

**Rehabilitation of Prospective Memory in Paediatric Acquired Brain Injury:  
A Preliminary Study**

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Thesis submitted in part fulfilment of the degree of  
Doctorate in Clinical Psychology (Clin.Psy.D)  
University of East Anglia, 2011

**Word Count: 36,628**

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**Abstract**

**Objectives:** Prospective memory (PM) problems are common after Acquired Brain Injury (ABI) in childhood and are associated with negative functional consequences. Despite this, little is known about the impact of paediatric brain injury on PM, or appropriate rehabilitation approaches. Building on work by Fish et al (2007), this study aimed to adapt and pilot an executive function focussed intervention for adolescents with PM difficulties following ABI.

**Design:** A single-case series design with randomised alternating treatments was used to examine the effects of brief Goal Management Training (GMT) and external content-free cueing (in the form of text messages) on PM task performance.

**Methods:** Seven adolescents (12-17 years) with ABI completed a PM task which involved making three phone calls per day at specific times each day for 3 weeks. After one week of calls they received brief GMT, where they were taught to use the mnemonic 'STOP' to cue them to stop for a moment and mentally review their tasks and goals. To encourage use of this strategy, six text messages reading 'STOP' were sent to participants' mobile phones at random times on 5 of the 10 following working days. The number and accuracy of phone calls was compared across cued and un-cued days to determine the effectiveness of the intervention for each participant.

**Results:** At an individual level, significant effects of cueing were seen for four participants. For the group as a whole, preliminary analyses revealed significantly

better phone call performance on cued days. Five participants also reported gains in real-life PM achievement.

**Conclusions:** The intervention shows promise for adolescents with ABI. However, future studies are needed to consider the generalisability of findings on a larger scale, and whether GMT and content-free cueing can systematically promote the attainment of real-life PM goals in adolescents following brain injury.

**Table of Contents**

Abstract	i
List of Appendices	ix
List of Tables	x
List of Figures	xi
Acknowledgements	xii
<b>Chapter One: Introduction</b>	<b>1</b>
1.1 Chapter Overview	1
1.2 Paediatric Acquired Brain Injury (pABI)	2
1.2.1 Epidemiology	2
1.2.2 Neuropathology following pABI	4
1.2.3 Severity	5
1.2.4 Outcomes following pABI	6
<i>1.2.4.1 Neurocognitive and behavioural consequences.</i>	7
<i>1.2.4.2 Memory impairments.</i>	8
1.3 Prospective Memory	10
1.3.1 Theoretical models	10
1.3.2 Prospective memory retrieval	11
<i>1.3.2.1 Motivation.</i>	13
1.3.3 Frontal lobe involvement in prospective memory	13
1.3.4 Executive functioning theory and PM	15
1.3.5 Development of PM in neurologically healthy children	17
<i>1.3.5.1 Early childhood.</i>	17
<i>1.3.5.2 Mid-childhood through to adolescence and young adulthood.</i>	18

1.3.5.3 <i>PM across adulthood</i>	20
1.3.6 PM in children with ABI	20
1.3.6.1 <i>Summary of PM in children with ABI.</i>	23
1.4 Assessment of PM	24
1.5 How Can we Rehabilitate PM Impairments?	27
1.5.1 Literature review	29
1.5.2 Restoration	30
1.5.2.1 <i>Evidence in children with ABI.</i>	32
1.5.3. Compensation	35
1.5.3.1 <i>Non-electronic aids.</i>	36
1.5.3.2 <i>Electronic aids.</i>	36
1.5.3.3 <i>Evidence in children with ABI.</i>	39
1.5.4 Meta-cognition.	40
1.5.4.1 <i>Evidence in children with ABI.</i>	44
1.5.5 Mixed/Other.	47
1.5.5.1 <i>Evidence in children with ABI.</i>	48
1.5.6 PM rehabilitation: Summary and conclusions	49
1.5.6.1 <i>PM rehabilitation in adults.</i>	50
1.5.6.2 <i>PM rehabilitation in children.</i>	51
1.5.6.3 <i>Theoretical context.</i>	53
1.5.6.4 <i>Clinical context.</i>	54
1.5.6.5 <i>Conclusions.</i>	55
1.6 Summary, Aims and Rationale for the Study	55
1.7 Research Questions and Hypotheses	56
1.7.1 <i>Research questions</i>	56

