarily been to facilitate recruitment via their residential and community services, and to provide a clinical perspective where appropriate.

### **2.4.2. Participant Inclusion and exclusion criteria**

In order to participate in the research, participants must have experienced an ABI which has resulted in enduring neurocognitive impacts, be between the ages of twelve and seventeen, and be currently accessing services provided by the collaborating organisation. A requirement was made that a member of the organisation's clinical or research teams had informally assessed participants and concluded that there were no clinical reasons that could render their participation problematic. These criteria were chosen as it was felt it would enable the recruitment of a diverse sample to help ensure that participants were representative of the population. It was also considered important to set broad

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<sup>4</sup> Organisation name not included to protect participant anonymity.

criteria for practical reasons, particularly given that CYP who have experienced an ABI represent a relatively small and over-researched group (Rumney, Anderson, & Ryan, 2015; Oliver, 2002). Whilst the possibility of recruiting from multiple third sector organisations was explored, the probability that this would cause significant delays in the project that could not be tolerated within the constraints of a time-limited thesis. A minimum participant age of twelve was set as it was felt that younger children would be unlikely to have developed sufficient cognitive maturity to contribute to somewhat abstract discussions about resource development (Piaget, 1932). A maximum age of seventeen was set as it was consistent with the entry criteria for accessing the collaborating organisation's services. The requirement that participants had been informally assessed was made due to concerns that some CYP, particularly those earlier in their personal recovery journey, may experience discussions in interviews as re-traumatising.

Non-English speakers were excluded from participating due to financial restrictions preventing interpreter use for interviews and the translation of study materials. CYP with significant difficulties in the domains of expressive and receptive communication were also excluded due to the barriers this would cause in their participation. This decision was made with regret and after exploring possible alternatives, such as the use of alternative and augmented communication supports, which were unfortunately not possible with the constraints of interview processes involving a cognitive load on expressive and receptive communication.

#### 2.4.3. Recruitment

Recruitment was facilitated by members of the organisation's research team in liaison with their clinical colleagues. Two recruitment streams were identified; CYP accessing the organisation's residential services, and those accessing their community-based service. Both streams began with a process of informing members of the various clinical teams of the projects aims and what participation entails, which was led by the researcher.

#### 2.4.3.1. *Recruitment through residential service*

Clinicians working in the residential services reviewed their caseloads to identify CYP who met the study's inclusion criteria, and used their clinical judgement to assess their readiness to participate in the research. CYP were approached by clinicians to gauge interest in participating, and provide a copy of the study's information sheet if appropriate (Appendix B) An elaborated version of the information sheet was also provided to parents, guardians and carers of CYP (Appendix C). CYP were invited to take their time to consider whether they would like to participate, to discuss this with their parents, and to inform their clinician if they wished to participate. Clinicians then liaised with the research team, who scheduled an interview on the organisation's premises at a time that fitted around the young person's schedule, and informed the researcher of this.

#### 2.4.3.2. *Recruitment through community service*

Clinicians working in the community-based service reviewed their caseloads to identify CYP who met the study's inclusion criteria and used their clinical judgement to assess their readiness to participate in the research. Copies of the studies information sheets (Appendix B; C) were sent to all eligible CYP and their families, who were advised to contact the researcher directly by e-mail if they wished to participate. The researcher liaised with families to arrange a suitable time to meet either at their own homes or on the organisation's premises. Clinicians working in the community-based service were informed when CYP elected to participate in the research, and when this would happen.

#### 2.4.4. Participant demographics

Participant's clinicians at the collaborating organisation provided demographic information. A total of four participants took part in the study. Two participants were interviewed during both phases two and four of the project, with a further one being interviewed in phase two, and one in phase four. Of the four participants, three were male and one female (mean age 14.75). Two participants had experienced a non-traumatic brain injury (NTBI) and two a traumatic brain injury (TBI). All CYP. One participant was recruited from the collaborating

organisations residential service, with the remaining three from the community service. All CYP recruited had experienced an ABI resulting in enduring impacts on their cognitive and psychosocial functioning. A summary of participant demographics, and the phase of the research they participated in, can be found in Table 2 below.

*Table 2. Participant demographics.*

Participant	Gender	Age	Ethnicity	Injury Typology	Recruitment source	Participation Phase
P1	M	15	White (British)	NTBI	Community	2 and 4
P2	M	13	White (British)	NTBI	Community	2 and 4
P3	M	17	Asian (Other)	TBI	Residential	2
P4	F	14	Asian (Other)	TBI	Community	4

## **2.5. Procedure**

The purpose of this section is to provide a detailed account of the procedure followed in each of the four phases of the research process.

### **2.5.1. Phase One**

Following the completion of the review of the literature detailed in the introduction chapter, the researcher began a process of developing initial ideas for the resource. Consideration was given to what therapeutic framework would be most appropriate for the purposes of a new psychoeducational resource for CYP who have experienced an ABI. Key neuropsychological concepts were then identified, and the researcher sought to develop ideas for how these could be incorporated within the therapeutic frame in a developmentally appropriate way. Finally; the researcher drew on pedagogical theories to develop a range of ideas for how a new psychoeducational resource may be accessed or delivered for maximum impact. The first phase concluded with the development of an interview schedule for phase two (Appendix D) and accompanying visuals (Appendix E).

### 2.5.2. Phase Two

On arrival at interviews; all participants and their families were asked to re-read the studies information sheets (Appendix B; C) and ask any questions they wished. When happy to proceed, participants and parents were asked to sign consent forms (Appendix F; G) to state that they understood the nature of the research and their rights as participants. Parents were invited to observe the interview, which broadly adhered to the interview schedule (Appendix D) and was audio-recorded. Interview questions were designed to gain participant's views on a range of topics including; their knowledge of the currently available informational resources, the most important things to say about ABI, and what is important to include in a new psychoeducational resource. The researcher also shared the initial ideas generated in the first phase of the research both verbally and visually (Appendix E), and invited feedback on thoughts for further development. Specific questions were asked to assess participants' views on the conceptual basis for the resource, character development, audience and accessibility, and the format in which it should be made available. At the end of the interview all participants and parents were given a verbal and written debrief (Appendix H; I), which included contact information for the researcher and sources of available support, and were offered the chance to ask any questions they had.

### 2.5.3. Phase Three

The researcher embarked on a process of developing a prototype resource. This involved identifying areas of similarity and difference between the ideas generated by the researcher and the views expressed participants. The researcher sought to integrate the ideas generated into a prototype resource that maintained consistency with the theoretical parameters for the resource, whilst incorporating participant's views. This process culminated in the development of a prototype resource that could be shared with stakeholders (Appendix J).

#### 2.5.4. Phase Four

Regardless of whether they had participated in the first phase, all participants and their families were asked to re-read the studies information sheets (Appendix B; C) and ask any questions they wished. When happy to proceed, participants and parents were asked to sign consent forms (Appendix F; G) to state that they understood the nature of the research and their rights as participants. Parents of participants were invited to observe. The researcher presented the prototype resource, which was in the form of a PowerPoint presentation, with participants, either via laptop or full-page printouts depending on their preference. At the end of each section of the presentation, participants were asked to complete the relevant item on a bespoke feedback form designed by the researcher (Appendix K). Each item began by asking participants to provide a quantitative rating for the aspect of the resource that had been presented on a five-point scale, ranging from 'really don't like' to 'like'. Three follow up questions requiring qualitative responses were then asked, through which participants were invited to comment on what had made them choose that rating, what they liked or did not like about it, and what could be better or different. Participants were offered the choice of completing the feedback form themselves in writing, or verbally, in which case their responses were recorded and transcribed by the researcher within three days. Once the participant had completed the feedback form, they and their parents were given a verbal and written debrief (Appendix H; I), which included contact information for the researcher and sources of available support, and were offered the chance to ask any questions.

### 2.6. ***Data Analysis Process***

#### 2.6.1. Transcription

Qualitative data, collected via interviews during phase two, were transcribed verbatim and included all speech from both the participant and researcher. Responses, prompts and encouragement given by parents were not transcribed unless it gave context to information provided by the participant. Transcriptions were punctuated for readability and comprehension using Banister et al's (2001) framework. This facilitated the researcher's familiarity with the data and enabled reflection on the content of, and process underpinning, information provided by

participants. A more detailed approach to transcription was considered unnecessary for the purposes of the research.

## 2.6.2. Approach to analysis

Separate analysis was conducted for data collected at phases two and four.

Transcribed interviews conducted during phase two of the research were analysed using thematic analysis (TA). TA is an atheoretical form of analysis, which refers to a range of approaches that seek to analyse patterns within qualitative data sets (Braun & Clarke, 2006; Joffe, 2012). TA was selected for its flexibility and consistency with a pragmatist epistemology. It was chosen over constructivist approaches such as Interpretative Phenomenological Analysis (IPA; Smith & Osborne, 2008) and Discourse Analysis (Willig, 2009), as exploring participant's individual constructions of ABI was beyond the scope of this project.

TA adhered to the six-step process described by Braun and Clarke (2006). The process and steps taken is detailed in *table 3* below. An exemplar extract from an analysed transcript can be found in Appendix L.

*Table 3. Summary of steps taken during analysis*

Step	Process and steps taken
<b>Familiarisation with the data</b>	Interviews were each listened to numerous times by the researcher, who also undertook in the transcription process. Once transcribed, the researcher read through, and subsequently re-read, transcripts to develop familiarisation with the data.
<b>Generating initial codes</b>	Initial codes were generated on a line-by-line basis. As this process progressed, codes were dynamically collapsed and expanded as deemed appropriate by the researcher. The relevant extracts were referenced using participant's assigned pseudonym and the line number that it related to in the interview transcript.
<b>Searching for themes</b>	Data codes were sorted into broad themes, first within and subsequently between transcripts. Similarities and differences between codes generated in transcripts were recorded in the researcher's journal.
<b>Reviewing themes</b>	Extracts associated with each identified theme were reviewed for their coherence and fit. This resulted in a process of merging, amending and splitting themes to more accurately fit the data.
<b>Defining and naming</b>	The researcher sought to develop a coherent narrative about the data, which

<b>themes</b>	led to the naming of distinct themes reflecting the data provided by participants. Data codes, themes and super-ordinate themes were reviewed for consistency and coherence.
<b>Producing the report</b>	Quotes, reflecting data codes and sorted thematically, have been reported to facilitate the evaluation of the robustness of the research.

Both quantitative and qualitative data were collected during phase four of the research. Quantitative data was reported in terms of frequency of responses given. This approach was chosen over statistical models due to the small sample size and the utility of frequency data for highlighting data trends between participants. Qualitative data collected during phase four was analysed using TA

### 2.6.3. Reflexivity and the researchers position

Due to the researcher's role in interpreting participant's responses in qualitative research, it is important to attend to the researcher's position and their reflexive ability (Bengough & Karin, 2017). This is exacerbated in this thesis as the researcher not only adopts a dual-role as data collector and analyser, but also actively engages in 'top down' aspects of the research process. The researcher was an adult white-British male Trainee Clinical Psychologist from a relatively middle-class family background. They had pre-training experience in child development and neurodevelopmental services, in addition to paediatric placement experience during training, and was motivated to pursue a career in similar services post-qualification. Whilst the researcher had not experienced an ABI or neurological impairment, they had been labelled as having a musculoskeletal condition, although did not consider this integral to their identity and broadly rejected their disability labelling. The researcher did not have any children of their own, and there was no history of ABI within their personal networks. The basis for this thesis was originally the conception of a member of the academic team at the training institution, and the researcher was drawn to it for its practical applications and relevance to their desired future career. It is acknowledged that one's own personal and work experiences and ambitions can influence the interpretation of qualitative data (Willig & Stainton-Rogers, 2016), and therefore a reflective diary was kept in relation to the research process.

### 2.7. ***Ethical considerations***

The School of Psychology Research and Ethics Sub-Committee (SREC) of the University of East London granted ethical approval for the research (Appendix M; N). An amendment to the original ethical form enabling home interviews was later accepted by the SREC (Appendix O).

Additional permission was formally granted from the collaborating organisation's Research Ethics Committee (Appendix P). As all data were collected via a third-sector organisation, NHS ethical approval was not required. The purpose of this section is to outline how key ethical issues were met in this research.

#### 2.7.1. CYP as participants in research

The researcher drew on best practice guidelines for conducting research with CYP, which emphasise their position as competent and willing to engage in decision-making about participating in research (Munford & Sanders, 2004; Shaw, Brady & Davey, 2011). These guidelines emphasise the importance of maintaining an awareness of the power imbalances between researcher and participant, as well as that between adult and child. In order to minimise these, the researcher sought to develop rapport with CYP prior to the interview commencing. It is also recommended that researchers liaise closely with individuals who know participants well, such as their parents or clinicians working with them. This was accomplished through close working with the collaborating organisation's clinical and research teams, and through ensuring parental presence during interviews.

#### 2.7.2. Informed Consent

Participants and their parents were given in-depth information about the studies aims and what participation entailed through the studies information sheets. Participants were also given the opportunity to ask any questions they wished about the research process before, during and after they participated in the study. All participants and their parents signed a consent form prior to being interviewed at both phase two and four of the research. Consent forms provided confirmation that the purpose and process of the research was understood, and that they were aware of their rights as participants. No deception was involved in this study.

### 2.7.3. Confidentiality and anonymity

All personal information collected through participating in this research has been kept confidential, and was saved electronically on a password-protected computer file that only the researcher had access to. All paper copies were destroyed immediately after being scanned. Participants were made aware that their basic demographic information and brief details of the type of ABI they had experienced would be reported on in this thesis and any subsequent publications. Participants were reassured that any information that could potentially identify them individually would be removed, but that information they gave in interviews could be reported as quotes in written reports. Participants were anonymised in all forms of dissemination.

### 2.7.4. Protection from harm

Wellbeing of participants remained paramount throughout interviews and any concerns regarding their physical or emotional wellbeing were treated with the utmost importance. It was agreed that interviews would be paused or terminated if any person present identified concerns about participant welfare.

CYP who have experienced an ABI are at increased risk of health conditions such as epilepsy and physical difficulty (Katz-Leurer, Rotem, Keren & Meyer, 2010). It was therefore important to ensure that robust and effective procedures were in place to protect participants from harm. Interviews adhered to the collaborating organisation's established risk protocols, and were supervised by participant's parents due to the likelihood that they are best placed to understand their individual needs. CYP who have experienced an ABI often report high levels of fatigue (van Markus-Doornbosch, 2016). Participants and their parents were therefore offered the opportunity to pause or stop the interviews at any time they felt appropriate, and the researcher also remained mindful of this throughout.

### 2.7.5. Right to withdraw

Participants and their parents were informed prior to interviews, both verbally and in the information sheets, that they could withdraw from the study at any point up

to the completion of the interview. It was explained that due to the nature of the research process, participants could not withdraw their data from the study once the interview had been completed. Participants were however informed that they could request any specific comments be withdrawn and not included in any form of analysis if they so wished, as long as this happened within five days of the interview.

#### 2.7.6. Support to participants

Whilst the study did not require participants to disclose extensive details about their experiences of ABI, however it is acknowledged that discussing this topic may evoke curiosity about their condition amongst participants. Pre-empting this possibility, the researcher made it clear in the information sheet that they were unable to respond directly to specific questions about participant's conditions, however could signpost to sources of information and support. These included informational resources available online, the clinical team at the collaborating organisation and their GP. The researcher was also aware that talking about ABI had the potential of being upsetting or re-traumatising for some participants. All participants were therefore given details, verbally and in writing in the debrief form, of registered support agencies who offer confidential face-to-face and telephone support services to CYP, and encouraged to discuss any concerns that they had about their emotional wellbeing with their GP or allocated clinician at the collaborating organisation. Participants were also encouraged to contact the researcher's supervisor if they had any concerns or complaints about the researchers conduct or the interview process.

### 3. Results

This chapter is organised into four sections, one for each phase of this thesis. The first section provides a description of how the researcher developed initial ideas for a new psychoeducational by drawing on the theoretical and research evidence base. The second section provides a summary of the main themes identified through analysis of interviews with CYP who had experienced an ABI in relation to what they felt was important in a new resource. The third section provides a description of how the researcher integrated these data sources to develop a prototype psychoeducational resource, whilst the fourth section provides a preliminary evaluation its acceptability from the perspective of CYP who have experienced an ABI.

#### 3.1. Phase One: Developing initial ideas

This section provides a description of how the researcher developed initial ideas for a new psychoeducational resource for CYP who have experienced an ABI by drawing on the theoretical literature and research evidence. This section outlines the evidence in four theoretical domains that contributed to this process; neuropsychological, therapeutic, pedagogical and developmental.

##### 3.1.1. Neuropsychological

A review of the literature identified six key neuropsychological concepts that would be important for a new psychoeducational resource to communicate to CYP who have experienced an ABI (Table 4.)

*Table 4: Key neuropsychological concepts*

Key neuropsychological concepts
Localisation and specialisation in function <ul style="list-style-type: none"><li>• Functions associated with the frontal lobes</li><li>• Functions associated with the occipital lobe</li><li>• Functions associated with the parietal lobes</li><li>• Functions associated with the temporal lobe</li></ul>
Interconnectivity
Neuroplasticity

Neurocognitive stalling
Impacts and consequences of ABI <ul style="list-style-type: none"> <li>• Physical</li> <li>• Neurocognitive</li> <li>• Psychosocial</li> <li>• Systemic</li> </ul>
Neurorehabilitation

### 3.1.2. Therapeutic

The efficacy of psychoeducation, a therapeutic approach seeking to convey information to equip individuals with the tools to regain control of their lives (Goldman, 1988; Vermuelen, 2013), is likely to be increased if embedded within a therapeutic framework. A range of frameworks were identified through reviewing clinical guidelines (NICE, 2014), including behaviourist (Bandura, 1976; Skinner, 1971; Watson, 1913), CBT (Beck, 2011) and ACT (Hayes et al., 1999). The narrative framework (White & Epstein, 1990), which seeks to explore subjugated narratives of strength and resilience to enable change within systems and contexts (Kurri, 2015), was considered to be the most appropriate framework given its evidence base in working with issues of identity and adjustment after a significant or traumatic life event such as ABI (Perkins, 2015; Segal, 2018). Inspiration was particularly taken from externalisation techniques (Ullman, 2016) in order to develop the conceptual basis for a new resource, provisionally entitled ‘The Lobe Family’.

This led to the development of four characters, who together make up the Lobe family. Each character was developed to act as an external representation of one of the brain’s four lobes, embodying associated functions through their appearance, preferences, and strengths (Table 5.). It was envisaged that ‘The Lobe Family’ would be presented as a series of four stories, each revolving around one of the characters. Stories would begin by learning about the skills of each character (i.e. localisation and specialisation in function), and how they work together to complete tasks (i.e. interconnectivity), prior to the stories main character experiencing an ABI. This would provide the basis for exploring the range of impacts and consequences of ABI, and how these evolve over (i.e.

neurocognitive stalling). Stories would conclude by exploring issues of recovery and neurorehabilitation, such as compensation and neuroplasticity.

*Table 5. 'The Lobe Family' characters*

Character	Example areas of strength prior to/difficulty after ABI
Freddy Frontal Lobe	<ul style="list-style-type: none"> <li>• Organisation and planning</li> <li>• Working out what other people are thinking</li> <li>• Solving problems</li> </ul>
Olly Occipital Lobe	<ul style="list-style-type: none"> <li>• Seeing things correctly</li> <li>• Noticing differences between different shapes and colours</li> <li>• Spotting when something is moving</li> </ul>
Patricia Parietal Lobe	<ul style="list-style-type: none"> <li>• Making sense of things from all her senses</li> <li>• Coordinating bodily movements</li> <li>• Using words and numbers</li> </ul>
Tamara Temporal Lobe	<ul style="list-style-type: none"> <li>• Paying attention and concentrating</li> <li>• Recognising people and remembering things</li> <li>• Listening and speaking</li> </ul>

### 3.1.3. Developmental and pedagogical

A key challenge involved in developing initial ideas for the resource was establishing a developmentally appropriate mechanism for delivery with pedagogical efficiency. Whilst it was acknowledged that age is a poor predictor of ability of cognitive ability within ABI cohorts (Catroppe et al., 2012; Gordon, 2014), stage theories of development informed preliminary resource development (e.g. Piaget, 1936), with a view to this being further addressed through the subsequent phases of this thesis.

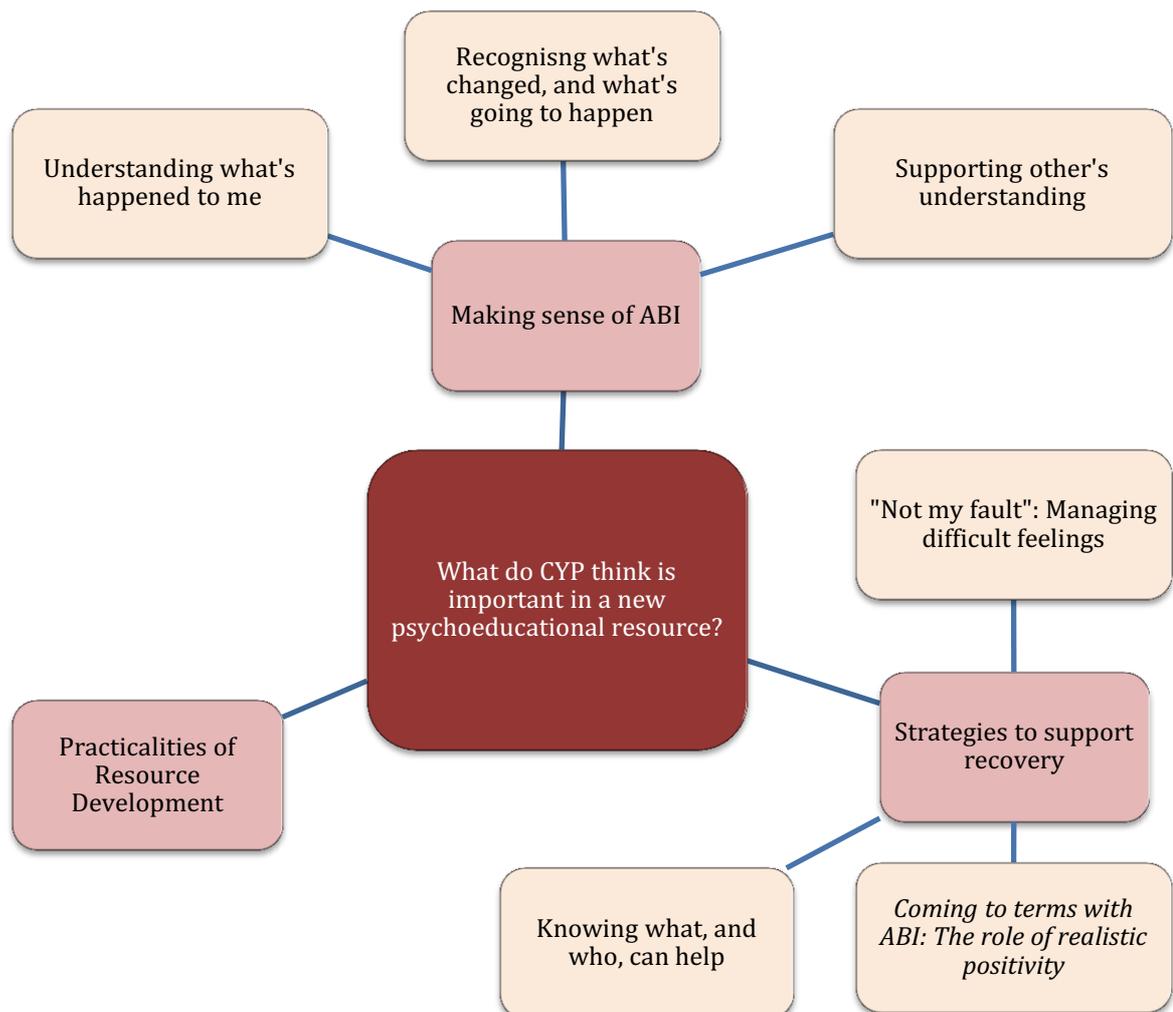
Learner-centered pedagogy (O'Sullivan, 2004), whereby exploratory and participatory learning is facilitated, was chosen as the most appropriate framework for a new resource. It was anticipated that this could be achieved through the resource communicating neuropsychological concepts in an accessible and engaging manner that encouraged CYP to relate this knowledge to their own injuries and experiences.

### 3.2. Phase Two: Views of CYP who have experienced an ABI

This section provides an account of the themes that emerged when CYP who have experienced an ABI talked about what they felt was important in a new psychoeducational resource. Using TA, initial data codes were organised into sub-themes, which were subsequently organised into super-ordinate themes.

Three super-ordinate themes were identified during analysis. Two of these, 'making sense of ABI' and 'strategies to support recovery', comprised of three sub-themes apiece, whereas the third theme, 'practicalities of resource development', stood independently (*figure 1.*)

Figure 1: Thematic map



### 3.2.1. Theme One: Making sense of ABI

The first identified theme related to the importance of the new psychoeducational resource helping make sense of ABI. This theme comprised of three sub-themes; 'understanding what has happened to me', 'recognising what's changed, and what's going to happen', and 'supporting other's understanding'.

#### 3.2.1.1. *Understanding what's happened to me*

The first sub-theme related to the views expressed by participants on the importance of a new psychoeducational resource helping CYP who have experienced an ABI better understand their conditions.

Participants spoke from personal experience of struggling to understand the events that led to and followed their ABI. Whilst participants had experienced ABI due to a mix of traumatic and non-traumatic causes, they discussed experiences of hospitalisation and first learning that they had an ABI. Participants talked about how doctors had attempted to explain what had happened and what meaning this would have for them, but that they had not fully understood this at the time. This led participants to discuss the importance of a new psychoeducational resource helping CYP who have experienced an ABI realise what had happened to them.

My brain injury came about through illness. Which was really unfair... I spent 6 weeks week in hospital and spent my seventh birthday in hospital. 215 days in hospital. It was only after I learned what had happened. People told me what happened.... But.... But I didn't get it really... I wanted to know... but it was difficult. (P2)

Well... it was after my accident... I was in hospital and I had many people, doctors, coming up to me and it was mainly, like, obviously, trying to explain things to me what happened and that my way of thinking wouldn't be the same as it was before. I didn't really get it. (P1)

If you mentioned the day and time when it happened, why it happened, and... Er... Yeah. Like when you have just had it happen. Help you realise what has happened. (P3)

Participants reflected that most of their learning around ABI to date had been acquired through their lived experience and interventions delivered by health professionals. Participants spoke of their limited awareness of, and exposure to, existing psychoeducational resources relating to ABI, and criticised those that they had accessed for being too tailored to a younger audience or being overly medicalised.

Yeah I learnt as I went through. I never got nothing to say this is what's gonna happen. You had to pick it up as you go. (P1)

There were a few things in books... But... Nobody really told me about it. But I just Googled it and learnt a bit myself... I don't know more than that there's four of them and they do slightly different things. It should say more than that! That wasn't enough for me. (P2)

All the stuff that's out there is very medical, very scientific. Even if you think it's aimed at kids, it's not (P2)

Everything that's been sent to me is very childish and I don't like that . It's like urrrgghhh. Sorry. (P2)

Participants comment on their lack of understanding of ABI, but also of how the brain works more generally. This led participants to highlight the importance of a new psychoeducational resource for CYP who have experienced an ABI being able to help support understanding around this. Two participants expressed how keen they would be to access a finalised resource to support their understanding.

People who have had a brain injury... Young people... We don't... Erm... Know how the brain works. (P1)

You got no way of understanding things in the brain after, but the more info you get the more your brain grows up, and you start seeing things clearer and knowing things better. (P1)

Yeah. Its got to say what brain injury is. What it feels like. And that thinking is different. (P3)

I don't mind so long as it helps me know more about the brain. . I think it would help. (P1)

I would like to know how the brain works. If it says that that's good. (P3)

Acknowledging the complexity and heterogeneity of conditions under the overarching ABI term, one participant spoke of the need for a new psychoeducational resource to provide information applicable to all, but also tailored to specific aetiologies.

It has to be relevant to me. But also able to be relevant to anyone with a brain injury. (P2)

Brain injuries come in all shapes and sizes, but they're all brain injuries... There's traumatic and acquired brain injuries. It's like the difference between punching the glass, or pouring acid on the glass. They both end up breaking it, but in different ways. (P2)

### *3.2.1.2. Recognising what's changed, and what's going to happen*

The second sub-theme related to participant's views around the importance of a new psychoeducational resource supporting CYP to recognise and understand changes in their abilities experienced as a result of ABI, and communicating realistic expectations for what the future may hold.

Participants emphasised that a new psychoeducational resource should make it clear that CYP should expect to see changes in their abilities following an ABI. Whilst now aware that their cognitive skills had been affected by their injuries, participants spoke of difficulty in recognising and understanding what this meant for them in their lives. Participants spoke of their experiences of gradually recognising and understanding the changes in their abilities through their own self-discovery, and stated that it is important that a new psychoeducational resource supports CYP who have experienced an ABI in this learning.

They should expect to change. I don't know how they should expect to change though as that depends on what happened to them, but there will be change. (P2)

I was trying to understand what my difficulties were and trying to. I knew that my way of thinking was different since the accident. But I never really understand how it was different. (P1)

You change person yourself after a brain injury. You don't notice it much at the time. But after a while you look back and you start noticing how things are different. I had to do that on my own. Something that helps that... Yeah... That would be good. (P2)

Participants also discussed the challenges they faced in being able to understand what ABI is likely to mean for them in the future. Whilst participants expressed frustration at the inability of clinicians to be able to accurately detail their likely prognosis, they appeared to understand that predicting the longer-term impacts of ABI is not always possible. Participants expressed their view that it is important that a new psychoeducational resource is able to forewarn CYP to expect changes in abilities after an ABI, but that what these are likely to be may not be predictable. Participants discussed how the varying impacts and consequences of their injury changed over time, with some difficulties only emerging with age and in relation to peers of a similar age.

I remember it was hard because they didn't tell me what it was going to be like in the future. You want to know. (P2)

You also need to tell them that you can't predict everything. You can't be sure what's going to change. It's annoying. (P1)

But it could all change you know... Things come out of nowhere. You only... You only really notice it when you compare yourself to others though. (P1)

It didn't feel much at first, but as I've grown up I've felt more and more different than those around me. (P2)

### 3.2.1.3. *Supporting other's understanding*

The third sub-theme related to participant's views around the importance of a new psychoeducational resource supporting the understanding of other people within the networks of CYP who have experienced an ABI, such as their teachers and peers.

Participants spoke extensively about the lack of awareness and understanding around ABI that they have encountered amongst people within their networks. Participants talked about a number of misconceptions and inaccurate beliefs about ABI, such as that it always results in severe impairment, and how this can be a barrier to others recognising and understanding their more subtle and non-visible impacts of ABI. Whilst participants spoke of their attempts to explain their injury to others, they cited the complexity and heterogeneity of ABI as barriers to this.

I don't think many people are aware of the effects, and like, what people have gone through, and what brain injury actually means. (P1)

People don't understand my brain injury. They don't know what it's about. Adults as well as kids. (P2)

The people who had one of the really bad ones, or comatosed. That's what people think a brain injury is. They don't think what I have is a brain injury. Nobody accepts it as I look normal and speak normal and can do things. They think there's nothing wrong with me. (P2)

They need to know because they don't know what brain injury is (P3)

I try and explain it but they don't understand it. There's so many different kinds of brain injury that they don't understand that they are so different. You need to explain what ABI is. But also what types of.... types of ABI you got. (P2)

Participants talked about the challenges that they face as a direct consequence of other's lack of knowledge and understanding around ABI. They spoke of how

others, particularly their teachers, can misinterpret their areas of difficulty, such as fatigue or finding particular tasks difficult, as a lack of ability or effort. Participants expressed their frustration of the way that their difficulties can become framed as misbehaviour, particularly when this is subsequently punished.

It's not about being naughty, it's genuinely because your struggling, then it's unfair and frustrating and it's because they don't understand it. (P2)

One of the disadvantages for me is that I get really tired very quickly. So like I would have to take some breaks in-between doing things and people need to know that or they would just think I'm lazy. (P3)

They might just end up thinking that they are stupid or can't be arsed. Teachers did end up thinking I just couldn't be arsed and I got in trouble for it. (P1)

Instead of following their policy of 'if someone can't do something find an alternative', they'll cancel something for the whole class. Then they'll blame it on me and tell everyone that nobody can do it because of my naughty behaviour. (P2)

Participants therefore argued that a new resource should be sharable with people within their networks to help support understanding of ABI, which would be particularly helpful in opening discussion to help them understand and accept the impact that ABI has had on their abilities. Participants hoped that this would result in greater recognition and acceptance of their difficulties amongst people in their networks, leading to them being able to offer an appropriate level of support.

Not just kids with brain injuries, but other kids too. Say like a friend, a relative, or a friend. Then they can understand it. They wouldn't see the person, like, ah he's a bit different, they'd read it and understand why he is different and what's going on. It'd be useful for lots of different people. (P1)

Yeah. It's not just for me. But for parents, teachers and other, other, kids. So we can talk about it and understand more. (P2)

It could tell me about the brain. It would help you with brain injury. Can give it to other people too.... Like friends and other people. (P3)

With more people aware there's a chance that they might start accepting it, accepting that I'm different now, and see that I'm struggling with this. (P1)

### 3.2.2. Theme two: Strategies to support recovery

The second super-ordinate theme identified related to the importance of the new psychoeducational resource discussing strategies to support recovery. This theme comprised of three sub-themes; 'coming to terms with ABI', "Not my fault": managing difficult feelings', and 'knowing what, and who, can help'.

#### 3.2.2.1. *Coming to terms with ABI: The role of realistic positivity*

The first sub-theme related to the views expressed by participants around the challenges associated with coming to terms with ABI, and the problems that denying or hiding can have in hindering recovery. Participants advocated that a new psychoeducational resource should present a realistic yet positive message to CYP who have experienced an ABI.

Participants talked about how understanding ABI and recognising the impacts of their injuries is not in itself sufficient, but that being able to come to terms with what had happened to them was key to enabling recovery. Participants spoke from their personal experiences of trying to deny the impact of ABI, seeking to hide the extent of their difficulties from others, and how this has been problematic for them. Participants emphasised the importance of being able to accept ABI and associated changes in abilities as a key strategy to support recovery.

When I first realised that I had a brain injury, then I denied it all. Like I lied about stuff saying that I didn't think it was difficult. I was saying I was able to deal with it and I was fine with it. And that nothing was different. (P1)

They shouldn't hide it cos if they keep on hiding it then nobody's going to know what is wrong with them. But you need to accept its happened because if you haven't then I want to hide it. (P1)

You have to be prepared for accepting how things have changed and stop trying to go back to what you were before. (P2)

I want to tell them not to fight the changes, as that is frustrating and it causes even more damage. Just try and accept the changes. (P2)

Acknowledging that accepting ABI can be very difficult, particularly given the lack of certainty about how their condition may progress, participants emphasised the importance of a new psychoeducational resource communicating a realistic message regarding the likelihood of recovery. Participants spoke of the dangers associated with being presented with an over-optimistic view of recovery, highlighting the importance of a new psychoeducational resource communicating a realistic message regarding what the future may hold.

That might be hard because you might not see that you different yourself. But if you don't accept that then you'll drive yourself crazy. (P2)

What you want to do is say as early as possible that you might not get better because you might not. It's about. It's about. You want them to say that you will be different, and that being different is ok. (P2)

They need to know that life isn't going to be the same as before, like before they had the injury, and they need to find ways to kind of like. How do I say it... They need to find ways to cope with getting used to it (P1)

The thing is you don't know if you'll get back to who you were. If they keep saying that "your going to get better, your going to get better", then all your doing is your making this person more desperate to get back to who they were before. (P2)

Participants spoke extensively about the importance of remaining positive in supporting recovery. Participants talked about the importance of drawing on their

own strength and resilience, as this acts as a protective factor in the process of coming to terms with ABI. Participants were clear that whilst a new psychoeducational resource should communicate a realistic vision of the future, it should also act to support CYP to recognise their own strengths and instil hope.

So I want them to understand that they understand that they are going to have problems with their memory and their speech and stuff like that, but you will try, they will find ways around it and get help. And they shouldn't put themselves down because of it. You got to be positive. (P1)

Having a sense of humour helps. That really helps. (P2)

I would tell the person that you shouldn't worry about it, and you should get over it quickly, because you're strong and you have all that life to go. (P3)

#### 3.2.2.2. *"Not my fault": Managing difficult feelings*

The second sub-theme related to participant's views on the importance of a new psychoeducational resource normalising difficult feelings that are often experienced following an ABI, such as low mood and guilt. Participants also discussed how recognising the relational aspects of their difficulties can also be a helpful strategy to support recovery.

Participants spoke from personal experience of the difficult feelings that are often experienced following an ABI. Participants described experiencing low mood as a result of their difficulties, avoiding situations that would expose their vulnerabilities, and of feeling left out. Participants also talked about their tendency to be self-critical and self-punishing when they encountered difficulties.

For some people it can be very affective and make them feel bad. They won't talk to their family about it, won't tell anyone about it, and feel left out most of the time. (P3)

I tend to just sit in the corner and that. I. I know I'm acting different and I feel guilty for that, but I don't feel I'm well equipped to go near those others. (P2)

I was trying to have a serious conversation and I was going. Uh. Uh. Uh. I was stuttering every three seconds... I used to really feel bad about myself because I can't remember stuff or stay stuff. (P1)

And you can't keep putting yourself down because you can't think like the rest of them and you can't talk like the rest of them. And just. And just stuff like. you can't put yourself down because I had problems with that. I used to beat myself up because I was saying the wrong stuff. (P1)

Participants spoke extensively about feelings of guilt and shame that they had experienced following their ABI, with two participants stating that they had initially blamed themselves for their injury. Participants talked about how these feelings had been exacerbated by experiences of bullying and being taken advantage of by their peers, and strongly argued the importance of a new psychoeducational resource emphatically communicating that ABI is not their fault.

One of the really difficult things for me was guilt. It was really difficult... I thought it was my fault. (P2)

Feeling sad. Guilty because it happened. Feeling sad and bad. (P3)

Guilt... It isn't helped by kids making fun of you for having difficulties that aren't your fault... It took a lot out of me... What happened to me isn't my fault. (P2)

Also to accept that I've got troubles with my memory, and I was ashamed to ask for help. I felt stupid if I asked for help (P1)

I think it needs to talk about like if people are bullied because of changes that happen, and to make sure they know that it's not their fault. (P2)

Participants expressed their view that ABI in itself is not necessarily problematic if CYP are able to recognise and come to terms with the changes that occur as a result, and that the difficult feelings that can be experienced after an ABI are largely related to the actions of others and one's own desire to fit in and be normal. Participants appeared to suggest that recognising this could be a helpful strategy to support recovery.

It isn't a problem. Brain injury isn't a problem. It only is made a problem by other people. (P1)

I guess you feel guilty because, because, you really want to fit in and be normal and you feel. I guess you feel guilty because you're trying to fit in and be normal. Your not able to do what people are expecting to do, but you want to be able to do it. And you feel you are disappointing or hurting those around you and you don't want to do that. You just want to be the same as the others but when you can't. (P2)

### 3.2.2.3. *Knowing what, and who, can help*

The third sub-theme related to participant's views around the importance of a new psychoeducational resource making it clear to CYP that they can gain support from a range of sources, and providing information about what this support may look like.

Participants spoke positively about the various systems of support that had been available to them, and how important these were in supporting their recovery. Participants were appreciative of their parent's role in offering support and acting as an advocate. Whilst participants had previously talked of the challenges associated with limited knowledge and understanding of ABI amongst teachers and peers, these groups were also talked about as valuable sources of support.

I was lucky to have parents that accepted and helped me get through my difficulties and introduced me to the <charity> so I could get help. (P1)

If your family... if your parents are around then they can help you. (P2)

Stay together as much as you can with your family because you need them. And be nice to your friends because you don't know what's going to happen in the future and you're going to need their help with things. (P3)

Teachers.... like when your in lessons... they will like. They need to find ways to remember things and stuff. Like I used to write down stuff. Like yeah, it was stupid stuff like, but it helped me get through and with my exams and all of that. (P1)

Friends.... If they are true friends then they will understand and they won't hold anything against you and all that. Say you can't remember an event then they won't hold it against you. (P1)

Participants discussed the importance of a new psychoeducational resource being able to provide practical information about strategies that might help them in daily life. Whilst participants stated that they were aware of the existence of strategies that might be helpful for them, they were unsure of where they could learn about these. Participants talked positively of the support they had been given by the collaborating organisation, and expressed a wish for a new psychoeducational resource to direct CYP to similar sources of support or provide details of some of the strategies that are frequently suggested.