1.7.2 Main hypotheses	57
1.7.2.1 Hypothesis 1.	57
1.7.2.1 Hypothesis 2.	57
1.7.3 Supplementary hypotheses	58
1.7.3.1 Hypothesis 3.	58
1.7.3.2 Hypothesis 4.	59
<b>Chapter Two: Method</b>	<b>60</b>
2.1 Design	60
2.2 Participants	61
2.2.1 Sample size	61
2.2.2 Inclusion criteria	62
2.2.3 Exclusion criteria	63
2.2.4 Recruitment	64
2.2.5 Sample characteristics	65
2.3 Prospective Memory Intervention	68
2.4 Measures	69
2.4.1 Background assessment	70
2.4.2 Neurocognitive measures	70
2.4.2.1 <i>General intellectual functioning.</i>	70
2.4.2.2 <i>Verbal memory.</i>	71
2.4.2.3 <i>Prospective memory.</i>	72
2.4.2.4 <i>Attention.</i>	72
2.4.2.5 <i>Executive functioning.</i>	73
2.4.2.6 <i>Developmental considerations.</i>	73
2.4.2.7 <i>Practice effects.</i>	74

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

2.4.3 Behavioural questionnaires	74
2.4.3.1 <i>Everyday executive functioning.</i>	75
2.4.3.2 <i>Everyday prospective and retrospective memory.</i>	75
2.4.3.3 <i>Prospective memory log (PML).</i>	76
2.4.4 Outcome measure	76
2.4.4.1 <i>Primary outcome measure (Telephone task).</i>	76
2.4.4.2 <i>Feedback form.</i>	77
2.5 Ethical Considerations	78
2.5.1 Consent and coercion	78
2.5.2 Confidentiality	80
2.5.3 Managing risk and distress	80
2.6 Procedure	82
2.6.1 Consent and background assessment	82
2.6.2 Prospective memory telephone task	82
2.6.3 Intervention	84
2.6.4 Debrief	84
2.7 Pilot Study	84
2.8 Overview of Analysis	86
<b>Chapter Three: Results</b>	<b>90</b>
3.1 Baseline Assessment	90
3.2 Treatment of Data	95
3.2.1 Testing data assumptions for analyses	95
3.2.2 Calls excluded during the study	95
3.3 Telephone Task	96
3.3.1 Descriptive data	96

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

3.3.1.1 <i>Week 1 (pre-intervention).</i>	96
3.3.1.2 <i>Intervention phase.</i>	97
3.4 Hypothesis Testing (Primary Hypotheses)	97
3.4.1 Hypothesis 1	97
3.4.1.1 <i>Single case analysis.</i>	98
3.4.1.2 <i>Group analysis</i>	104
3.4.2 Hypotheses 2	104
3.4.2.1 <i>Proportion and composite score relationship.</i>	105
3.4.3 Supplementary hypotheses	105
3.4.3.1 <i>Hypothesis 3.</i>	105
3.4.3.2 <i>Factors associated with response to cueing.</i>	106
3.4.3.4 <i>Hypothesis 4.</i>	109
3.4.3.5 <i>Neurocognitive and behavioural correlates of week 1         telephone task performance.</i>	109
3.5 Participants' Qualitative Feedback and Evaluation of the Intervention	112
3.5.1 Questionnaire evaluation	112
3.5.2 Qualitative feedback	115
3.6 Summary of Results	117
3.6.1 Background assessment	117
3.6.2 Main hypotheses	117
3.6.2.1 <i>Hypothesis 1.</i>	117
3.6.2.2 <i>Hypothesis 2.</i>	117
3.6.3 Supplementary hypotheses	118
3.6.3.1 <i>Hypothesis 3.</i>	118
3.6.3.2 <i>Hypothesis 4.</i>	119