Yeah that's important. You need to have ideas for what will help them manage things. (P1)

There's lots of things they can do to help. But. You don't know it. Something that says the kind of things they can do. You know. Just so you know they can (P2)

I had a doctor try and help out of me. She would see her like once a day and she would spend some time trying to help my memory. Like tricks and stuff that would trigger. It would be good if you could tell people about things like that (P1)

### 3.2.3. Theme three: Practicalities of resource development

The third super-ordinate theme identified related to the views expressed by participants on the more practical aspects of resource development. This included the comments made by CYP relating to what they felt was important in terms of the format, delivery, style and accessibility of a new psychoeducational resource.

When asked for their thoughts on what a new psychoeducational resource should look like, participants expressed a strong preference for multi-modal forms of delivery. Participants acknowledged that there are differences in how CYP like to access information, as well as a generational gap in technological preferences. In the context of their views around the importance of a new psychoeducational resource being suitable for supporting the understanding of CYP and people in their network, participants talked about the need for a new resource to be available in multiple formats, perhaps adopted a franchise model involving a range of approaches.

It should be lots of things. Definitely the game, then the video, then the comic. It should be more than one though, cos say, someone already makes the comic then they can read that and still not understand it because it's not showing everything and stuff. But if you get the game, and the comic, then people might still not understand. But as soon as you get the video, game and comic they might build a bigger picture of everything. Everyone has different ideas about what they like. (P1)

I reckon a comic would be better off because, like, you get, if you do a magazine people are just going to skim through it, if it's a comic people might pay more attention because kids wouldn't think of it as work or that.... The comic might make it more relatable and interesting because it's visual. I might read it all the way through and see what's going on. (P1)

It should be all of them. Everyone wants different things. If it's all of them different things... you know... everyone picks what they want. (P3)

Maybe it should be like Marvel. In Marvel you have a whole universe of stories in books, films, comics magazines, DVD, games, videos.... everything.... it would be good if this was in everything so people could pick and choose what works best for them. (P2)

Participants talked about the importance of a new psychoeducational resource being interactive to facilitate meaningful and active engagement. One participant talked about how modern technologies, such as virtual reality, could be incorporated in order to allow others to experience what it is like to have an ABI. The idea of a new psychoeducational resource being presented as a game accessible on mobile devices appeared to be preferable, and this would provide benefits in enabling personalisation options.

Everyone likes different ways. But something personal and interactive would be best. (P2)

A game would be better off because, again, it's more interactive and, I don't know. It would be like you playing it and understanding stuff as you go. You would be doing stuff. So say there's an adventure you need to do, then the characters could do it, but it'd be harder if they had a brain injury. (P1)

A game would be really good because it would be interactive. (P2)

I know this is more unrealistic but if it was virtual reality you could get other people like teachers to find out what it's like having a brain injury too! (P2)

Participants discussed their desire for a new psychoeducational resource to be personalisable in order to maximise relevance to different audiences. Acknowledging the wide range of causes and consequences of ABI, participants talked about the need for a new resource to provide both generic and aetiology specific information. Participants spoke of their anticipated frustration with the resource if it was not able to do this, particularly as they feared this could further fuel the misconceptions and inaccurate beliefs others may hold about their ABI. Participants talked about how this could be achieved by being given the option to

select key variables, such as injury typology and character age. One participant also talked about how the resource could be designed to interactively link to other sources of information so CYP can access further learning.

It has to be relevant to me. But also able to be relevant to anyone with a brain injury. (P3)

What I would find really frustrating, if I was having difficulties - like I am - with Freddy's stuff. If I had people who had seen the app telling me to try things to help with things Tamara or Patricia are good at I'd find that really frustrating because this is stuff I can do fine. But it's this stuff, Freddy's stuff. It would be really good if the other kids in school had it, but were able to know which is me. (P2)

You could select how old the person is and what they are called. And you could choose who has an injury so it like makes the story personal. That would be really good. ! If it was a game you could really play with them and get to know what they are good at and what they're not (P2)

It should link like online to other websites and things with information so it keeps spawning information on and on. Because that would mean you could keep learning and learning (P2)

Participants talked about the need for a new psychoeducational resource to be pitched at an appropriate developmental level to enable independent access by CYP. Nevertheless, participants also felt that it was important that a new resource did not alienate adolescent or adult audiences by being too infantile. This was particularly evident in relation to the proposed characters names, which participants criticised for being too childish.

It would be good. It would have been good if like I was able to see it on my own and learn about it and stuff. That might have been good. (P1)

I personally think that would be good. Not comics like Explosm™ level of comic because that's stupid, but something that anyone can read.



two that the resource communicated neuropsychological principles relating to how the brain works and ABI, participants appeared to place significantly greater emphasis on the importance of it discussing psychosocial and emotional issues. It was therefore considered important that these issues were given greater prominence in 'The Lobe Family' resource. It was envisaged that this could be achieved through increasing the emotional content throughout the resource, acknowledging and normalising difficult feelings such as low mood, fear and guilt that CYP may experience in relation to their ABI.

Whilst the initial ideas for the resource had not considered the format that 'The Lobe Family' should be delivered through, participants expressed a clear preference for a multi-modal, interactive and personalisable resource. Participants showed creativity in their format suggestions with some ideas being beyond the resources available for this thesis, such as a virtual reality or a game. Whilst these were taken into account as potential long-term ambitions, it was queried whether such technologies would be accessible for the full range of intended audiences. It was therefore decided that 'The Lobe Family' should be made in three formats in the first instance; a series of four comics and books (i.e. for each of the main characters) and an interactive website that can be accessed online and on mobile devices. It was intended that the books would have their content and language tailored to the theorised developmental level of younger children, whereas comics would be aimed at an adolescent audience. Given specific feedback from participants regarding the developmental appropriateness of the character names, it was decided that they should be differentially named in the resource. Whilst personalisable resources were considered as a possible solution, providing a free choice to name their character was considered problematic given the likelihood that CYP would name their character after themselves, which would risk diminishing the therapeutic value of externalisation. It was therefore decided that characters in books would be given names that may be considered more child-friendly (i.e. Freddy, Olly, Tammy, and Patty), whereas in comics they would have more adult names (i.e. Frederik, Oliver, Tamara, and Patricia). It was envisaged that the web-based version could offer personalisation options so that CYP are able to select their preferred characters names, as well as being able to tailor content to specific aetiologies (e.g. head injury,

encephalitis, stroke) and familial structure (e.g. single parent, adopted, same-sex). It was felt that this approach would maximise how relatable the resource is, and to ensure that it is appropriate to a range of developmental levels.

Furthermore, it was thought that the web-based version could provide links to other validated sources of information, and to offer a social function of 'inviting friends' to view. It was felt that this would enable CYP to access the resource independently, but also facilitate the engagement of people in their networks who could support CYP's access.

The process of creating a prototype resource culminated in the researcher developing a storyline for 'The Lobe Family' resource that could be broadly split into four sections; 'How the brain works', 'After brain injury', 'Understanding brain injury', and 'What, and who, can help after brain injury'. It was not envisaged that these would appear as visibly distinct chapters in the final resource, but would be presented as part of a continuous narrative. A summary of the content and narrative of each of section of the prototype resource is detailed in Table 5.

Table 5: Summary of 'The Lobe Family' prototype resource

Section	Summary of content
How the brain works	<ul style="list-style-type: none"> <li>• The four members of the Lobe family are introduced to the reader.</li> <li>• The functions of each of the brain's lobes are explored through the strengths and preferences of the corresponding character.</li> <li>• The four members of the Lobe family work together to complete tasks in order to demonstrate how the brain works.</li> </ul>
After brain injury	<ul style="list-style-type: none"> <li>• The central character experiences an ABI and is admitted to hospital where they undergo a number of assessments.</li> <li>• The central character and their parent(s) first learn that they have experienced an ABI.</li> <li>• It is acknowledged that having a brain injury can be a frightening experience, and that getting used to life after ABI can be challenging.</li> <li>• The central character finds it hard to understand what happened, and to accept that their circumstances have changed. Their parent(s) also find this difficult.</li> <li>• On their return to education, the central character finds that their teachers don't understand, and some of the other young people try to take advantage of them.</li> <li>• The central character experiences difficult feelings including low mood, anger, and frustration. They also report feeling guilty and blame themselves for what has happened.</li> </ul>

Understanding brain injury	<ul style="list-style-type: none"> <li>• The central character discovers that they are no longer good at the things that they were prior to the injury.</li> <li>• The remaining three children in the Lobe family learn to find new ways to complete tasks without relying on the abilities of the story's central character.</li> </ul>
What, and who, can help after brain injury?	<ul style="list-style-type: none"> <li>• It is acknowledged that it can be hard to know who can help CYP after brain injury, and what they can do.</li> <li>• Supplementary characters (i.e. parent(s), teachers, and peers) are introduced to communicate how they might be able to offer support after an ABI.</li> <li>• The Lobe family meet with a health professional who recommends some neurorehabilitation techniques that are commonly recommended for their areas of difficulty (e.g. using a planner to organise oneself after injury to the frontal lobe)</li> <li>• The central character learns that they are not defined by their ABI, and can draw on their own strength and resilience as a key source of support in a positive yet realistic manner.</li> </ul>

### **3.4. Phase Four**

This section reports on the results of a preliminary evaluation of the acceptability of the prototype resource from the perspective of CYP who have experienced an ABI. After being presented with a prototype of 'The Lobe Family' (Appendix J), participants were asked to provide ratings on a series of five-point scales with regards to the characters, content, and format of the resource. Participants were also asked to comment on what led them to choose their response, what it is they like or do not like, and to suggest any changes they felt appropriate. Participants were also asked to provide an overall rating of their thoughts on the acceptability of 'The Lobe Family' psychoeducational resource.

#### **3.4.1. Quantitative findings**

Participants were asked to provide ratings on a series of five-point scales with regards to the characters, content, and format of the resource. All participants indicated that they 'liked' or 'really liked' all aspects of the resource (*Figure 2*).

The areas where there seemed to be the most room for improvement related to 'characters', in addition to the sections on 'how the brain works', and 'after ABI'. A

summary of the qualitative feedback with illustrative quotes will be presented in the following sections.

#### 3.4.2. Feedback on characters

Participants commented that they had found the characters engaging, relatable, and helpful in supporting learning about ABI due to their visual nature. Nevertheless, one participant highlighted the characters lack of colourfulness as a potential area for improvement.

They are helpful to visualise the lobes and I find that helpful because otherwise you can't see them and you remember more about people than concepts. (P1)

I like that each character clearly shows what their purpose is. (P2)

They are relatable and don't make people feel bored when learning about the brain. (P2)

The names begin with the same letters the lobes begin with, which helps remember better. (P4)

They aren't quite as colourful as I would like more colour. (P1)

#### 3.4.3. Resource content

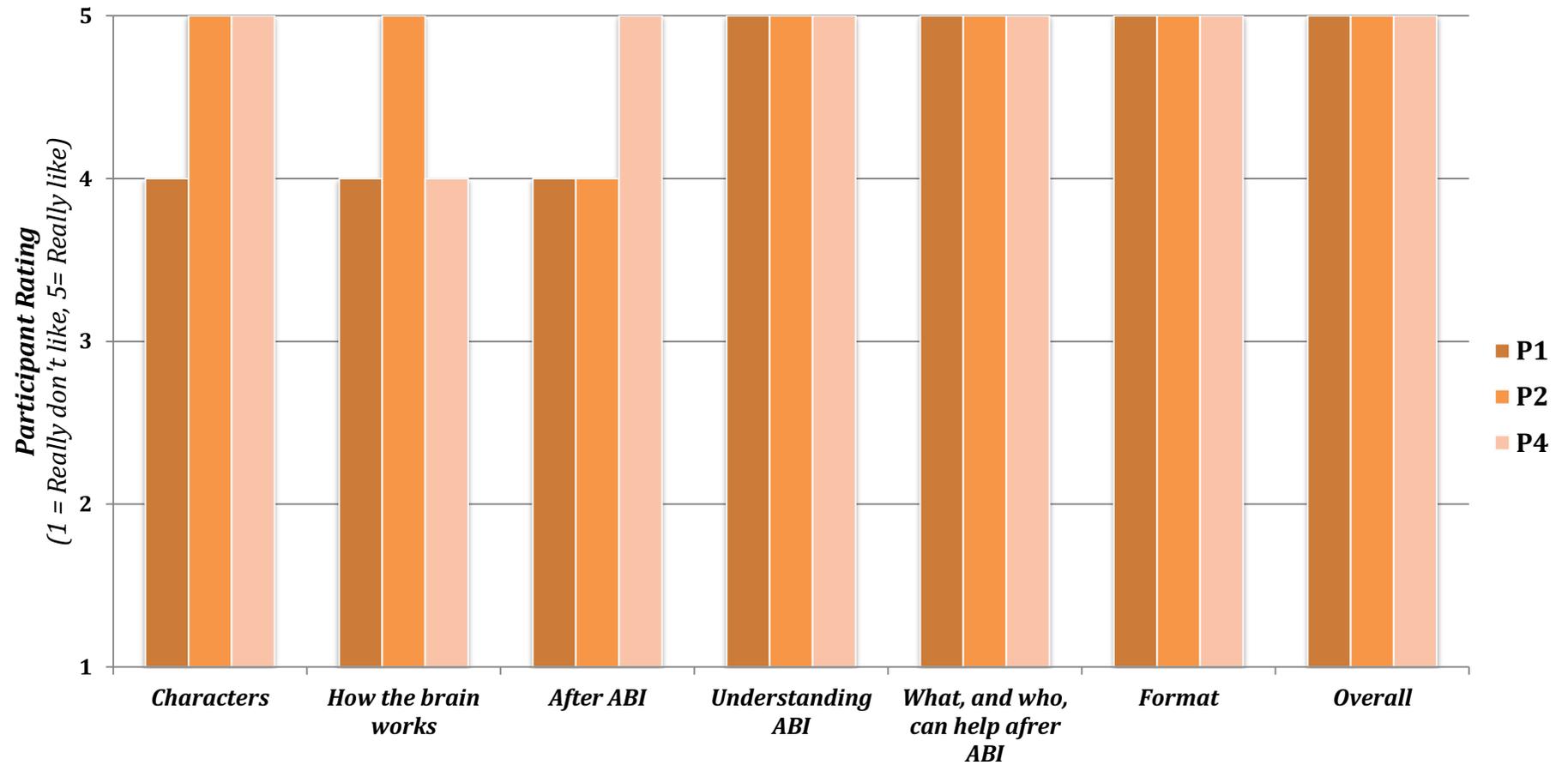
Participants made positive comments in relation to resource content, expressing their view that it communicates how the brain works in an accessible and engaging way.

This really helps it be put in terms that everyone will understand. (P1)

It doesn't feel like I'm reading from a source, rather that I'm looking at a story. (P2)

I like how when introducing them they say what skills they have, which link to what part of the lobe is good at. (P4)

Figure 2: Participant feedback ratings on 'The Lobe Family'



When asked to consider the acceptability of the way 'The Lobe Family' explains some of the difficult things that happen after an ABI, one participant provided a rating indicating that they 'really liked' how this was communicated, whilst two participants 'liked' this. Participants provided positive comments relating to how understandable, accessible and relatable this section of the resource was, and that this could help make ABI feel less scary for CYP. Nevertheless, one participant commented that they felt that a potential area for improvement was in ensuring the resource also talks about issues around engaging in social situations.

I like how it goes through the difficulties after brain injury for people to understand. (P4)

It adds a more personal touch to the story and makes it more relatable.... I like that it shows what life is actually like for someone with a brain injury. (P2)

It's all hard to think about. I think that it is good because it makes it seem less scary. (P1)

You could talk about how it'll affect his social life. (P2)

When asked to consider the way 'The Lobe Family' explains ABI, all three participants provided a rating indicating that they 'really liked' how this was communicated. Participants commented that they liked how the resource helped explain the variety of difficulties that can be experienced after an ABI, and that this was done in a way that was easy to understand, but not patronising. Participants also commented positively on how this section of the resource made it more relatable to their everyday life and experiences. Nevertheless, participants suggested that this section could be improved by providing some practical strategies for managing difficulties, or by elaborating on the injury itself.

Cause it shows that not all brain injuries are the same. (P2)

It says it in a way that does not condescend... but it says it in easy to understand terms. (P1)

I like that it shows the struggles of everyday tasks after a brain injury. (P2)

It could give you other ways to solve your problems when having had a brain injury. (P4).

They could explain how the accident gives a brain injury, like what damaged the brain. (P4)

When asked to consider the way 'The Lobe Family' explains what, and who, can help after ABI, all three participants provided a rating indicating that they 'really liked' this. Participants provided positive comments about how the resource would be able to help CYP to realise the variety of support that could be available to them following an ABI, and that this was likely to make them feel less alone. Furthermore, one participant stated that they felt that accessing the resource might help CYP to feel more comfortable with the process of seeking support by reducing feelings of shame and guilt.

I like how they help you know and understand who and what can help you after experiencing brain injury... It helps you know and understand what and who can help you after brain injury if you ever unfortunately have to experience it. (P4)

I like that it gives you a variety of options. (P2)

It makes you see like you are not alone as you can have support. (P1)

It makes it ok and sensible to think about. It tells you to be you and you are not a horrible person. (P1)

#### 3.4.4. Feedback on resource format

Participants provided positive comments on the resource being available in multiple formats, and that having choice in how CYP could view 'The Lobe Family' was helpful in enabling access to the resource. Participants also commented favourably on the how personalisable the resource was, and its ability to provide interactive links to other validated informational resources.

Because it gives various options when it comes to learning about brain injury.... I like that you could select your research to best fit my lifestyle. (P2)

It is personalisable and helps you to access some similar things. (P1)

I really like how they have made it into an interactive and personalisable app because it would be much easier to access... I think it would be much easier to access rather than having to go through the effort and time of logging and switching on a computer to access it. (P4)

#### 3.4.5. Overall feedback on 'The Lobe Family'

When asked to consider the overall acceptability of 'The Lobe Family' resource, all three participants provided a rating indicating that they 'really liked' it. Participants provided positive comments regarding how the resource would be helpful in supporting CYP to understand ABI, and the various sources of support that could be available.

It is a resource that really puts everything into understandable terms. (P1)

Because I feel the resource is helpful and will give a better understanding of brain injury. (P2)

I like the idea of it all, people may find it easier to understand. (P4).

I like that they show what part of the brain does what, and talks about the help that you can get after the injury. (P2)

Whilst feedback was overwhelmingly positive, participants also suggested some potential areas for improvement. One participant commented that the resource could be improved through increased graphical qualities and introducing 'fun facts' throughout the resource. A second participant commented that it might be helpful for some of the characters to be animals, whilst a third felt that the resource could be expanded to discuss issues related to engaging in social situations.

## **4. Discussion**

This thesis describes the collaborative development and preliminary evaluation of 'The Lobe Family', a new psychoeducational resource for CYP who have experienced an ABI. This chapter critically discusses the key findings of this thesis in relation to the academic literature and existing resource, and how these have contributed to resource development. This thesis is then subjected to a critical and reflexive examination, with exploration of the implications of the findings. It will be concluded that with further development and evaluation, 'The Lobe Family' may represent an acceptable psychoeducational resource with the potential to meet the outstanding informational needs of CYP who have experienced an ABI.

### **4.1. Summary of key findings**

This section provides a summary of the key findings from this thesis, and a critical discussion of how they have contributed to the development of a prototype psychoeducational resource for CYP who have experienced an ABI, 'The Lobe Family'. This is a strengths-based approach rooted in the narrative framework (White & Epstein, 1990), whereby four characters act as external representation of the lobes of the brain, embodying their associated neurocognitive functions through preferences, strength and appearance. Through four storylines, one for each character, 'The Lobe Family' seeks to meet the informational needs of CYP through the communication of key neuropsychological and psychosocial difficulties experienced post-injury. The remainder of this section seeks to summarise the findings from this thesis, and to critically discuss how they have contributed to the development of 'The Lobe Family'.

#### **4.1.1. Meeting informational needs**

Despite information being a key need for CYP following ABI (Murray, Maslany & Jeffery, 2006; Sweeney, Vilner, Booy & Christie, 2013), little attention has been paid to meeting these needs in the academic literature (Forsyth et al, 2017). The need for a new psychoeducational resource was reinforced by the views of participants, who emphasised the importance of developing an understanding of

their condition as part of their recovery. Whilst participants spoke of having acquired a relatively good understanding of ABI, this had involved a time-consuming process of self-discovery with the support of the collaborating organisation. Given that many CYP who experience an ABI do not have access to such comprehensive neurorehabilitation services (Emanuelson et al., 2013; Javouhey et al., 2006; Slomine et al., 2006), the enthusiasm showed by participants towards the development of a new psychoeducational resource took on greater salience. The remainder of this section critically explores how ‘The Lobe Family’ seeks to meet these outstanding informational needs.

#### *4.1.1.1. Neuropsychological*

Whilst it was considered important that a new resource communicates how anatomical structures become localised and specialised in function, it was felt that this should be conceptualised at a lobal level as CYP typically experience both focal and diffuse damage as a consequence of ABI (Bigler et al., 2016; Boll, 1983). Whilst this may be considered reductionist, the accessibility of this approach was deemed appropriate given the views of CYP that a new resource should communicate how the brain works, and thus led to the development of the four characters in ‘The Lobe Family’. It was also felt that the resource should be able to communicate concepts of neuroplasticity and interconnectivity in the context of the developing brain (Macher & Olie, 2009; Meunier, Achard, Morcom & Bullmore, 2009). This was addressed in ‘The Lobe Family’ through exploring character interaction before and after an ABI. The extent to which ‘The Lobe Family’ communicates the evolving nature of ABI may be questioned given the current lack of explicit discussion of neurocognitive stalling (Chapman, 2007), and this may therefore represent an area of that requires greater consideration in further development.

#### *4.1.1.2. Psychosocial*

Consistent with literature demonstrating that ABI can have a profound impact on wellbeing, sense of self and identity (Myles, 2004; Rittman et al., 2007; Wilson et al., 2015), participants were clear in arguing that psychosocial issues relating to ABI need to be addressed in a new psychoeducational resource. Participants

talked about the challenges of coming to terms with ABI, and the range of difficult feelings that may be experienced throughout this process such as low mood and guilt. This is consistent with a literature suggesting that feelings of frustration, anger and depression are common amongst CYP who have experienced an ABI (Hart et al., 2017), as are psychosocial difficulties such as low self-esteem, guilt, social rejection, and poor emotional wellbeing (Carrol & Coetzer, 2011; Hawley, 2012; Mealings & Douglas, 2010). A key finding from this thesis was the importance CYP placed on a new resource communicating a strong message that ABI is not the fault of CYP. 'The Lobe Family' sought to address this through exploring the intrapsychic experiences of the character that experiences an ABI with a view to normalising difficult feelings (von Mensenkampff et al., 2015). Nevertheless, 'The Lobe Family' stops short of providing therapeutic strategies for managing psychosocial difficulties associated with ABI, and this may therefore represent an area that requires further consideration (see section 4.1.2.).

#### 4.1.1.3. *Systemic*

Participants acknowledged that they had been fortunate to have benefited from the persistence of their parents in offering support and advocating on their behalf, and from accessing specialist neurorehabilitation services. However parental resources are often stretched by the demands of caring for a child with ABI (Paulos, Cole & Tankard, 2009; Gan et al., 2006; Wade et al., 1996; Wade, Wolfe, Brown & Pestian, 2005), and few have access to specialist support services (Emanuelson et al., 2013; Slomine et al., 2006). This is further compounded by the findings of this thesis that it can be difficult for CYP to know support may be available. Whilst 'The Lobe Family' sought to address this through the introduction of supplementary characters, participant feedback that providing strategies to promote recovery would enhance the resource suggests that this may be an area for further development. Consistent with research suggesting that feeling of guilt and shame can be a barrier to help-seeking behaviour (John et al., 2016) participants felt that explicating what support may be available in a new resource may help normalise such behaviours and make them more acceptable to CYP.

A further key finding related to the importance of a new psychoeducational resource being able to address the lack of awareness and understanding of ABI amongst people in the networks of CYP. Whilst supporting others understanding of ABI had not been previously considered a primary aim of this thesis, these findings are consistent with research highlighting a lack of knowledge of ABI amongst parents and teachers (Bigler, Clark, & Farmer, 1997; Glang & Todis, 1993), and holds parallels in the adult literature of carer's understanding of ABI (Durham & Ramcharan, 2017). Attribution theory (Heider, 1958) suggests that people are 'naive psychologists' operating in a social world, and show a tendency to attribute the behaviour of others to internal characteristics rather than external or circumstantial factors (Weiner, 1992). McClure (2011) links misattributions of the behaviour of CYP who have experienced an ABI behaviour to two features; the lack of visible markers and the tendency to draw comparison to peers rather than pre-injury performance. It is therefore anticipated that increased knowledge of ABI would result in a reduction in the misattribution of CYP's difficulties after ABI. This may be extended upon in relation to the views of one participant that ABI is not in itself problematic, but can become so in relation to the beliefs and actions of others, a view consistent with the social model of disability (Oliver, 2006).

#### 4.1.2. Therapeutic value

Whilst psychoeducation may be considered a therapeutic approach in its own right (Goldman, 1988), its efficacy may be enhanced if framed within a wider framework. A review of therapeutic approaches recommended by clinical guidelines (NICE, 2014) led to the narrative framework (White & Epstein, 1990) being chosen as the most appropriate therapeutic approach to ground resource development. The technique of externalisation was drawn upon due to its established therapeutic efficacy in meeting the psychosocial needs of CYP who have experienced an ABI, particularly around issues of identity and adjustment (Perkins, 2015; Segal, 2018; Ullman, 2016). This led the researcher to develop the conceptual basis for 'The Lobe Family' whereby characters acted as external representations of the four lobes of the brain to communicate neuropsychological concepts. As a strengths-based approach, the use of the narrative framework is

supported by the views expressed by participants that one's own strength and resilience plays in facilitating recovery, although this needs to be carefully balanced with a realistic acknowledgement of the difficulties that CYP are likely to face after experiencing an ABI.

Whilst behavioural (Bandura, 1976; Skinner, 1971; Watson, 1913) and cognitive-behavioural (Beck, 2011) approaches were rejected, participant feedback that providing strategies to support recovery would enhance 'The Lobe Family' suggests that the integration of these may be of therapeutic value. Whilst issues of epistemological compatibility with the narrative framework would need to be addressed, this represents an area for consideration in further development.

Challenges associated with acceptance featured prominently in the views expressed by participants, who spoke from personal experience of taking steps to deny or hide the extent of their difficulties after ABI, and highlighted the importance of accepting one's own difficulties as the first step towards recovery. This may be considered consistent with theories of grief that suggest that in order to achieve healthy normality individuals must progress through a series of stages following a traumatic event such as denial, anger, bargaining, depression, and finally acceptance (Kubler-Ross, 1969). Whilst such theories have been heavily criticised for their linearity and ethnocentrism (Klass, Silverman & Nickman, 1996), the concept of acceptance has been shown to have therapeutic value in working with CYP who have experienced an ABI (Brown et al., 2013; Hayes et al., 1999). It may therefore be argued that incorporating techniques from acceptance and commitment therapy (ACT; Hayes et al., 1999) would enhance the therapeutic value of 'The Lobe Family'.

#### 4.1.3. Developmental and pedagogical appropriateness

Despite the importance of tailoring information to an appropriate developmental level for the intended audience (Falk, von Wendt & Klang, 2008; Gagnon, Swaine, Champagne & Lefebvre, 2008), it was acknowledged that age is a poor predictor of cognitive ability within the ABI population (Catroppe et al., 2012; Gordon, 2014). This presented a dilemma in resource development as the theoretical literature advocated drawing on stage theories of cognitive

development premised on age (e.g. Piaget, 1936). This challenge was further complicated by the views of participants that a new resource should strike a balance between being accessible, although not infantilising. This was taken to relate to both the content of 'The Lobe Family', the language complexity and concreteness (Kass et al., 2011; Mayer & Moreno, 2003; Tait et al., 2007), and the style in which it was delivered.

When presented with initial ideas for 'The Lobe Family', participants took particular issue with the character names as it was felt that they were somewhat infantilising. This was considered a particularly significant finding given that meaningfulness and relatability of resources is associated with increased engagement and learning (Bakker et al., 2018). This was addressed through the decision to create multiple versions of 'The Lobe Family' pitched at different developmental levels in terms of language complexity, concreteness and complexity (Kass et al., 2011; Mayer & Moreno, 2003; Tait et al., 2007). This fitted well with another key finding that a new psychoeducational resource should be delivered in multiple formats. The main benefit of this from the perspective of participants was that it would enable both CYP and adults with a range of informational and technological preferences to meaningfully engage the resource. This is consistent with research indicating that CYP and adults have different informational needs and learning styles (e.g. Barbe, Swassing & Milone, 1979; Turkstra et al., 2016). This led to it being proposed that 'The Lobe Family' should be made available in two paper-based formats; books tailored to a younger developmental ability, and comics for older. Given participant feedback that a new resource should be personalisable, interactive and accessible on mobile devices, a web-based app version of 'The Lobe Family' was also proposed. This view is consistent with research indicating that adopting preferred technologies of intended audiences increases engagement and learning (Ann, McCall, Hee & Kim, 2015). Whilst it was anticipated that 'The Lobe Family' would be independently accessible by CYP, supported learning through a parental or professional facilitator may provide additional benefits by ensuring information is presented in the hypothesised 'zone of proximal development' where optimum learning is thought to occur (Vygotsky, 1934; 1978).

Learner-centred pedagogy (O'Sullivan, 2004) was chosen as the most appropriate framework for the delivery of the resource. This approach encouraged guided participatory exploration to enable learning (Rogoff, 1990), providing additional benefits to the didactic teacher-centred and experiential learner-centred approaches (Waring & Evans, 2015). This was addressed in 'The Lobe Family' through the communication of neuropsychological and psychosocial concepts for CYP to relate to their own injuries and experiences. This is consistent with the social constructionist epistemology of the narrative framework, which acknowledges that individuals construct their own realities.

#### 4.1.4. Acceptability of 'The Lobe Family'

Whilst some resources for CYP who have experienced milder forms of ABI have been evaluated (e.g. Olsson et al., 2015), this thesis describes the first evaluation of a psychoeducational resource for CYP who have experienced an ABI resulting in enduring difficulties. Feedback provided by participants was overwhelmingly positive, suggesting that the resource is highly acceptable to CYP who have experienced an ABI. Participants expressed their view that the characters in 'The Lobe Family' were engaging, relatable and helpful in supporting learning about ABI. They also reported liking the proposed three formats for the resource, commenting particularly on the web-based app's ability to be personalised and link to other validated informational sources. Nevertheless, participants suggested that the resource could be enhanced through the use of improved graphical and illustrative qualities.

Participants provided positive feedback on each of the four sections of the prototype resource, indicating that they felt that it would meet the informational needs of CYP who have experienced an ABI in an accessible and engaging manner. Participants particularly liked how relatable the content of 'The Lobe Family' resource was to their own experiences, and felt that this would help reduce the likelihood of difficult feelings associated with ABI. Nevertheless, participants suggested a number of areas in which the resource could be enhanced. These suggestions tended to be ideas for what could be added, rather than what could be changed about the content of the resource. These included placing greater emphasis on the social challenges faced by CYP after ABI, and

providing clearer examples of what support may be available from people in their networks. One participant suggested that some of the characters could be animals, whilst another felt that ‘fun fact’ additions would enhance the resource. These are ideas that should be considered as a priority in any further development of the resource.

#### 4.1.5. Comparison to existing resources

Whilst there is a growing body of research relating to post-concussion symptoms in student athlete populations (Bagley et al., 2012; Cuisimano, Chiman, Donnelly & Hutchinson; 2014; Hunt, 2015), these are primarily aimed at enabling rapid response and preventing deterioration. Furthermore, whilst a small number of informational resources designed to support symptom management post mild ABI have been described in the academic literature (Ponsford et al., 2001; Olsson et al., 2015; Renaud et al., 2016), these are unlikely to be meaningful to CYP with enduring impairments in neurocognitive functioning. This thesis therefore makes a significant contribution to the existing literature by being the first study to describe the development and preliminary evaluation of a new psychoeducational resource for CYP who have experienced a moderate to severe ABI that has resulted in enduring impairment in neurocognitive functioning.

‘The Lobe Family’ may also be compared to the existing informational resources that have not been described or evaluated in the academic literature. A review of such resources identified that these tend to take the form of physical resources such as illustrated books and comics, and tell stories of characters who have experienced an ABI (e.g. Batchelor & Mayer-Hall, 2005; Channa, 2006; Chilman-Blair, 2014; Palmer, 1998). In presenting a single narrative about ABI and communicating the impacts and consequences that a character experiences as a consequence of ABI, these resources fit well with a didactic teacher-centred pedagogy (Hancock, Bray & Nason, 2003). This differs significantly from the learner-centred pedagogical approach adopted by ‘The Lobe Family’ (O’Sullivan, 2004), whereby meaningful engagement in the learning process is guided by the communication of key neuropsychological concepts in a way that CYP can relate to their own experiences. Additionally, ‘The Lobe Family’ marks a departure from the problem-focused approaches of these resources through its grounding in the

strengths-based narrative framework (White & Epstein, 1990), with the aim of thickening subjugated themes of resilience to facilitate recovery. The importance of presenting information at a developmental appropriate level, both in terms of content and style, was a key finding of this thesis. The majority of existing resources are targeted at younger audiences, typically between the ages of five and eleven, and do not communicate complex and nuanced aspects of ABI. Whilst some resources are designed for adolescent audiences (e.g. Arnold, 2008; The Children's Trust, 2018), the extent to which these meet the informational needs of CYP who have experienced an ABI is unclear, as they have not been formally evaluated.

## **4.2. Critical review**

This section subjects this thesis to a rigorous critical and reflexive review. Limitations relating to the methodology are discussed with reference to their influence on shaping the findings and resource development. Issues of reliability and validity are addressed in terms of contribution, credibility and rigour (Spencer and Richie; 2011). This is followed by an exploration of issues of power inherent in the research process, and how these may have influenced this thesis.

### **4.2.1. Sample limitations**

A relatively small sample was recruited to participate in this thesis, limiting the diversity of views that contributed to resource development and evaluation of acceptability. Despite anticipating a larger sample size, and the significant efforts of the collaborating organisation, recruitment was challenging. Given that CYP who have experienced an ABI represent a small and over-researched population (Rumney, Anderson, & Ryan, 2015), it is possible that clinicians were reticent about approaching some CYP they were working with. It is also likely that many CYP accessing the collaborating organisation's services were excluded due to the recentness of their injuries and potential for participating to be perceived as re-traumatising. A small number of potential participants decided not to proceed with participating after receiving the study's information sheets, although gave no reasons for this. Despite it being difficult to draw reliable conclusions from such a small sample, the views of participants were highly influential in influencing

resource development. It is therefore difficult to conclude as to whether 'The Lobe Family' meets the informational needs or is acceptable to the full spectrum of CYP who have experienced an ABI.

Ensuring diversity was challenging in the context of a small sample. All participants in the second phase of the research were male, and therefore things that may have been of particular importance in a new psychoeducational resource to young females could not be assessed. Whilst the young female participating in the fourth phase gave similar feedback to that of the young males, her suggestion that the resource may have been enhanced if the characters were animals may suggest some preferential differences. All participants were of a similar age, potentially restricting the generalisability of the findings of this resource to those outside this range. Nevertheless, the sample was broadly consistent with epidemiological research indicating higher prevalence in boys, and those of similar age to recruited participants (Colantonio et al., 2011; Yates et al., 2006). Whilst no data on severity was collected in this research, it is likely that those recruited from residential services would have a greater degree of impairment. Given that only one participant from residential services was recruited, it is possible that the views of CYP with more severe impairments have not been fully captured in this thesis. This is further compounded by the exclusion of CYP who use augmented and alternative communication tools, as this is likely to represent a group with a greater degree of impairment. It is acknowledged that all participants had been in receipt of extensive neurorehabilitation support from the collaborating organisation. Given that only a small proportion of those who experience an ABI receive appropriate neurorehabilitation services (Emanuelson & von Weldt; Javouhey et al., 2006), with those from more complex familial circumstances being least likely to have access (Slomine et al., 2006), the results may be potentially biased towards those with a better experience of services. It may be argued that CYP who have not benefited from such services may have a poorer relationship to help (Reder & Fredman, 1996), and they may therefore have different informational needs.

Only two ethnic groups were represented and cultural diversity was fully not accounted for. Given previous research suggesting variation amongst cultural

and ethnic groups in beliefs about ABI and challenges faced in participation post-injury (Diaz, 2013), it is difficult to reliably conclude whether 'The Lobe Family' is universally acceptable. Despite the researcher using supervision to consider these issues from an early stage, it is acknowledged that their implicit biases as a white-British male may have exacerbated the impact of the lack of sample diversity in resource development. This was particularly evident in the westernised connotations present in both the names given to characters and their skin tone in material presented to participants. Whilst participants made no comments relating to the ethnicity of characters, the lack of ethnic diversity may present a barrier to some audiences identifying and engaging with the resource. One possible solution may be to provide a personalisation option in the web-based app relating to ethnicity, whilst another may be for characters to be drawn with different skin-tones.

Reflecting on the challenges of recruitment, the researcher acknowledged the significant learning that had occurred whilst engaging in these processes. It was considered significant that the project's original Director of Studies (DoS), who held a dual role at the academic institution and collaborating organisation, was only available during the development phase of this thesis. Whilst the researcher was academically well supported by their newly allocated DoS, the loss of a direct connection with the collaborating organisation was keenly felt. This resulted in the project's progress being somewhat delayed as the researcher needed to develop new relationships with the collaborating organisation, and to renegotiate recruitment streams with their new field supervisor and the organisation's service leads. Taking the time to establish these relationships was found to have significant benefits for the researcher, such as enhancing recruitment processes and from the clinical expertise and consultation they were able to provide. In reflecting on this, the researcher was struck by the consistency between their learning and the leadership development framework for Clinical Psychologists (BPS, 2010), which highlights the importance of communication and collaboration in professional and research contexts

#### 4.2.2. Interviews

Interviews broadly adhered to the interview schedule, although were tailored according to what the researcher perceived to be an appropriate level for each participant. On reviewing interview transcripts it became evident that interviews had varied in the extent to which the researcher had scaffolded participant's responses. This potentially introduced a source of bias as the scaffolding provided by the researcher may have shaped participant's responses. This may have been further compounded by parents' tendency to express their views or prompt participants. Whilst parental speech was not transcribed during the analytic process, entries were made in transcripts to denote their interventions to provide context for participant's comments and to ensure that the researcher remained mindful of the impact this may have had.

#### 4.2.3. Quality assurance: Reliability and validity

This section explores issues of quality assurance, reliability and validity. This is presented in relation to the three principles of quality in qualitative research described by Spencer and Richie (2011) contribution, credibility, and rigour.

##### 4.2.3.1. *Contribution*

Contribution refers to the value and relevance of research evidence in relation to theory, policy and practice. A full review of the academic literature, coupled with a less formalised review of existing informational resources for CYP who have experienced an ABI, led to the identification of a clear rationale for the development of a new psychoeducational resource. This thesis may therefore be said to go beyond the existing literature and make a significant contribution through the development of a resource that helps meet the informational needs of CYP who have experienced an ABI.

##### 4.2.3.2. *Credibility*

Credibility refers to the validity of the claims made by the research. Credibility can be understood as being the product of defensibility and plausibility of the findings, and the clarity with which conclusions are reached (Spencer & Richie, 2011).

Analytic processes closely adhered to the six-step process detailed by Braun and Clarke (2006), and an exemplar extract from analysis is included (Appendix L). Whilst the researcher conducted this thesis independently, supervision has been provided on a regular basis from both the collaborating organisation and the academic institution. Initial findings were discussed in these forums, providing a sense-check on the believability of the themes identified by the researcher. Participants positive feedback on the prototype resource suggests some degree of member-validation (Angen, 2000), although time-restraints on submission have prevented a full summary of findings being provided at this time, although this is a key goal of dissemination.

#### 4.2.3.3. *Rigour*

Given that concepts of reliability and consistency are problematic in the context of assumed subjectivity inherent in interpretation process of qualitative research, demonstrating this principle may be best understood as the transparency with which processes are described (Yardley, 2000). The researcher sought to provide a clear rationale for the decisions made relating to the epistemology, methodology, methods, data sources and analytic procedure adopted throughout this thesis. Despite the relatively small sample size for the present research, the researcher sought to maintain a balance in the data extracts provided in the results chapter to help avoid under or over-analysis (Nowell, Norris & White, 2017).