3.6.4 Qualitative feedback	119
<b>Chapter Four: Discussion</b>	<b>120</b>
4.1 Overview	120
4.2 Summary of Findings	120
4.2.1 Hypothesis 1	121
4.2.2 Hypothesis 2	125
4.2.3 Supplementary hypotheses	126
4.2.3.1 Hypothesis 3.	126
4.2.3.2. Hypothesis 4.	127
4.3 Theoretical Implications	130
4.4 Clinical Implications	133
4.4.1 Implications for the assessment for PM in pABI	134
4.4.2 Implications for the treatment for PM in pABI	135
4.5 Methodological Strengths and Limitations of the Preliminary Study	137
4.5.1 Design.	137
4.5.2 Participants.	140
4.5.3 Intervention.	141
4.5.4 Measures	142
4.5.5 Procedure	145
4.5.6 Data analysis	146
4.6 Directions for Future Research	147
4.7 Conclusion	150
<b>References</b>	<b>152</b>
<b>Appendices</b>	<b>200</b>

**List of Appendices**

Appendix A: Recruitment site letter

Appendix B: Information sheets: Parents, adolescent (16-17 years) and young adolescent (12-15 years) versions

Appendix C: Permission to contact form

Appendix D: Media advertisement

Appendix E: Data of non-study completers

Appendix F: Severity of injury classification

Appendix G: Neuro-radiology findings

Appendix: H: Brief GMT package: PowerPoint presentation, hand-outs and quiz

Appendix I: Participant background assessment

Appendix J: PRMQ: Self and proxy ratings

Appendix K: Prospective Memory Log (PML)

Appendix L: Feedback form

Appendix M: Cambridgeshire 4 REC approval

Appendix N: Research and Development (R&D) approval

Appendix O: Parent consent form

Appendix P: Adolescent assent form (ages 12-15 years)

Appendix Q: Adolescent consent form (ages 16-17 years)

Appendix R: Written record of call times

Appendix S: Pilot study information sheets: Parents, adolescent (16-17 years) and young adolescent (12-15 years) versions

Appendix T: Pilot study summary

Appendix U: Distribution statistics for cued and un-cued data

Appendix V: Rater agreement for phone-call task omissions

**List of Tables**

Table 1.	Table 1 Demographic and injury-related characteristics of sample	67
Table 2.	Table 2 Participant baseline neurocognitive assessment	92
Table 3	Participant baseline questionnaire and behavioural assessment	94
Table 4	Mann-Whitney <i>U</i> analyses of proportion and composite scores across cued and un-cued telephone task conditions for each participant.	103
Table 5	Correlation co-efficients for relationships between cognitive and behavioural assessments of neurocognitive functioning, injury age, current age and the size of the cueing effect for daily average proportion and composite telephone task scores (cued minus un-cued).	108
Table 6	Correlation co-efficients for relationships between cognitive and behavioural assessments of neurocognitive functioning and daily average week 1 proportion and composite telephone task scores.	111
Table 7	Qualitative feedback from participants about their experiences of the GMT and content-free cueing.	116

**List of Figures**

<i>Figure 1a.</i>	Group mean week 1 telephone task proportion scores.	96
<i>Figure 1b.</i>	Group mean week 1 telephone task composite scores.	97
<i>Figure 2.</i>	Telephone task proportion and composite scores over week 1 and randomly allocated cued and un-cued days for each participant.	99
<i>Figure 3.</i>	Questionnaire feedback from participants about their experiences of the GMT and content-free cueing.	113

### **Acknowledgements**

There are several individuals and organisation that deserve special thanks for their help over the course of this research. First, I would like to thank my supervisors Dr Anna Adlam and Professor Malcolm Adams for their continued interest and guidance. I would also like to thank my external collaborators, Dr Tom Manly and Dr Jessica Fish, for their involvement, and for allowing me to adapt their protocol. I would like to express thanks to Eve Greenfield for sharing some of her research knowledge and practical advice. In addition, I would like to thank The Oliver Zangwill Centre (OZC), for allowing me to use NeuroPage.