#### 4.2.4. Power relations and collaboration

CYP, particularly those with disabilities, are amongst societies most oppressed groups (Pratto, Stewart & Zeineddine, 2006), and their voices are frequently marginalised in service contexts. Whilst conventional models involve CYP solely as data-giving participants, involvement and participation in the research process is associated with increased relevance and robustness (Staley, 2009). These principles are highly consistent with neurorehabilitation policy (Kirkwood et al., 2008; NICE, 2014) and the therapeutic aims of psychoeducation, and can support the reduction of inequality by balancing power relations (Meyer & McKenzie, 2017). National Children's Bureau (2011) guidelines for research with

CYP discuss varying levels of user-involvement in research, ranging from acting as consultees in the planning process to full ownership. Whilst involvement of CYP through participatory action research was considered as an epistemologically consistent methodology (Kemmis & McTaggart, 2005), it was felt that relinquishing full ownership of the project risked the possibility of developing a resource that was not grounded in the theoretical and research evidence, and would therefore not meet the populations informational needs. Whilst this remains the researcher's position, it is acknowledged that this thesis would have been enhanced by user-participation in the development of the research proposal. An example of where this may have been particularly beneficial would have been in seeking feedback on information sheets and recruitment strategies, as this may have facilitated greater sample size.

Whilst this thesis sought to prioritise collaboration with CYP who have experienced an ABI in the development of a new psychoeducational resource, it may be argued that this was not fully achieved given power imbalances inherent in the research process (Bhopal & Deucha, 2015). It is acknowledged that whilst participants contributed to the development of 'The Lobe Family' and were invited to provide feedback on its acceptability in, the researcher held full responsibility for study design and resource development. It is possible that the researcher's lens may have led them to interpret the comments made by CYP differently to how they had been conceived, introducing a potential source of bias. It is also likely that the researcher's status as an adult may have exacerbated power imbalances inherent in the researcher-participant dynamic. Efforts were made to minimise these imbalances by seeking to establish a relationship with participants prior to interviews commencing, and being explicit in giving permission to express critical views. Whilst it is not possible to fully evaluate how successful this was in minimising issues related to power imbalances, it was noted that participants were forthright with their views at times of disagreement with ideas suggested by the researcher, such as in relation to character names.

Guidelines also recommend that researchers remunerate CYP appropriately (Kirby et al., 2003), which raises an important ethical issue that payment may disproportionately attract disadvantaged people to participate when they

otherwise wouldn't. This thesis did not adhere to these guidelines as no remuneration was offered to participants, although they were promised a copy of finalised resource and the possibility of their contribution being recognised as a collaborator. This raises an ethical dilemma as participant's rights to anonymity contradict recommendations that the contributions of CYP should be meaningfully recognised (Stickley, 2006). Nevertheless, participants and their parents were enthusiastic about the prospect of waiving their right to anonymity in order to be named on a final resource, and this should be explored prior to any publication.

#### 4.2.5. Researcher reflexivity

Engaging in praxis is an integral part of the Clinical Psychologist role (Bengough & Karin, 2017; BPS, 2017), and is of particular importance in qualitative research due to the researchers role in interpreting participant's responses. One area of concern related to the discrepancy between the ideas generated by the researcher and the views expressed by participants in relation to the prominence with which psychosocial issues featured. Whilst a review of the literature had identified research highlighting psychosocial issues as a key impact of ABI (e.g. Carrol & Coetzer, 2011; Hawley, 2012; Mealings & Douglas, 2010), these had not featured in the initial ideas generated by the researcher. Reflecting on possible explanations for this, the researcher considered whether their lack of experience working with paediatric ABI populations may contributed to this, although given their experiences working clinically with other child populations this was unlikely to be a complete explanation. The researcher acknowledged that phase one had been conducted rapidly at a time when they were encountering significant additional academic and clinical demands. Whilst this was unavoidable given time restraints, the researcher considered it likely that their reflexive capacity may have been reduced by the competing demands placed upon them. This is likely to have resulted in the researcher becoming increasingly task-focused in their attempts to develop a resource that was consistent with the literature base, leading to the neglect of challenges faced by CYP who have experienced an ABI.

### **4.3.            *Implications***

This section considers the implications of the findings of this thesis. This includes considering the implications for clinical practice, as well as what the findings may mean at a policy level.

#### **4.3.1.            Clinical psychology practice**

The findings of this thesis reinforce the view that CYP have outstanding informational needs that accessing psychoeducational resources such as ‘The Lobe Family’ may help meet. Whilst it is acknowledged that a number of alternative resources exist (e.g. Batchelor & Mayer-Hall, 2005; Channa, 2006; Chilman-Blair, 2014; Ray & Parsons, 2013), these tend to be targeted at younger CYP and have not been formally evaluated. It is therefore argued that ‘The Lobe Family’ has the potential to be a valuable addition to the range of resources available to CYP who have experienced an ABI. Nevertheless, the findings of this research also suggest that awareness of existing resources is low amongst CYP who have experienced an ABI. One possible explanation of this is that most resources have been developed by specialist neurorehabilitation or third-sector organisations, which only a small proportion of CYP who experience an ABI have access to (Emanuelson et al., 2013). Whilst this suggests that greater public investment is required in such services to increase their capacity to meet the demand, it also implies that more could be done to publicise the existence of psychoeducational. It is therefore recommended that efforts are made to raise awareness of existing resources and ‘The Lobe Family’ once a final version is produced. These should ideally be made available on a free-to-access basis and promoted in a range of educational, health and social care settings accessed by CYP who have experienced an ABI. This may be best achieved through exploring whether ‘The Lobe Family’ could be embedded within the existing informational website of the collaborating organisation, and distributing book and comic versions to institutions and services.

#### **4.3.2.        Policy**

Despite being recommended by best practice guidelines (Kirkwood et al., 2008; NICE, 2014), information is often not provided to CYP (Falk, von Wendt & Soderkvist, 2009; Grootens-Wiegers et al., 2015). This is reflected in the findings of this thesis regarding the importance of a new psychoeducational resource being able to help make sense of ABI, which suggests that this needs to be addressed at a policy level. Despite the wealth of evidence suggesting that information plays a mediating role in the efficacy of physical, cognitive and psychosocial neurorehabilitation (Danzi, Etter, Andretta & Kitzman, 2012), the standard contract for paediatric neurosciences only makes reference to the information around the use of medications (NHS England, 2013). The findings of this thesis emphasise the positive contribution that information has neurorehabilitation and recovery processes, and demonstrates the need for policy review to ensure these needs are met.

Lack of knowledge and understanding about ABI amongst teachers has a profound impact on CYP who have experienced an ABI, and educational institutions are ill prepared to cope with CYP who have sustained an ABI (Linden, Braiden & Miller, 2013). A review of gaps in paediatric neurorehabilitation identified this as a key issue, noting that teacher training does not sufficiently cover ABI and that schools do not routinely seek input if an attending child experiences an ABI (Hamilton et al, 2017). The findings of this thesis are supportive of Hamilton and colleagues' recommendations that professionals working with CYP who have experienced an ABI have access to an online training package, and developing this should be prioritised.

#### **4.4.            *Directions for future research***

This thesis provides preliminary evidence suggesting that 'The Lobe Family' has the potential to be an acceptable psychoeducational resource for CYP who have experienced an ABI. Nevertheless; it is acknowledged that 'The Lobe Family' has been developed collaboratively with a group of CYP that may not be fully representative of the ABI population, and it is difficult to reliably conclude on the acceptability of this resource to groups excluded from participating in this

research. Further validation of the acceptability of 'The Lobe Family' amongst a range of groups is recommended, most significantly amongst those who have not benefited from accessing specialist neurorehabilitation services. Whilst it is acknowledged that CYP who have experienced an ABI represent an over-researched population (Rumney, Anderson, & Ryan, 2015), it is hoped that the collaborating organisation may continue such evaluation. With the benefit of a greater understanding of the acceptability of 'The Lobe Family', It is recommended that further development of the resource should involve active and meaningful service-user participation from representatives of the ABI community.

Once a finalised resource is created, a robust examination of its ability to meet the informational needs of CYP will be required. This may involve a mixed-methods evaluation in which quantitative data, collected from pre and post measures of ABI-related knowledge and mastery over one's condition, are combined with qualitative data on whether CYP feel the resource met their needs. This evaluation would be significantly enhanced by assessing the secondary impact the resource has on neurorehabilitation processes given its theorised mediating role (Bains, Powell & Lorenc, 2007; Cunningham, 2009; Danzi, Etter, Andretta & Kitzman, 2012; Forsyth et al, 2017). Whilst this may be difficult to quantify, a correlational study comparing increases in knowledge and mastery over one's condition with established neurorehabilitation assessment tools may be of value. Further research may also seek to consider the differential impact of different formats on knowledge acquisition, and how factors such as learning style (e.g. Barbe, Swassing & Milone, 1979) mediate this. Given participant's views on the importance of 'The Lobe Family' supporting understanding of ABI amongst people in their networks, it may also be beneficial to evaluate the ability of 'The Lobe Family' to increase knowledge and understanding of parents, teachers, siblings and peers, and what benefits this might lead to.

#### **4.5. Conclusions**

This thesis describes the collaborative development and preliminary evaluation of 'The Lobe Family', a new strengths-based psychoeducational resource grounded in the narrative framework (White & Epstein, 1990) for CYP who have

experienced an ABI. Developed through integration of researcher-generated ideas derived from a review of the literature and the views of CYP who have experienced an ABI, 'The Lobe Family' seeks to communicate key neuropsychological concepts in a developmentally and pedagogically appropriate manner to CYP and others in their networks. The findings of this thesis suggest that multiple versions of 'The Lobe Family' should be developed to meet the diverse informational needs and format preferences of the ABI population, including both paper and web-based modalities. Findings also suggest there is room for further development, particularly around the therapeutic value of incorporating strategies to support recovery and acceptance-based techniques into a finalised resource.

This thesis makes a significant contribution to the academic literature in being the first study to describe the collaborative development of a psychoeducational resource for CYP who have experienced an ABI that has resulted in enduring neurocognitive difficulties, complementing research around mild TBI and managing post-concussion symptoms (Ponsford et al., 2001; Olsson et al., 2015; Renaud et al., 2016). Whilst a preliminary evaluation suggests 'The Lobe Family' may be acceptable to this population, methodological issues relating to the sample necessitate further exploration of how best to meet the diverse informational needs of the population. It is recommended that 'The Lobe Family' is further refined in the context of further research findings, and that this process should occur in partnership with CYP who have experienced an ABI wherever possible.

## 5. References

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## APPENDICES

### ***Appendix A: Literature search procedure***

#### **1. Databases Searched**

- Psychinfo
- Academic Search Complete
- CINAHL
- Science Direct
- PubMed
- ERIC

#### **2. PICO Strategy**

<b>P (Participant)</b>	Children and Young People who have Experienced an Acquired Brain Injury
<b>I (Intervention)</b>	Psychoeducative Approaches
<b>C (Comparison)</b>	Treatment as Usual
<b>O (Outcome)</b>	Increased Knowledge, Mastery, Self-Concept, Positive Identity, Confidence, Self-Blame, Self-Efficacy, Quality of Life

#### **3. Generic Search Terms**

#	PICO	Type	Area	Terms
1	P	Free Text	CYP	"Child*" OR "Young Person" OR "Young People" OR "Childhood" OR "Paediatric" OR "Pediatric" OR "Teenagers" OR "Adolescents" OR "CYP" OR "Youth"
2	P	Thesaurus	ABI	<i>Database vocabulary term(s) relating to ABI. *</i>
3	P	Free Text	ABI	"ABI" OR "Acquired Brain Injury" OR "TBI" OR "Traumatic Brain Injury" OR "Brain Injury" OR "Concussion" OR "Anoxic" OR "Hypoxic" OR "Encephalitis" OR "Meningitis"

4	I	Thesaurus	Psychoeducation	<i>Database vocabulary term(s) relating to psychoeducation.*</i>
5	I	Free Text	Psychoeducation	"Psychoeducation" OR "psycho-education" OR "psychoeducative" OR "psycho-educative" OR "psycho-ed" OR "Intervention" OR "information" OR "resource" OR "Health Education" OR Patient Education"
6	C	Free Text	Treatment as Usual	"Treatment as Usual" OR "TAU" OR "Care as Usual" OR "CAU" OR "Control" OR "Comparison" OR "Compared"
7	O	Free Text	Outcome	"Knowledge" OR "mastery" OR "Self-Concept" OR "Self Concept" OR "Self-Construct" OR "Self Construct" OR "Identity" OR "Confidence" OR "Self-Blame" OR "Self Blame" OR "Insight" OR "Self-Efficacy" OR "Self Efficacy" OR "Quality of Life" OR "QoL" OR "HRQoL" OR "Wellbeing" OR "Mental Health" OR "Symptomatology" OR "Adherence"

#### 4. Database Specific Search Terms (P - ABI)

Database	Thesaurus Terms
Psycinfo	DE "Traumatic Brain Injury" OR DE "Brain Damage" OR DE "Brain Concussion" OR DE "Cognitive Rehabilitation" OR DE "Head Injuries" OR DE "Periventricular Leukomalacia" OR DE "Encephalitis" OR DE "Meningitis" OR DE "Bacterial Meningitis" OR DE "Central Nervous System" DE "Brain Lesions (Disorders)" DE "Brain Disorders"
Academic Search Complete	N/A
CINAHL	MH Brain Injuries MH Head Injuries MH Rehabilitation, Cognitive MH Brain Diseases, Metabolic, Inborn MH Meningitis MH Encephalitis MH Brain Concussion MH Hypoxia, Brain

<b>PubMed</b>	MeSH: Brain Injuries MeSH: Brain Injury, Chronic MeSH: Head Injuries, Penetrating MeSH: Head Injuries, Closed MeSH: Head Injuries, Penetrating MeSH: Brain Diseases MeSH: Encephalitis MeSH: Meningitis
<b>Science Direct</b>	N/A
<b>ERIC</b>	DE Head Injuries DE Neurological Impairments

### 5. Database Specific Search Terms (I - Psychoeducation)

<b>Database</b>	<b>Thesaurus Terms</b>
<b>Psycinfo</b>	DE "Psychoeducation" DE "Client Education" DE "Rehabilitation Education" DE "Health Education"
<b>Academic Search Complete</b>	N/A
<b>CINAHL</b>	MH Psychoeducation
<b>PubMed</b>	MeSH: Health Education MeSH: Patient Education
<b>Science Direct</b>	N/A
<b>ERIC</b>	DE Psychoeducational Methods DE Health Education DE Medical Education DE Patient Education

### 6. Exclusion criteria

- Books/Theses/Dissertations
- Parenting/carer interventions
- Staff interventions
- Systematic reviews / editorials
- Relating to adult ABI
- Non-human participants
- Not relevant to ABI
- Not relevant to psychoeducation
- Not relevant to resources/interventions/packages

## **Appendix B: Information sheet (CYP)**



School of Psychology  
University of East London  
Stratford Campus  
Water Lane  
London E15 4LZ

### **The Principle Investigator**

Xxxxxx Xxxxxx

*Trainee Clinical Psychologist, University of East London*

### **Contact Details**

E-Mail: [xxxxxxxxxx@uel.ac.uk](mailto:xxxxxxxxxx@uel.ac.uk)

## **Development of a Psychoeducational Resource for Children who have Experienced an Acquired Brain Injury (ABI)**

Dear xxxxxxxxxxxx,

We are happy that you want to know more about our research! This letter gives you some more information about what we want to do.

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

We want to make something with you that helps children to understand brain injury and what we can do to help brains recover. We have some ideas, but we want to know what you think!

### **What do I need to do?**

- We will ask you to sign something to say you know what the research is about
- We will meet with you twice to talk about brain injury. We will also ask you what you think of some ideas we've got.

**What if I don't want to?**

That's ok. You don't have to!

If we have started talking and you want to stop, please tell us. We will stop. If you decide to stop we will still listen to what you have said.

**What if I say yes now, and change my mind later?**

That's also ok. You can change your mind at any time.

**What happens to my information?**

We will keep it safe for as long as we need it. This will be no more than three years. We think it'll be a lot less than this!

When the research is over I will destroy it. We won't give your information to anyone!

**What are we making?**

We want to create something that helps children to understand brain injury and what we can do to help brains recover. We need your help to make this.

We want to meet with you twice. We will first ask you to come and have a look at some of our ideas and tell us what you think of them. We will then go and use what you tell us to make it better. We will then want to meet with you again so you can see what we have made together.

**What will happen after?**

- You get to keep what we make together
- We would like to share our work together with people whose job it is to help children with brain injury. We will write something so they can read all about it.
- We will also tell you about what we have found out.

## **Why should I take part?**

- We need your knowledge!
- You will help us make our ideas better.
- Lots of children with brain injury will be able to use what we make.
- You will get to keep what we make

## **Is it safe?**

We don't think there are many risks of talking with us.

We will be talking with you about what you think of our ideas. We will ask you for your ideas too. We do know that sometimes talking about the brain may be upsetting, so if that happens we will talk with your parents to make sure you are ok.

If you tell us something that makes us worried that something bad might happen to you, we will try and keep you safe. If this happens then we would pass on our concerns to other people, such as the police. The reason we would do this is to make sure you stay safe. We would always try to talk to you about this first.

You can bring someone in with you to help keep you safe.

## **I want to take part... What happens next?**

We will ask you to sign a form to say that you agree to take part.

We hope to hear back from you.

XXXXXX XXXXXX  
*Trainee Clinical Psychologist*  
*University of East London*

Dr XXXXXXXX  
XXXXXXXXXXXXXXXXXX  
*University of East London*

## **Appendix C: Information sheet (Parent/carer)**



School of Psychology  
University of East London  
Stratford Campus  
Water Lane  
London E15 4LZ

### **The Principle Investigator**

xxxxxxxxxxx

*Trainee Clinical Psychologist, University of East London*

### **Contact Details**

E-Mail: xxxxxxxx@[uel.ac.uk](mailto:xxxxxxx@uel.ac.uk)

## **Development of a Psychoeducational Resource for Children who have Experienced an Acquired Brain Injury (ABI)**

Dear xxxxxxxx

Thank you for your interest in participating in our research project. The purpose of this letter is to provide you with the information that you need to make an informed decision as to whether you would like your child to take part.

### **Who are we?**

This study is being conducted by xxxxxx xxxxxxx (Trainee Clinical Psychologist) as part of a Professional Doctorate degree in Clinical Psychology (DClinPsy) at the University of East London.

Dr. xxxxxxxxxxx (xxxxxxxxx, University of East London) is supervising this project alongside Dr. xxxxxxx (xxxxxxxxxxxxx) and Dr. xxxxxx (xxxxxxxxx) from xxxxxxxx.

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

We want to make a resource that will help children and young people with an Acquired Brain Injury (ABI) understand brain injury and what helps the brain recover. Research and policy documents have recommended that we help children and young people understand brain injury so that they are more able to live the life they want. However, there are very few resources out there that do this, and even fewer that were really designed specifically for children and young people.

We want to work together with children and young people who have experienced a brain injury. We want to combine their expertise from their experiences with our ideas of what might work to create a fun and child-friendly, innovative and creative resource. We have some ideas about what might work, and we would like to share them with your child and see what they think. We also want to hear what ideas they have!

### **Why are we doing this?**

Research tells us that providing information to children and young people with a range of physical, neurological and mental health difficulties can be effective in supporting their wellbeing and sense of mastery over their life. This has been shown to be helpful in enabling them to live their life in the way they wish to.

Despite numerous research and policy documents recommending that we help children and young people understand their brain injury, there are very few resources available that do this, and even fewer that are really designed with children and young people at its centre. We want to fill this gap by making one together with your child!

### **What will happen if we decide to take part?**

You are under no obligation to participate. If you decide that you wish to take part then we will ask you, and your child, to sign a form to say that you understand what the research involves and that you understand your rights as a participant.

We will then invite your child to attend two interviews with myself, the principle investigator. The first interview will involve me asking your child what they think it is important for children to know about brain injury, and seeing what they think of our idea for a resource to help explain it. We will use this information to improve the resource we make together. The second interview will take place 2-3 months afterwards. We will bring a prototype of the resource we have created using the information your child gave us, and see what they think of it. This will help us understand if it meets the needs of young people with a brain injury.

Interviews will last approximately 45 minutes. Most children enjoy participating, and I will do my best to make sure it is a pleasurable experience for them. We would encourage you to join us and observe the interview. If you would like to participate, but cannot yet commit to the second interview then please let us know as you may still be able to participate.

### **What happens to the information I provide?**

The information you provide will be kept confidential and seen only by us.

We will record the discussions we and write them up, word for word. We will then go through this very carefully, and identify all the themes that come up. We will combine this with the information you and your child provide us through the short questionnaires you complete for us.

At the end of the research process we will dispose of this information in a way that makes sure that nobody else will ever see it. We will keep the information your child provides for an absolute maximum of three years before destroying it, although we anticipate it will be much less than this.

### **What if I change my mind?**

That's ok! You can change your mind about participating at any time.

If you or your child decide to stop participating during an interview then that's also ok. You don't have to give us a reason for why you want to do this if you don't want to continue, and doing so will not lead to you being disadvantaged in any way.

However, we would reserve the right to use the information your child has given us up to the point you decide to withdraw. As with all other information we are given in this research, we will use this in a way that ensures neither of you are identifiable in any way.

### **What happens to the results of the research?**

I will write up the results of this research in a report, and submit this to the University of East London as my doctorate thesis. We also hope to publish the study in an academic journal, and share the results with charities such as xxxxxxxx.

We will make sure that neither you, nor your child, will be identifiable in any way from anything that we publish.

We will also provide you with a summary of the results, and the developed resourced.

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

You and your child would be helping to create a resource that we hope will help a lot of children with ABI. We intend to take the information your child gives us in this research and use it to develop the resource.

### **Will I be paid for taking part?**

You will not receive financial payment for taking part, however, we will make sure that you receive a copy of the developed resource as soon as it is made.

**Are there any risks of taking part?**

We do not anticipate any risks to your child’s health and safety when taking part in this research.

We will only ask you brief and necessary details of your child’s brain injury so we can better understand you and your child. Despite this, we know that our discussions could remind you or your child of distressing times, and therefore we will be providing details of places where you can get immediate, and possibly longer-term, support if you, or your child, feel it would be helpful.

If you or your child tells us something that makes us think that they (or anyone else) is at risk of harm during the interview, then we have a duty to act on that information. If this happens then we would need to share our concerns with the relevant authorities, such as the police or social services. We would only be doing this to make sure that your child remains safe. If this happens and it is safe to do so, we would talk to you about this first.

**I have more questions... Who can I ask?**

You can contact me and I will be happy to answer your questions. My contact details are on the first page of this letter.

**I want to participate, what do I do now?**

Please contact me on [xxxxxxxxx@uel.ac.uk](mailto:xxxxxxxxx@uel.ac.uk)

I will then send you out a consent form. I will then be in contact to invite you to the interview.

**Xxxxx xxxxxx**  
***Trainee Clinical Psychologist***  
***University of East London***

**Dr xxxxxx xxxxxx**  
**xxxxxxxxxxxxxxxx**  
***University of East London***

## **Appendix D: Interview Schedule (Phase two)**

### **“The Lobe Family”**

### **Phase Two – Interview Schedule**

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#### **SECTION 1: BUILDING ENGAGEMENT**

- *Introductions and set-up*
- *Consent form and information sheet (go through together)*
- *Set expectations (time, what will happen etc.)*
- *Game?*

#### **SECTION 2: GENERAL THOUGHTS ON THE IDEA**

***We want to make something that helps children learn about brain injury.***

- *Do you like that idea?*
- *What do you like / not like about it?*
- *Do you know a lot about brain injury? – How much?*
- *Where did you learn about brain injury?*
- *Has anything helped you learn about brain injury?*

***We also want what we make to help explain how brains can get better.***

- *Do you like that idea?*
- *What do you like / not like about it?*
- *Do you know a lot about how brains can get better?*
- *Where did you learn about how brains can get better?*

***(\* We're really happy that you like our idea. Would you to make it together?***

***(\* I'm going to ask you some more questions. These questions will help us know exactly what to make. We'll then make it, and bring it back to see what you think. Is that ok?***

### **SECTION 3: WHAT DOES THE RESOURCE NEED TO COMMUNICATE**

***Before we start making something together. We'd like to know what you think children need to know about brain injury.***

***What do you think children need to know about brain injury?***

- *General prompts and discussion*

***(As appropriate) What is it important to say about;***

- *What its like to have a brain injury*
- *What happens after children have a brain injury?*
- *What skills children might feel harder after a brain injury?*
  - o *What about being able to think really hard (concentration)*
  - o *What about working things out (problem solving)*
  - o *What about using words (expressive)*
  - o *What about understanding what other people say (receptive)*
  - o *What about remembering things? (memory)*
  - o *Etc.*
- *How it makes children feel to have a brain injury?*
- *The things in life that change after a brain injury?*
  - o *How brain injury changes life at home with families*
  - o *How brain injury changes life at school*
  - o *How brain injury changes things with friends*
- *What is good about having a brain injury*

***Is there anything else that's important to say about brain injuries?***

*General discussion*

***What else would you like children to know about brain injury?***

*General discussion*

***Apart from having a brain injury, what would you like other people to know about you?***

*General discussion*

## **SECTION 3: THE LOBE FAMILY**

### **A. The Lobe Family**

***We have an idea for what we can make together. Our idea is called “The Lobe Family”. There are four people in the Lobe Family, one for each of the four areas of the brain.***

***We know that the four different areas of our brain have different skills. Just like the four areas of the brain, the four people in The Lobe Family have different skills.***

***We could use the four people in The Lobe Family to help children learn about brain injury?***

- *What do you think of that idea?*
- *Did you know that the brain had four areas?*
- *Did you know that these areas had different skills?*

***I'd like to introduce you to the four members of The Lobe Family. Is that ok?***

### **B. Characters**

***This is Freddy. Freddy is really good at things we know the front area of our brain does. We call this area the Frontal Lobe. This bit of the brain helps us be organised, plan things to do, solve problems, helps us keep control of how we feel, and stops us doing things that might be dangerous.***

***Just like the Frontal Lobe, Freddy is good at these things.***

- *What do you imagine Freddy to be like?*
- *What sort of things does Freddy like to do?*
- *What doesn't Freddy like to do?*
- *What does Freddy look like?*
- *Would you be friends with Freddy?*

**This is Tamara. Tamara is really good at things we know the side areas of our brain does. We call this area the Temporal Lobe. This bit of the brain helps us to know what things are when we see or hear them. It also helps us remember things, know who people are, and work out what different words mean.**

***Just like the Temporal Lobe, Tamara is good at these things.***

- *What do you imagine Tamara to be like?*
- *What sort of things does Tamara like to do?*
- *What doesn't Tamara like to do?*
- *What does Tamara look like?*
- *Would you be friends with Tamara?*

**This is Olly. Olly is really good at things we know the back area of our brain does. We call this area the Occipital Lobe. This bit of the brain helps us to see things like colours and movement.**

***Just like the Occipital Lobe, Olly is good at these things.***

- *What do you imagine Olly to be like?*
- *What sort of things does Olly like to do?*
- *What doesn't Olly like to do?*
- *What does Olly look like?*
- *Would you be friends with Olly?*

**This is Patricia. Patricia is really good at things we know the top area of our brain does. We call this area the Parietal Lobe. This bit of the brain helps us to understand what all the things we feel, hear, and see mean. It also helps us keep our balance, use words, read, write and do maths.**

***Just like the Parietal Lobe, Patricia is really good at these things.***

- *What do you imagine Patricia to be like?*
- *What sort of things does Patricia like to do?*

- *What doesn't Patricia like to do?*
- *What does Patricia look like?*
- *Would you be friends with Patricia?*

### **C. Character Interaction**

***The four areas of the brain work together very closely. If one area of the brain is injured, then the other areas can use what they are good at to help out.***

***Just like the four areas of the brain; if Freddy, Tamara, Olly or Patricia has a brain injury, the others can use what they are good at to help out.***

***The family members can use what they are good at to help***

- *How could Freddy use what he is good at to help?*
  - o *General prompts*
- *How could Tamara use what she is good at to help?*
  - o *General prompts*
- *How could Olly use what he is good at to help?*
  - o *General prompts*
- *How could Patricia use what he is good at to help?*
  - o *General prompts*

## **SECTION 4: BRAIN RECOVERY IDEAS**

***We also want The Lobe Family to help explain how brains can get better after an injury.***

***We have some ideas, but we want to know what you think can help brains get better after an injury***

- What do you think helps brains get better after an injury?
- What can families do to help brains get better after an injury?
- What can schools do to help brains get better after an injury?
- What can friends do to help brains get better after an injury?
- Is there anyone else who can get brains better after an injury?

## **SECTION 5: LOGISTICS**

***Thank you for everything you've said so far! We will use what you've said to help us make The Lobe Family even better!***

***We'd like to ask a few questions now on what you think we should do with The Lobe Family? I'm going to give some ideas for how children could use The Lobe Family to learn about brain injury. I'd like to know what you think of them.***

***Children could learn about brain injury by reading about The Lobe Family in a book, a magazine, or a comic.***

- *Do you like this idea*
- *What do you like / not like about it?*
- *Would you want to learn about brain injury by reading about the Lobe Family in a book, magazine or comic?*
- *Do you think anyone else would like this? Who?*

***Children could learn about brain injury by watching the Lobe Family on a video, DVD or on youtube.***

- *Do you like this idea*
- *What do you like / not like about it?*
- *Would you want to learn about brain injury by watching the Lobe Family on a video, DVD or on Youtube?*
- *Do you think anyone else would like this?*

**Children could learn about brain injury by playing with the lobe family on a website, an app, or in a game.**

- *Do you like this idea*
- *What do you like / not like about it?*
- *Would you want to learn about brain injury by playing with the Lobe Family on a website, an app, or in a game?*
- *Do you think anyone else would like this?*

**Do you have any other ideas for how children could learn about brain injury using the Lobe Family**

- *General discussion*

**Finally; I have some more general questions about The Lobe Family.**

**Freddy, Tamara, Olly and Patricia are all human. They don't have to be. They could be animals, robots, or even aliens.**

- *Do you like that Freddy, Tamara, Olly and Patricia are humans?*
- *What do you like / not like about that?*
- *\* What do you think they should be?*

**There are lots and lots of different types of brain injury. If Freddy had a type of brain injury that wasn't the same as your brain injury, would that upset you?**

## Appendix E: Interview visuals (Phase two)

### "The Lobe Family"

Phase 2  
Visuals

### The Lobe Family

- The brain has 4 areas. Each are helps us do certain things
  - Frontal
  - Parietal
  - Temporal
  - Occipital
- "The Lobe Family"
  - Freddy Frontal Lobe
  - Patricia Parietal Lobe
  - Tamara Temporal Lobe
  - Olly Occipital Lobe

### Freddy Frontal Lobe



- Organisation
- Planning
- Working out what other people are thinking
- Solving Problems
- Being in control
- Managing his feelings

### Tamara Temporal Lobe



- Concentrating
- Paying attention
- Remembering things (memory)
- Speaking
- Listening
- Recognizing people

### Olly Occipital Lobe



- Seeing things correctly
- Noticing differences between different colours and shapes
- Noticing when something is moving

### Patricia Parietal Lobe



- Making sense of things she sees, touches, hears, and smells.
- Knowing where things are
- Coordinating body movements
- Good with words
- Good with numbers

## Names

- Freddy Frontal Lobe
- Tamara Temporal Lobe
- Patricia Parietal Lobe
- Olly Occipital Lobe

**Appendix F: Consent form (CYP)**



School of Psychology  
University of East London  
Stratford Campus  
Water Lane  
London E15 4LZ

**The Principle Investigator**

XXXXXXXXXX

*Trainee Clinical Psychologist, University of East London*

**Contact Details**

E-Mail: [XXXXXXXXXX@uel.ac.uk](mailto:XXXXXXXXXX@uel.ac.uk)

**Development of a Psychoeducational Resource for Children who have  
Experienced an Acquired Brain Injury (ABI)**

**My Name is....**

---

**Todays Date is...**

---

	Please Tick
I have read the information sheet.	
I understand what this research is about.	
I understand that I don't have to take part in this research.	
I know that I can change my mind about taking part at any stage of the research until it is completed.	
I understand that the information I provide about myself will be kept confidential. I agree that this can only be shared with others if I might be at risk of harm	
I agree to take part in this research	

**Appendix G: Consent form (Parent/carer)**



School of Psychology  
University of East London  
Stratford Campus  
Water Lane  
London E15 4LZ

**The Principle Investigator**

xxxxxxx

*Trainee Clinical Psychologist, University of East London*

**Contact Details**

E-Mail: [xxxxxxxx@uel.ac.uk](mailto:xxxxxxxx@uel.ac.uk)

**Development of a Psychoeducational Resource for Children who have  
Experienced an Acquired Brain Injury (ABI)**

**Name:**

---

**Child's Name:**

---

**Today's Date:**

---

	Please Tick
<p><b>I confirm that I have read the information sheet for the above study and have been given a copy to keep. The nature and purposes of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained.</b></p>	
<p><b>I understand that my participation is voluntary and that I am free to withdraw from the study without giving any reason. If I choose to withdraw I know there will not be any consequences.</b></p>	
<p><b>I understand that there are limits to confidentiality if any serious concerns arise about my safety, my child's safety, or the safety of another person during the study. Under these circumstances information I will be required to pass on the information to relevant authorities, such as the police or social services. If this happens then I will try and talk with you before doing this.</b></p>	

## **Appendix H: Debrief sheet (CYP)**



School of Psychology  
University of East London  
Stratford Campus  
Water Lane  
London E15 4LZ

### **The Principle Investigator**

XXXXXXXXXXXX

*Trainee Clinical Psychologist, University of East London*

### **Contact Details**

E-Mail: [XXXXXXXXXXXX@uel.ac.uk](mailto:XXXXXXXXXXXX@uel.ac.uk)

## **Development of a Psychoeducational Resource for Children who have Experienced an Acquired Brain Injury (ABI)**

Dear XXXXXXX

Thank you for helping us make something that helps children to understand brain injury and what we can do to help brains recover. We hope you have enjoyed coming to meet with us!

### **What happens next?**

- We will use what you have told us to make the resource better!
- We will send you the finished version as soon as it is ready. This may take some time though.
- We will tell you what we found in our research.

### **What happens to the information I gave?**

We will think carefully about everything that you told us, and use it to make the resource better.

We will also share our work together with others, such as people who help children with brain injury. We will write something so they can read all about it.

We will keep your information safe until we have finished making the resource. We will then destroy everything safely. Nobody will know that you have taken part.

### **Taking part upset me. What can I do?**

We are sorry to hear that taking part was upsetting. We understand that it can be hard to talk about difficult things like brain injury.

The best thing to do is tell your parents that you are upset. Your parents will be able to help get you the support that you need. This might involve going to see your doctor.

If you do not feel able to tell your parents that you are upset, you can tell us and we will help as best we can. We might need to talk to your parents though. You could also talk to a teacher at your school, or somewhere involved in looking after you.

### **I have questions...**

We would be happy to answer any questions you have about this research. My contact details are at the top of this sheet.

### **We have really enjoyed working with you.**

#### **Thank you**

XXXXXXXXXX

*Trainee Clinical Psychologist*

*University of East London*

Dr XXXXXXXX

XXXXXXXXXX

*University of East London*

## **Appendix I: Debrief sheet (Parent/Carer)**



School of Psychology  
University of East London  
Stratford Campus  
Water Lane  
London E15 4LZ

### **The Principle Investigator**

XXXXXXXXXX

*Trainee Clinical Psychologist, University of East London*

### **Contact Details**

E-Mail: [u1524999@uel.ac.uk](mailto:u1524999@uel.ac.uk)

## **Development of a Psychoeducational Resource for Children who have Experienced an Acquired Brain Injury (ABI)**

Dear xxxxxx,

Thank you for helping us create a resource that will help children and young people with an Acquired Brain Injury (ABI) understand how the brain works and what helps the brain recover. We hope you and your child have enjoyed the experience of taking part. The purpose of this letter is to let you know what we will be doing with the information you and your child have provided us with.

### **What happens to the information I gave?**

We have recorded our conversation with your child, and we will be transcribing this word for word so we have a written record of what we talked about. We will then combine this with the conversations we've had with other children and look for similarities and differences. We will then write a report based on this, and try and get it published in an academic journal. We will also share our learning with health

and social care professionals, teachers and parents of children who have experienced a brain injury. This will help us know how to improve our psychoeducational resource to make sure it is as helpful as possible.

We will keep all of the information you have given us secure, so that nobody but ourselves can access it. We will keep it for only as long as we need to, and this will be for a maximum of three years at the very most (although we expect it will be much less than this). As soon as we have finished writing our report, we will destroy all the information we have collected.

We would like to reassure you once again that neither you nor your child will be indefinable in any of the ways we share our research.

### **How can I stay involved?**

Once we have written our report, we will write to you to summarise the key things that we have learnt. We will also send your child a short summary.

We will then set about the task of finishing making the resource. Whilst this might take a bit more time, we will send you a copy as soon as we have made it.

You can also contact us if you have any more questions.

### **Taking part in the research brought up some difficult issues for us. What can I do?**

We are sorry to hear that taking part was upsetting. We understand that it can be hard to talk about difficult things like brain injury.

Whilst we are not best placed to provide any support around these issues, we would like to suggest some places that you might want to consider going to access this.

- If you want to give us some feedback on the study, or would like to make a complaint about anything we did, then you can contact my supervisor Dr xxxxxxxxxxxx (xxxxxxxxxx). She can be contacted on [xxxxxxxxxx@uel.ac.uk](mailto:xxxxxxxxxx@uel.ac.uk).
- Your GP is in the best position to know what is available in your local area, and is therefore usually the best place to ask for support in the first instance.
- You could also ask any health or social care professional, or a teacher, for help. Whilst they might not be the person who can offer this, they are likely to have some ideas of who can.

- If you feel that you as a parent would like some advice and support around mental health, then we would recommend the charity **Young Minds**. You can learn more about what they offer here (<https://youngminds.org.uk>), or you can call their confidential helpline on 0808 802 5544.

### **I have questions...**

I would also be happy to answer any questions you have about this research. My contact details are at the top of this sheet.

We have really enjoyed working with you, and we wish you the best for the future.

**Thank you!**

xxxxxxx

*Trainee Clinical Psychologist*

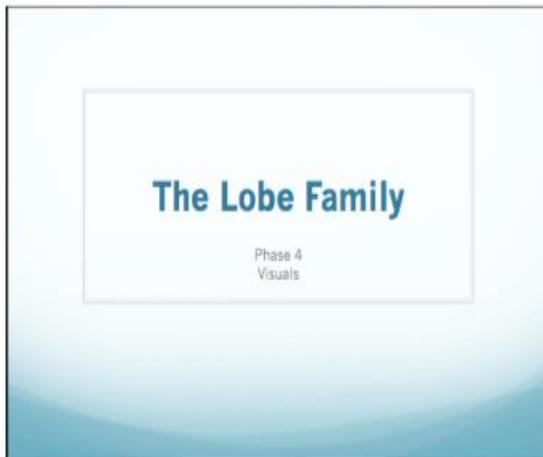
*University of East London*

Dr xxxxxxxx

xxxxxxxxxx

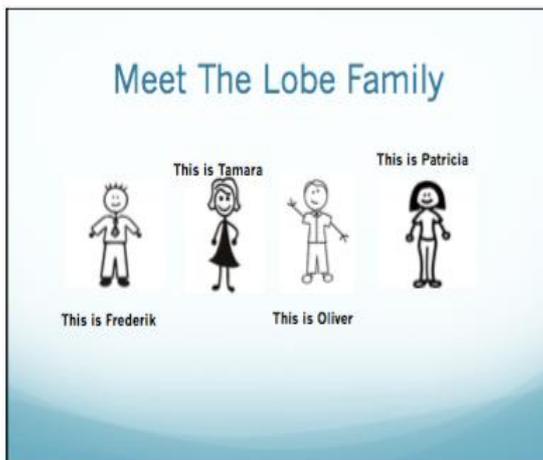
*University of East London*

## Appendix J: The Lobe Family' prototype resource



### The Lobe Family

- A resource to help explain what brain injury is.
- Made for young people, but can be shared with family, friends, and teachers.
- A series of stories about four children (characters)... one for each lobe of the brain.
- These stories will come in a few different ways...
  - A book and/or a comic
  - A website and/or an app



### Meet The Lobe Family

- This is Freddy / Frederik Frontal Lobe
- Freddy is good at all the things we know the Frontal Lobe of the brain is good at;
  - Organisation and planning
  - Working out what other people are thinking
  - Solving problems
  - Managing his feelings

## Meet The Lobe Family



- This is Tammy / Tamara Temporal Lobe
- Tamara is good at all the things we know the Temporal Lobe of the brain is good at;
  - Concentrating and paying attention
  - Remembering things (memory)
  - Speaking and listening to others

## Meet The Lobe Family



- This is Olly / Oliver Occipital Lobe
- Olly is good at all the things we know the Occipital Lobe of the brain is good at;
  - Seeing things correctly
  - Noticing differences between things
  - Spotting when things are moving

## Meet The Lobe Family.



- This is Patty / Patricia Parietal Lobe
- Patricia is good at all the things we know the Temporal Lobe of the brain is good at;
  - Making sense of things she sees, touches, hears, and smells
  - Coordinating her body movements and balance
  - Using words and numbers

## How the brain works

- Each one of the family have some things they are really good at....