Next, I would like to thank all those who supported the recruitment process, with a special thanks to Dr Fergus Gracey and the team at the Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR); Dr Amos Burke at Addenbrooke's Hospital; the Encephalitis Society; the Child Brain Injury Trust; The Children's Trust, Tadworth; Headway; The Oliver Zangwill Centre (OZC); Different Strokes; and finally, the Child Stroke Support Site, in particular Soniya Mundy.

Finally, I would like to express enormous gratitude to all my family and friends who have supported me during this thesis and my clinical doctorate as a whole, especially my partner Owain, my parents, and Gill Williamson.

## **Chapter 1**

### **Introduction**

#### **1.1 Overview**

Prospective memory (PM) is commonly defined as remembering to carry out intended actions in the future (Ellis, 1996). In comparison to retrospective memory (RM), the recall and recognition of past information, research into PM has been relatively neglected, only gaining interest in recent years (McFarland & Glisky, 2009). PM problems are common following paediatric acquired brain injury (pABI) and are linked to poorer functional consequences. Despite this, little is known about the impact of pABI on PM, or the most suitable rehabilitation approaches. Therefore, the aim of this thesis is to pilot and evaluate a PM intervention for a paediatric group.

This Chapter starts with an overview of pABI, including information about the incidence and prevalence, the neuropathology of damage, and the consequences and outcomes associated with sustaining an injury during childhood. Next, attention is given to memory impairments, a common consequence of ABI, with a particular emphasis on PM. Theoretical models of PM are discussed in detail, including theories of executive functioning that have relevance to PM. The development of PM across childhood and adulthood is considered, before discussing what is known about PM in pABI. Next, issues linked to the assessment of PM are reported. Following this, the literature related to the rehabilitation of PM is presented, including an appraisal of both the adult and child research. Particular reference will be made to a promising technique which uses automated cues to prompt people to think about their intentions, and whether this intervention is potentially effective in a

paediatric group. To finish, this Chapter will highlight the aims and rationale for the study, including the specific hypotheses to be tested.

## **1.2 Paediatric Acquired Brain Injury (pABI)**

Acquired brain injury (ABI) is a non-degenerative injury to the brain after birth, not as a result of a developmental or congenital disorder (Appleton, 1998). The term encompasses both traumatic and non-traumatic causes of damage to the brain and mechanisms of injury may include open or closed traumatic head injury, vascular events (e.g. stroke, sub-arachnoid haemorrhage), infection (e.g. meningitis, encephalitis), cerebral hypoxia, and brain tumours (Royal College of Physicians, 2003).

Typically, the causes of paediatric injury vary by age. Infants and young children mostly suffer from falls, whilst older children and adolescents are more likely to sustain injuries through road traffic accidents and playing sport (Bishop, 2006; Noppens & Brambrink, 2004; Reddy, Collins, & Gioia, 2008). However, in those less than 1 year old non-accidental trauma such as ‘shaken impact syndrome’ (Bruce & Zimmerman, 1989) is also known to be a significant cause of childhood brain injury and morbidity (Hawley, Ward, Long, Owen, & Magnay, 2003).

### **1.2.1 Epidemiology.**

Globally, brain injury is the dominant cause of death and disability among children, adolescents and young adults (Anderson & Yeates, 2010; World Health Organisation, 2009). Despite this, there are few population-based analyses of brain injury in a paediatric sample (Hawley et al., 2003), and because ABI represents a range of conditions that can result in many clinically distinct injuries, it is difficult to

obtain accurate figures of the prevalence of pABI (National Institute for Health and Clinical Excellence, 2007).