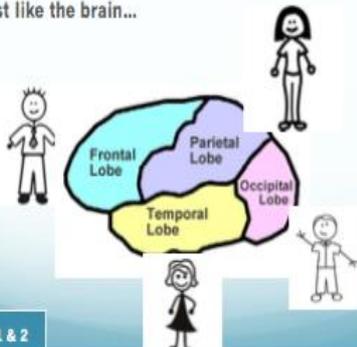
.... But also some things they are not good at.

- **When The Lobe Family work closely together they can each use their individual skills to become even better!**



## How the brain works

- Just like the brain...

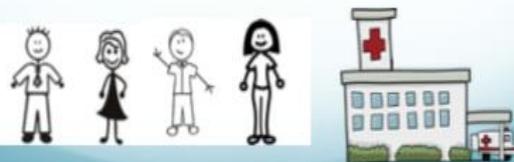


Question 1 & 2

## After brain injury

But then one of The Lobe Family has an accident or becomes unwell....

... and has to go to hospital



## After brain injury

After lots of tests of their thinking skills...  
... They say that the family member has had a brain injury.



## After brain injury

- Having a brain injury can be very scary.
- And getting used to life after a brain injury can be very hard.
- There are many challenges that you might face
  - *Such as at home, and at school*

## After brain injury

- **After a brain injury, young people might find that;**
  - They find it hard to understand what happened
  - They struggle to accept that things have changed now
  - Their parents also find it hard to accept
  - Some of the other young people try to take advantage
  - Their teachers don't understand
  - They sometimes feel sad, angry and frustrated
  - Sometimes they feel guilty and blames themselves

Question 3

## After brain injury

- **So the character who has a brain injury finds that;**
  - They find it hard to understand what happened
  - They struggle to accept that things have changed now
  - Their parents also find it hard to accept
  - Some of the other young people try to take advantage
  - Their teachers don't understand
  - They sometimes feel sad, angry and frustrated
  - Sometimes they feel guilty and blames themselves



Question 3

## Understanding brain injury

Having a brain injury means that some things become harder.

What becomes harder is different depending on which part of the brain is injured.

For example; if the frontal lobe is injured then things the frontal lobe is good at (like planning and being organised) become harder.

## Understanding brain injury

So if Freddy has a brain injury...

Freddy will find it harder to do the things he used to be good at.



## Understanding brain injury

But Tamara, Olly and Patricia might still be good at lots of things.

And they might have to find new ways to manage without Freddy's skills.



## Understanding brain injury

For example;

- The Lobe Family want to book a day out!
- But Freddy is the person who usually solves problems and makes all of the plans.



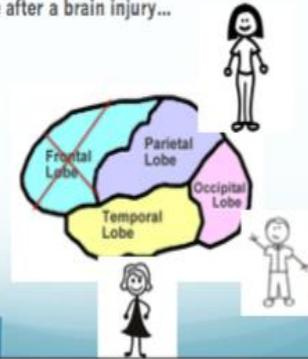
## Understanding brain injury

- So Tamara uses her skills. She concentrates really hard and tries to remember what they did last time.
- And Olly uses his seeing skills to look for places to go, and research things to do when they get there.
- And Patricia uses her reading skills to find out what they need to do, and her maths skills to find out how much it will cost.



## Understanding brain injury

- Just like after a brain injury...



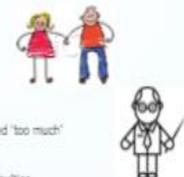
Question 4

## What can help after brain injury?

- It can be hard to know who can help after a brain injury.
- It can be even harder to know what they can do to help.
- After a member of The Lobe Family has a brain injury, they get help from a number of different people.

## What can help after brain injury?

- **Parents**
  - Offer support
  - Help with things that have become harder
- **Teachers**
  - Be understanding when things are hard
  - Getting the balance right between being helpful and 'too much'
- **Doctors, Psychologists and Health Workers**
  - Teaching you 'tips and tricks' to manage your difficulties
  - Help you get better at some things
- **Friends**
  - Offer support
  - Be understanding



## What can help after brain injury?

- **But most importantly.... yourself!**
  - Knowing what your good at
  - Remembering that it's not your fault
  - Accepting that things have changed
  - Having hope for the future
  - Having a sense of humour
  - Celebrating your achievements

Question 5

## The Lobe Family Resource

- A series of stories (one for each character)
- Available as;
  - Four books and/or comics
  - An interactive website and/or app
- Two versions for different age groups
  - For younger children (i.e. Freddy, Tammy etc.)
  - For older children (i.e. Frederik, Tamara etc.)

## The Lobe Family Resource



### Select a character

- Freddy / Frederik
- Tammy / Tamara
- Olly / Oliver
- Patty / Patricia

## The Lobe Family Resource



### Different family types

- 2 Parents
- 1 Parent
- 2 Mums
- 2 Dads
- And other family types

## The Lobe Family Resource



### Select an ABI type

- Traumatic
  - (e.g. head injury)
- Non-Traumatic
  - (e.g. encephalitis)

## The Lobe Family Resource



### Features

- Links to other websites with accurate information
- 'Invite friends' to download and view

Question 6

## The Lobe Family

Question 7 & 8



Thank you for participating

## **'The Lobe Family'**

### **Participant Feedback Form**

Thank you for helping make something to help young people learn about brain injury.

We met with young people who have had a brain injury to find out what they think is important to say about brain injury. We have listened to what they said, and used it to make a new resource called *'The Lobe Family'*.

We now want to know what you think of what we have made together.

**Q1: What do you think of the four characters?**

**\* Please Tick One**

<b>Really don't Like</b> 	<b>Don't Like</b> 	<b>Not Sure</b> 	<b>Like</b> 	<b>Really Like</b> 

What made you choose that answer?

What is it that you like / do not like about the characters?

How could they be better / what could be changed?

**Q2: What do you think of the way the Lobe Family explains how the brain works?**

\* Please Tick One

<b>Really</b>	<b>Don't</b>	<b>Not</b>	<b>Like</b>	<b>Really</b>
---------------	--------------	------------	-------------	---------------

<b>don't Like</b>  	<b>Like</b> 	<b>Sure</b> 		<b>Like</b>  

What made you choose that answer?

What is it that you like / do not like about the way The Lobe Family explains how the brain works?

How could it be better / what could be changed?

**Q3: What do you think of the way the Lobe Family describes the things that happen after a brain injury?**

\* Please Tick One

<b>Really don't Like</b>  	<b>Don't Like</b> 	<b>Not Sure</b> 	<b>Like</b> 	<b>Really Like</b>  
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What made you choose that answer?

What is it that you like / do not like about the way The Lobe Family describes some of the difficulties after brain injury?

How could it be better / what could be changed?

**Q4: What do you think of the way the Lobe Family explains brain injury?**

\* Please Tick One

Really don't Like  	Don't Like 	Not Sure 	Like 	Really Like  

What made you choose that answer?

What is it that you like / do not like about the way The Lobe Family explains brain injury?

How could it be better / what could be changed?

**Q5: What do you think of the way the Lobe Family explains what (and who) can help after brain injury?**

\* Please Tick One

<b>Really don't Like</b>  	<b>Don't Like</b> 	<b>Not Sure</b> 	<b>Like</b> 	<b>Really Like</b>  

What made you choose that answer?

What is it that you like / do not like about the way The Lobe Family explains what (and who) can help after brain injury?

How could it be better / what could be changed?

**Q6: What do you think of the way the Lobe Family is made into an interactive and personalisable app and book?**

\* Please Tick One

<b>Really don't Like</b>  	<b>Don't Like</b> 	<b>Not Sure</b> 	<b>Like</b> 	<b>Really Like</b>  

What made you choose that answer?

What is it that you like / do not like about the way The Lobe Family is made into an interactive and personalisable app and book?

How could it be better / what could be changed?

**Q7: What do you think of The Lobe Family overall now you have heard more about it?**

\* Please Tick One

<b>Really don't Like</b>  	<b>Don't Like</b> 	<b>Not Sure</b> 	<b>Like</b> 	<b>Really Like</b>  

What made you choose that answer?

**What is it that you like / do not like about The Lobe Family?**

**How could it be better / what could be changed?**

**Q8: Do you have anything else you would like to say about The Lobe Family?**

***Appendix L: Exemplar extract of analysed transcript***

Start Time	Transcript	Speaker	
00:07:22.9	Yeah that would have been good. XXXXXXXX had good stuff and anything more like that would be good. It would be good. It would of been good if like I was able to see it on my own and learn about it and stuff. That might of been good.	Participant 1	<p>Jon Ettey 10/5/2018 13:27 <input type="checkbox"/></p> <p><b>Comment [1]:</b> Neurorehabilitation / Support from services</p> <p>Jon Ettey 10/5/2018 13:27 <input type="checkbox"/></p> <p><b>Comment [2]:</b> Informational needs (CYP)</p>
00:07:25.7	Yeah, what would have been good about it?	Researcher	
00:07:32.3	Well... it would be good because everyone around needs to know more about brain injury, but it won't just be like one person and everyone else. Like everyone, everyone in the family and the school can be aware of like what's going on for you.	Participant 1	<p>Jon Ettey 10/5/2018 13:27 <input type="checkbox"/></p> <p><b>Comment [3]:</b> Accessible / Developmentally appropriate / Independent access</p> <p>Jon Ettey 10/5/2018 13:23 <input type="checkbox"/></p> <p><b>Comment [4]:</b> Other's lack of awareness / Informational needs (others)</p>
00:07:47.7	How about for you, because some things are private for you aren't they	Participant's Mother	<p>Jon Ettey 10/5/2018 13:23 <input type="checkbox"/></p> <p><b>Comment [5]:</b> Informational needs (school) / informational needs (peers)</p>
00:07:47.7	Yeah....	Participant 1	
00:07:50.3	Especially when you were trying to come to terms.	Participant's Mother	
00:07:50.3	Yeah. When I was first like. When I first got. When I first realised that I had a brain injury. Then I denied it all. Like I lied about stuff saying that I didn't think it was difficult. I was saying I was able to deal with it and I was fine with it. And that nothing was different. And it... But with more people aware there's a chance that they might start accepting it, accepting that I'm different now, and see that I'm struggling with this.	Participant 1	<p>Jon Ettey 10/5/2018 13:28 <input type="checkbox"/></p> <p><b>Comment [6]:</b> Coming to terms / Acceptance (CYP)/ Denial / Hiding difficulties / ?Guilt / ?Shame</p>
00:08:28.1	mm.	Researcher	<p>Jon Ettey 10/5/2018 13:26 <input type="checkbox"/></p> <p><b>Comment [7]:</b> Informational needs (others) / Acceptance (others)</p>
00:08:28.1	And I could read in my own time without anyone.	Participant 1	
00:08:40.5	So there are some things that you don't want to talk to other people about, and that you would prefer to learn yourself	Researcher	<p>Jon Ettey 10/5/2018 13:27 <input type="checkbox"/></p> <p><b>Comment [8]:</b> Accessible / Developmentally appropriate / Independent access</p>
00:08:40.5	Yeah.	Participant 1	
00:08:45.4	But there are some things that you found it helpful for people to help you with, to help you understand.	Researcher	
00:08:45.4	Yeah. Its good to have the balance.	Participant 1	
00:08:55.0	So thats really helpful to know. So I wonder. If you met someone who had a brain injury yesterday.	Researcher	
00:08:59.3	Yeah.	Participant 1	
00:08:59.7	And if they came into this room now. What do you think they would need to know about brain injury?	Researcher	
00:09:03.5	They need to know that life isn't going to be the same as before, like before they had the injury, and they	Participant 1	

	need to find ways to kind of like. How do i say it. They need to find ways to cope with getting used to it. So say like they have difficulties with memories they need to try and find links to stuff so they can remember better. Say. Say what helped me. Say that they have coursework that that they need to get done, like find ways, like XXXXX showed me some apps to set reminders and use notes. I'd suggest them apps to them. And it would just help like. It would help them get to know their problems. You also need to tell them that you cant predict everything. You can't be sure what's going to change. It's annoying.		<p>Jon Ettey 10/5/2018 13:29 <b>Comment [9]:</b> Coming to terms / acceptance (CYP) / Recovery / ?Positivity</p> <p>Jon Ettey 10/5/2018 13:29 <b>Comment [10]:</b> Strategies (cognitive) / neurorehabilitation</p> <p>Jon Ettey 10/5/2018 13:31 <b>Comment [11]:</b> Informational needs (CYP), Strategies (external) / Understanding ABI</p>
00:09:46.4	mm. So you'd tell them that some things will change, and give them some ideas for how to manage them.	Researcher	<p>Jon Ettey 10/5/2018 13:32 <b>Comment [12]:</b> Expectations / The future / Understanding ABI / Neurocognitive stalling</p>
00:09:59.2	Yeah that's important. You need to have ideas for what will help them manage things.	Participant 1	
00:10:04.4	Hmm. Thats some good ideas. Is there anything else that you think it would be good for this person who had a brain injury yesterday to know?	Researcher	<p>Jon Ettey 10/5/2018 13:32 <b>Comment [13]:</b> Strategies / Approaches / Neurorehabilitation</p>
00:10:04.6	Also that.... They shouldn't hide it cos if they keep on hiding it then nobodies going to know what is wrong with them. But you need to accept its happened because if you haven't then I want to hide it. They might just end up thinking that they are stupid or can't be arsed. Teachers did end up thinking i just couldn't be arsed and I got in trouble for it. And like they end up going. And as soon like I. As soon as the. Xxxxxxxxxxxx got involved things started changing and teachers started to understand that I wasn't just trying to get away with work and stuff but I was genuinely having problems with it.	Participant 1	<p>Jon Ettey 10/5/2018 13:33 <b>Comment [14]:</b> Coming to terms / Acceptance (CYP) / Denial / Hiding difficulties / ?Guilt / ?Shame</p> <p>Jon Ettey 10/5/2018 13:35 <b>Comment [15]:</b> Informational needs (teachers) / Challenges (school) / acceptance (others)</p>
00:10:49.4	mm. So it sounds like there is a real learning need for schools. So it would be helpful if the resource we make could be shared with them as well?	Researcher	<p>Jon Ettey 10/5/2018 13:36 <b>Comment [16]:</b> Benefits of information (Others); Interventions (School)</p>
00:10:56.7	Yeah definitely	Participant 1	
00:11:00.4	And. What else would you like ti say to this imaginary young person who had a brain injury yesterday?	Researcher	
00:11:06.8	Like... Yeah... Life's going to be difficult. And your not going to be the same as other people. Or than what you were like. But your going to find a way to live your life. And you will end up trving to. living a normal life. i	Participant 1	

## **Appendix M: UEL SREC ethical application**

**UNIVERSITY OF EAST LONDON  
School of Psychology**

**APPLICATION FOR RESEARCH ETHICS APPROVAL  
FOR RESEARCH INVOLVING HUMAN PARTICIPANTS**

**FOR BSc RESEARCH**

**FOR MSc/MA RESEARCH**

**FOR PROFESSIONAL DOCTORATE RESEARCH IN CLINICAL, COUNSELLING &  
EDUCATIONAL PSYCHOLOGY**

**If you need to apply to have ethical clearance from another Research Ethics Committee (e.g. NRES, HRA through IRIS) you DO NOT need to apply to the School of Psychology for ethical clearance also. Please see details on**

**<https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Pages/NHS-Research-Ethics-Committees.aspx>**

**Among other things this site will tell you about UEL sponsorship**

Note that you do not need NHS ethics approval if collecting data from NHS staff except where the confidentiality of NHS patients could be compromised. You do need NHS approval is collecting data on NHS premises.

*Before completing this application please familiarise yourself with:*

The *Code of Ethics and Conduct (2009)* published by the British Psychological Society (BPS). This can be found in the Ethics folder in the Psychology Noticeboard (Moodle) and also on the BPS website

[http://www.bps.org.uk/system/files/Public%20files/aa%20Standard%20Docs/inf94\\_code\\_web\\_ethics\\_conduct.pdf](http://www.bps.org.uk/system/files/Public%20files/aa%20Standard%20Docs/inf94_code_web_ethics_conduct.pdf)

And please also see the UEL Code of Practice for Research Ethics (2015-16)

<https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Documents/Ethics%20forms/UEL-Code-of-Practice-for-Research-Ethics-2015-16.pdf>

## **SECTION 1. Your details**

**1. Your name:**

Jon Ettey

**2. Your supervisor's name:**

Whilst xxxxxxxxxx is the Director of Studies (DoS) for this project, she has recently taken maternity leave, and will be returning to work after the completion of this project. A new DoS will be assigned, and clinical oversight of the project will be taken over by members of xxxxxxxx research and Educational Psychology teams. Names and contact details included on letters and forms will be amended as appropriate.

**3. Title of your programme:**

Professional Doctorate in Clinical Psychology

**4. Submission date for your BSc/MSc/MA research:**

June 2018

**5. Please tick if your application includes a copy of a DBS certificate**

**6. Please tick if you need to submit a DBS certificate with this application but have emailed a copy to Dr Mary Spiller for confidentiality reasons (Chair of the School Research Ethics Committee) ([m.j.spiller@uel.ac.uk](mailto:m.j.spiller@uel.ac.uk))**

**7. Please tick to confirm that you have read and understood the British Psychological Society's Code of Ethics and Conduct (2009) and the UEL Code of Practice for Research Ethics (See links on page 1)**

## **SECTION 2. About your research**

**8. What your proposed research is about:**

Paediatric Acquired Brain injury (ABI) refers to neurological injuries occurring after a period of typical development (Forsyth and Kirkham, 2012). ABI is an extremely heterogeneous condition affecting a broad range of abilities including physical, cognitive and emotional functioning (Shah, 2016). Information has been identified as a key need for children following ABI however resources are typically aimed at parents/carers and professionals (Falk, von Wendt & Klang, 2008). Whilst some psychoeducational resources for children with ABI exist, they tend not to be theoretically grounded or be extensively evaluated (Olsson et al, 2014). There is scope to develop a

psychoeducational resource.

This study seeks to collaboratively develop a psychoeducational resource with children with ABI. Its purpose would be to convey information regarding ABI in an accessible way, with the intention of increasing children's knowledge and sense of mastery over their condition. We anticipate that this will be a tool that children can access independently, but will have significant value as a tool for parents of, and professionals working with, children with ABI.

We have given the resource a working title of '*The Lobe Family*', in which characters representing the four main lobes of the lobe (frontal, temporal, occipital and parietal) are involved in a story involving ABI. Inspiration for this idea came from a combination of practice-based experience of clinicians working in the field, and theoretical inspiration from the narrative framework (White and Epstein, 1990) and the technique of externalisation.

It is proposed that development of 'The Lobe Family' will be conducted across four research phases;

- (1) Developing initial ideas for the resource,
- (2) Presenting these ideas to young people who have experienced an ABI and seeking their views on further development in focus groups,
- (3) Developing the resource in the context of feedback provided, and
- (4) Seeking the views of the finalised prototype with participants in focus groups.

This project therefore intends to evaluate two research questions relating to data collection at phase two and four of the project;

- What are the views of young people who have experienced an ABI on our initial ideas for '*The Lobe Family*'?
- What are the views of young people who have experienced an ABI on a final prototype of '*The Lobe Family*'?

## **9. Design of the research:**

This project adopts a mixed-methods research design. Qualitative data will be conducted via focus groups with children with ABI, and analysed through thematic analysis. Supplementary quantitative data will be collected via feedback forms completed by CYP at the conclusion of each focus group. Data will be collected at both phase two and four of the project.

Should it not be possible to recruit a sample sizeable enough for focus groups to be a realistic prospect, the qualitative methodology would be amended to an interview format. In this scenario; a smaller sample of children meeting the entry criteria will be invited to participate in 30-45 minute interviews with the lead researcher. These interviews would follow the broad structure and themes that is detailed for focus groups in this application. Data from interviews would be analysed through thematic analysis, and be supplemented by quantitative data from feedback forms.

## **10. Recruitment and participants (Your sample):**

Children with ABI, aged between ten and fifteen years will be recruited for this study. This age group has been chosen because younger children may not have developed sufficient cognitive maturity to contribute to somewhat abstract discussions about resource development (Piaget, 1932), and that group dynamics will be facilitated by having a group of similarly aged children. Whilst it is acknowledged that chronological

age is not a direct predictor of cognitive ability, particularly when working with individuals who have experienced an ABI, setting parameters based on age will facilitate the recruitment process.

Non-English speakers will (regrettably) be excluded due to the complexities of using interpreters in focus groups and with children, financial implications of resource translation. Individuals with significant difficulties around receptive and/or expressive communication, and would therefore struggle to participate in the focus groups, will also be excluded.

It is proposed that a minimum of ten and maximum of sixteen CYP will be recruited to participate in phase two of the project, and be allocated to one of two focus groups. Should CYP who participate in phase two be unavailable for phase four of the project, further children will be recruited in their place. Should it not be possible to recruit sufficient children and it is necessary to utilise the fall-back position detailed previously, then between five and eight children will be recruited.

Recruitment will be co-ordinated through xxxxxxxxxxxxxxxx, a tertiary-charitable organisation offering residential and community-based rehabilitation services for children who have experienced ABI. The charity's database of families who have consented to be contacted for research purposes will be utilised for recruitment purposes. This will be done via phone calls and/or sending the information sheet as a letter, depending on what families have consented to with the charity. The charity's established links to similar organisations (e.g. xxxxxxxxxxxxxxxx) may also be exploited should sufficient numbers not be recruited from one site. A draft letter to prospective participants can be found in Appendix A.

#### **10. Measures, materials or equipment:**

Data will be collected at phases two and four of the research process.

At phase two; parents will be asked to complete a brief questionnaire providing information regarding their child's demographics, ABI typology, and their exposure to psychoeducational resources. Qualitative will also be collected at phase two via two focus groups, which will be transcribed. A comprehensive overview of focus group (or individual interview) content is not possible at this time as it is highly dependent on resource development (phase one). Broadly; focus groups will involve discussing ideas and visual stimuli relating to the resource in development. Supplementary quantitative data will be gained via a feedback form created as part of the research process, which will be completed by children participating in focus groups.

Phase four of the research will also collect qualitative and quantitative data through focus groups (or individual interviews) and feedback forms in a manner identical to that described above.

#### **11. If you are using copyrighted/pre-validated questionnaires, tests or other stimuli that you have not written or made yourself, are these questionnaires and tests suitable for the age group of your participants?**

No copyrighted / pre-validated questionnaires, tests or other stimuli are to be used within this project. All materials will be bespoke and tailored to the age and ability range of participants.

#### **12. Outline the data collection procedure involved in your research:**

Once CYP and their parents/carers have given their informed consent to participate in

this research, parents will be asked to complete the background information sheet. This will ask for demographic information, details regarding the child's ABI typology, and their exposure to psychoeducational resources.

CYP and their parents/carers will then be invited to attend a focus group held at xxxxxxxxxxx premises. Parents/carers and relevant professionals will be offered the opportunity to observe focus groups. The lead researcher will facilitate focus groups, which will take last approximately 60-90 minutes with time allocated for children to freely explore the resources. Focus groups will consist of between five and eight children each, with two focus groups at each of phase two and four being anticipated. Focus groups will be recorded and transcribed by the lead researcher. A similar process will be used should the fall-back position involving individual interviews in place of focus groups be required.

At the conclusion of each focus group, CYP will be provided with a bespoke feedback questionnaire collecting supplementary quantitative data.

This process applies equally to phase two and four of the proposed research process.

### **SECTION 3. Ethical considerations**

#### **13. Fully informing participants about the research (and parents/guardians if necessary):**

Recruitment will be facilitated by xxxxxx, a tertiary-level third-sector organisation offering residential and community-based rehabilitation services for children who have experienced ABI. Children may also be recruited via charities with existing research links to xxxxxx including; xxxxxxxx xxxxxxxx

A multi-modal approach to recruitment will be adopted involving:

- Directly contacting CYP and families known to xxxx xxxxx and xxxxx, who have consented to being contacted for research purposes (subject to approval from the named charities internal authorisation processes)
- Advertising the project in public areas of xxxxx, xxxxxx and xxxxxx premises (e.g. waiting rooms).
- Exploring the possibility of advertising participation in the study via xxxxx social media platform(s) and blogs, and similar mechanisms coordinated through xxxx and xxxxx.

CYP and parents/carers who express interest in participating will be provided with two information sheets. The first of these will be written for parents/carers and provides detailed information about the project, participant rights, the benefits of participating, and how to proceed if they remain interested (Appendix B). The second will contain similar information, but is written in an accessible and developmentally appropriate manner for CYP (Appendix C).

Participants will be given the opportunity to contact the lead researcher via e-mail to ask any questions they may have at any stage of the research process.

#### **14. Obtaining fully informed consent from participants (and from parents/guardians if necessary):**

Informed consent will be gained from all CYP and their parents who chose to participate in the project. CYP will be asked to sign a consent form (Appendix D), stating that they understanding the research and the rights as participant, before focus groups commence.

Parents/carers of CYP who chose to participate will also be gained for all participants via a separate consent form (Appendix E), which will be completed before focus groups commence

**15. Engaging in deception, if relevant:**

The proposed research involves no deception.

**16. Right of withdrawal:**

CYP and/or their parents will have the right to withdraw from the study at any time without disadvantage and without needing to give any reason.

Should a participant withdraw from the study, or be withdrawn by their parent, the researcher reserves the right to use any data provided by the participant up to the point of withdrawal. As with all other data collected in, this data will be used in data analysis and dissemination anonymously. This will be clearly articulated to participants in both the parent and child information sheet.

**17. Will the data be gathered anonymously?**

No

**18. If NO what steps will be taken to ensure confidentiality and protect the identity of participants?**

Correspondence with participants and their families will be made exclusively by- e-mail from university provided e-mail address ([xxxxxx@uel.ac.uk](mailto:xxxxxx@uel.ac.uk)) or a secure telephone line. E-mail correspondence will be kept for the duration of the project, and permanently deleted from 'inbox' and 'deleted items' at the conclusion of the project. Only the researcher and director of studies will have access to any correspondence.

Participants will be assigned a pseudonym to protect their anonymity, and will be given the opportunity to choose this for themselves should they wish. Names and contact details for participants and their parents will be stored in a password-protected computer file, of which only the researcher and director of studies will have access to.

Focus groups will be recorded and transcribed. Recordings will be stored on a password protected encrypted memory stick for the duration of the project, but will be destroyed on conclusion.

Consent forms and questionnaires completed by children and their parents will be scanned electronically, and saved in the aforementioned password-protected computer file. These electronic copies will be destroyed at the end of the study period. Hard copies will be destroyed immediately after they are scanned.

**19. Will participants be paid or reimbursed?**

Not in financial terms (see below)

**If YES, why is payment/reimbursement necessary and how much will the vouchers be worth?**

Participants will be reimbursed in the form of being provided with a copy of the final 'The Lobe Family' psychoeducational resource should they wish. No financial payment or reimbursement will be provided for participants.

#### **SECTION 4. Other permissions and ethical clearances**

**20. Is permission required from an external institution/organisation (e.g. a school, charity, workplace, local authority, care home etc.)?**

**Is permission from an external institution/organisation/workplace required?**

Yes

**If YES please give the name and address of the institution/organisation/workplace:**

Address: xxxxxxxxxx

E-Mail xxxxxxxxxx

Tel: xxxxxxxxxx

**Will your research be taking place on NHS Premises?**

No.

This research will be conducted on the premises of xxxxxxxxxx, a tertiary-level third-sector organisation offering residential and community-based rehabilitation services for children who have experienced ABI.

**21. Is ethical clearance required from any other ethics committee?**

Yes

**If YES please give the name and address of the organisation:**

xxxxxxxxxxxxxxxxxxxxx requires projects be reviewed and approved via their Research Committee Meetings.

**Has such ethical clearance been obtained yet?**

Yes, a scanned copy of the approval letter from xxxxxxxxxx can be found attached to this application (Appendix G)

## **SECTION 5. Risk Assessment**

*If you have serious concerns about the safety of a participant, or others, during the course of your research please see your supervisor as soon as possible.*

*If there is any unexpected occurrence while you are collecting your data (e.g. a participant or the researcher injures themselves), please report this to your supervisor as soon as possible.*

### **22. Protection of participants**

CYP who have experienced an ABI are at greater risk of a range of health conditions (e.g. epilepsy and physical disability). It is therefore important that the researcher remains aware of this context, and follows the health and safety procedures of xxxxx throughout the research process. As it is likely that parents/carers of participants are best placed to understand their individual needs, they will be encouraged to observe the focus group and provide support as and when they feel it is appropriate to do so.

Furthermore; there is a risk of causing participants high levels of fatigue due to the cognitive load of engaging in focus groups and the impact of their ABI. Whilst 60-90 minutes per focus group has been allocated, it is anticipated that a significant proportion of this time will be for participants to freely explore the resources. This will also provide opportunity for participants to take breaks if they, or their parents feel it is required. The lead researcher will suggest breaks to participants and/or their parents/carers if concerns are noted.

Whilst children and young people with significant difficulties around their receptive and/or expressive communication skills will be excluded from participating due to the verbal demands of the focus groups, there is a risk of communication being pitched at an inappropriate level for the audience. Care will be taken to ensure that the individual needs of participants are considered in the delivery of the focus group. This is likely to involve adapting language, allowing additional time for processing information, avoiding use of abstract concepts and metaphor, and using individuals preferred forms of communication if appropriate.

In addition to a formalised risk assessment completed as part of the thesis registration, an ad-hoc check of risks in the immediate focus group environment will be conducted prior to each focus group. This will involve checking for access issues (e.g. for wheelchair using participants), removing potential trip hazards, and items that may be hazardous to participants or others. Pragmatic and practical decisions will then be made to reduce identified risks.

All children participating in the research will have an existing relationship with xxxxxxxx, and therefore the charities contact details will be made available to participants at debrief. CYP and parents/carers will also signposted to appropriate sources of support on an ad-hoc basis, and encouraged to contact their GP if they have any health concerns. As the research will be conducted on xxxxxxxx premises, local risk procedures will be adhered to with regard to the risk.

Wellbeing of CYP will remain paramount throughout the research process. It is acknowledged that talking about the brain and injuries is likely to be an emotive topic for CYP engaging in focus groups. Prior to the start of focus groups, the facilitator will address parents/carers encouraging them to observe the process and to provide support to their child as and when they feel necessary. A separate, quiet, room will be provided for CYP and their parents/carers to access at any point should they feel it is

needed. Should the facilitator become concerned for the wellbeing of a participant, for example if they show signs of visible upset, then they will be prompted to access this space if they wish. Effort will be made to tailor facilitation of the focus groups to the needs of the CYP who are present, and to make participation a fun and engaging process. If a CYP becomes significantly distressed during the research process then the team responsible for their care will be informed. CYP and their parents/carers will be involved in this process and consent gained to share information if appropriate.

It is also acknowledged that participation in the focus groups may evoke curiosity about their condition amongst CYP. Pre-empting this possibility, the researcher will make clear the beginning of focus groups that he is unable to respond directly to specific questions about participants conditions, however can signpost to sources of information and support. Sources of support signposted to will vary depending on the specific query but may include information available online, professionals involved in the child's care, or advising they contact their GP to discuss these factors. Informational resources produced by xxxxx, including an informational booklet for parents, will also be made available at focus groups.

### **23. Protection of the researcher:**

The researcher may be exposed to health and safety risks in terms of travel to and from xxxxxxx premises in xxxxxx, and in setting up rooms for the focus groups. These risks will be mitigated with due care, and by following local health and safety procedures.

### **24. Debriefing participants:**

At the end of phase two of the research, participants and their parents/carers will be given a verbal debrief. This will recap the aims of the research, the purpose of this focus group, what will happen to the information provided and the ethical rights of participants. CYP and their parents/carers will be invited to attend focus groups in phase four of the research process. Contact details for the lead researcher and sources of support (as above) will be provided at this time.

At the end of phase four of the research, participants and their parents/carers will be given a written debrief (Appendix F). Contact details for the lead researcher and sources of support (as above) will be provided at this time. The debrief will include information about participant rights.

### **25. Other**

Whilst xxxxxxxx is the Director of Studies (DoS) for this project, she will shortly be taking maternity leave, returning to work after the completion of this project. A new DoS will be assigned and clinical oversight of the project will be taken over by members xxxxxx research and Educational Psychology teams. Names and contact details included on letters and forms will be amended as appropriate.

### **26. Will your research involve working with children or vulnerable adults? \***

Yes

**If YES have you obtained and attached a DBS certificate?**

Yes (Appendix H)

**If your research involves young people under 16 years of age and young people of limited competence will parental/guardian consent be obtained?**

Yes (see section 3, Question 14)

**If NO please give reasons. (Note that parental consent is always required for participants who are 16 years of age and younger)**

N/A

*\* You are required to have DBS clearance if your participant group involves (1) children and young people who are 16 years of age or under, and (2) 'vulnerable' people aged 16 and over with psychiatric illnesses, people who receive domestic care, elderly people (particularly those in nursing homes), people in palliative care, and people living in institutions and sheltered accommodation, for example. Vulnerable people are understood to be persons who are not necessarily able to freely consent to participating in your research, or who may find it difficult to withhold consent. If in doubt about the extent of the vulnerability of your intended participant group, speak to your supervisor. Methods that maximise the understanding and ability of vulnerable people to give consent should be used whenever possible. For more information about ethical research involving children see <https://uelac.sharepoint.com/ResearchInnovationandEnterprise/Pages/Research-involving-children.aspx>*

**27. Will you be collecting data overseas?**

No

**If YES in what country or countries (and province if appropriate) will you be collecting data?**

N/A

### **SECTION 6. Declarations**

**Declaration by student:**

*I confirm that I have discussed the ethics and feasibility of this research proposal with my supervisor.*

**Student's name: typed name acts as a signature**

xxxxxxx

**Student's number:**

U1524999

**Date:** 05/06/2017

***Appendix N: UEL SREC ethical approval***

School of Psychology Research Ethics Committee

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants  
BSc/MSc/MA/Professional Doctorates

REVIEWER: Mark Holloway

SUPERVISOR: Kenneth Gannon

COURSE: Professional Doctorate in Clinical Psychology

STUDENT: Jonathan Ettey

TITLE OF PROPOSED STUDY: TBC

DECISION OPTIONS:

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

DECISION ON THE ABOVE-NAMED PROPOSED RESEARCH STUDY

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

Approved with minor amendments

Minor amendments required *(for reviewer)*:

This is an exceptionally thoughtful and sensitively designed piece of research. I have one concern around participant numbers. Your fall back position for your qualitative research with children is that you will use between 5 and 8 children as participants if the focus groups don't happen. My understanding of the requirements of Thematic Analysis is that it usually

requires around 15-16 participants to reach saturation point (the point at which no new information is likely to be forthcoming from participants). I realise that you could potentially never reach saturation point as the next participant might have something novel to add, but 5-8 participants does seem to fall short of the requirements of TA. I would ask that you think about this and discuss it with your supervisor, as I wouldn't want your research to be undermined by something so relatively straightforward to address.

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

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

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

- HIGH  
 MEDIUM  
 LOW

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

**Reviewer (Typed name to act as signature):** Mark Holloway

**Date:** 19th October 2017

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

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

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

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



Date:

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

**PLEASE NOTE:**

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

## **Appendix O: UEL SREC ethics amendments approval**

### **UNIVERSITY OF EAST LONDON School of Psychology**

#### **REQUEST FOR AMENDMENT TO AN ETHICS APPLICATION**

#### **FOR BSc, MSc/MA & TAUGHT PROFESSIONAL DOCTORATE STUDENTS**

**Please complete this form if you are requesting approval for proposed amendment(s) to an ethics application that has been approved by the School of Psychology.**

Note that approval must be given for significant change to research procedure that impacts on ethical protocol. If you are not sure about whether your proposed amendment warrants approval consult your supervisor or contact Dr Mary Spiller (Chair of the School Research Ethics Committee).

#### **HOW TO COMPLETE & SUBMIT THE REQUEST**

1. Complete the request form electronically and accurately.
2. Type your name in the 'student's signature' section (page 2).
3. When submitting this request form, ensure that all necessary documents are attached (see below).
4. Using your UEL email address, email the completed request form along with associated documents to: Dr Mary Spiller at [m.j.spiller@uel.ac.uk](mailto:m.j.spiller@uel.ac.uk)
5. Your request form will be returned to you via your UEL email address with reviewer's response box completed. This will normally be within five days. Keep a copy of the approval to submit with your project/dissertation/thesis.
6. Recruitment and data collection are **not** to commence until your proposed amendment has been approved.

#### **REQUIRED DOCUMENTS**

1. A copy of your previously approved ethics application with proposed amendments(s) added as tracked changes.
2. Copies of updated documents that may relate to your proposed amendment(s). For example an updated recruitment notice, updated participant information letter, updated consent form etc.

3. A copy of the approval of your initial ethics application.

<b>Name of applicant:</b>	xxxxxxx
<b>Programme of study:</b>	Professional Doctorate in Clinical Psychology
<b>Title of research:</b>	Development of a Psychoeducational Resource for Children who have Experienced an Acquired Brain Injury (ABI)
<b>Name of supervisor:</b>	xxxxxxx

Briefly outline the nature of your proposed amendment(s) and associated rationale(s) in the boxes below

Proposed amendment	Rationale
<p>Where it is not possible for the participant to attend xxxxxxxxx premises in xxxxxx, and where it has been agreed with the projects Director of Studies, then the interview can take place at the participant's home.</p> <p>For home interviews; xxxxxxxx (Psychosocial Administrator, xxxxxxxx) will be informed of the time and the place of the interview. The projects field supervisors; xxxxxxxxxxxx) will also be given the relevant details, but due to demands on their availability are not best placed to be the first point of contact for risk procedures. These individuals will be the only other person in addition to the researcher to have access to the name and address of the participant, which they will only access in the event of an emergency.</p> <p>Should these individuals not be available then the projects Director of Studies (xxxxxxx be informed in their places. The researcher will also inform a relative, friend or partner of the time, date and approximate location of the interview and will inform them when they leave. Should the Director of Studies and/or other known person not be informed of the researcher leaving the interview then they will escalate according to standard risk escalation procedures.</p>	<p>Recruitment of children who have experienced an ABI, meet the study criteria, and who are currently accessing services based at xxxxxxxxx premises has been challenging and there are well-founded fears that recruiting the minimum required sample will not be possible.</p> <p>However, xxxxxxxx also offer an outreach service – The xxxxxxxx This is a nationwide team provide home-based assessment, treatment and support to children who have experienced an ABI and their families. It is likely that there are a range of children accessing the BICT service would meet the criteria for the study, but would not be able to attend an interview in xxxxxx. Should home interviews be enabled through this application then fears over potential recruitment challenges will be allayed.</p> <p>This proposal has been discussed with representatives of xxxxxx who are fully in favour of this approach. They also feel it would enhance the range of children who are able to participate, enriching the research.</p>

<p>All participants seen for interviews at their home will already be known to xxxxxxxx, and recruitment processes will be coordinated by the charity as previously agreed. The researcher will be given key risk and risk management information known to xxxxxx in advance of home interviews, and the researcher will have contact with participant and their families before the interview. If there are concerns the interview will not go ahead. On arrival, the researcher will appraise the risk and will leave should they feel at risk at any time.</p> <p>All interviews will be conducted in a secure, and safe, area with only those who the child agrees to being present (e.g. a parent/carer/guardian).</p>	
<p>Widening the recruitment age range to 10-18.</p>	<p>xxxxxx provides services for children aged up to 18, and widening the age range would enable recruitment of the full range of children accessing their services.</p> <p>It is also acknowledged that age is a poor predictor of cognitive ability, especially amongst a population of children who have experienced an ABI. The ability to participate in the research is therefore theoretically unaffected by their chronological age, and decisions regarding ability to participate will be taken on a case-by-case basis as described in the original ethics application</p>
<p>Minor formatting changes to participant information sheet, consent form and debrief sheets.</p>	<p>To reflect final versions, included here for completeness.</p>
<p>Changes to participant information sheet, and consent form, to reflect change of methodology from focus groups to individual interviews. The possibility for this was already built into the original ethics form.</p>	<p>To reflect final versions, included here for completeness.</p>



**Appendix P: Collaborating organisation's ethical approval**



Trainee Clinical Psychologist  
University of East London

Dear [redacted]

**Re: Development of a Psychoeducation Resource ('The Lobe Family') for Children who have experienced acquired brain injury (ABI)**  
**Project Reference No. [redacted]**

Thank you for submitting your project to the Research Committee for consideration. We are pleased to tell you that the proposal was reviewed and approved by the committee on Wednesday 15<sup>th</sup> March 2017. Please see attached Dr [redacted]'s comments for your information.

We would be grateful if you could forward your ethics approval letter as soon as possible. Once this has been received, we will look forward to hearing progress updates at future research meetings.

Yours sincerely



Head of Therapy & Research