However, TBI is by far the most frequent form of injury with estimated incidence rates ranging between 200 to 500 cases per 100,000 each year across the United States and Australia (Crowe, Anderson, Catroppa & Babl, 2010; Langlois, Rutland-Brown, & Thomas, 2006). In the UK, a population study estimated that 280 per 100,000 children required hospital admission for a minimum of 24 hours with a diagnosis of TBI. Of these, approximately 85 % comprised mild injuries, 9 % were moderate, and 6 % were severe (Hawley et al., 2003). High incidence rates have been seen in those less than 5 years, with a second peak in those aged 15 to 24 years (Kraus, Fife, & Conroy, 1987; Yates, Williams, Harris, Round, & Jenkins, 2006). Boys are consistently found to be at greater risk of traumatic head injury, a disparity which continues to increase with age (Rivara, 1994). There is also an increased incidence of head injury in children with pre-existing behavioural and cognitive problems, those from poorer socio-economic backgrounds, and those from urban areas (Colantonio et al., 2011; Hawley et al., 2003; Schwartz et al., 2003).

In contrast, other forms of pABI are less prevalent. For example, the estimated annual incidence rates per 100,000 child cases are 2-3 for stroke (DeVeber, Roach, Reila, & Wiznitzer, 2000), 16 for encephalitis (Health Protection Agency, 2005; Johnson, 1996), and 5 for brain tumours (Cancer Research UK, 2005). Nonetheless, non-traumatic brain injuries are still associated with devastating and lasting complications for children and families affected (Appleton, 1998), and as above, an underestimate of figures is likely.



### **1.2.2 Neuropathology following pABI.**

An ABI in childhood may be associated with focal or diffuse damage to the brain. Focal mechanisms are often as a result of an external force that causes localised damage at the site of penetration (e.g. a knife injury). This may involve insults such as skull fractures and cerebral lacerations or contusions (bruising). Stroke is another form of focal injury caused by a disruption of cerebral blood flow, either via haemorrhage (bleeding) or ischemia (a lack of oxygen). Presenting symptoms vary following focal damage as neurological impairments correspond to the location of lesion.

In contrast, diffuse or multi-focal damage is more widespread and includes non-penetrating injuries, diffuse cerebral hypoxia and inflammation of brain tissue as a result of infections such as encephalitis or meningitis. Motor vehicle accidents or falls are common mechanisms of diffuse damage in children (Ylvisaker, 1998). In such incidents, acceleration-deceleration forces often cause movement of the brain within the skull (either linear or rotational shaking), resulting in damage to neuronal pathways, termed diffuse axonal injury (DAI). DAI commonly affects several neural regions including the cerebral hemispheres, brain stem and cerebellum (Meythaler, Peduzzi, Eleftheriou, & Novak, 2001). In particular, given the acceleration-deceleration movements of the brain within the skull, pre-frontal regions of the brain are the areas most susceptible to damage following a traumatic head injury in both children and adults, (Ylvisaker, 1998). Executive functioning, the domain responsible for many higher order skills including organisation, planning, the regulation of goal directed behaviour (see below), and attentional functions are all associated with the frontal lobes, and are therefore frequently disrupted after diffuse brain injury (Prins & Giza, 2011).

### **1.2.3 Severity.**

Several methods exist to assess the severity of a brain injury and systems typically classify injuries as mild, moderate or severe. In general, more extensive neurocognitive and behavioural consequences are associated with increasing severity (although other variables such as age at injury, premorbid ability and family factors also moderate recovery, Donders, 2007).

For TBI, the Glasgow Coma Scale (Jennett & Teasdale, 1974), Paediatric Glasgow Coma Scale (Reilly, Simpson, Sprod & Thomas, 1988), duration of loss of consciousness (LOC), or post-traumatic amnesia (PTA) are common classification measures, with lower Glasgow Coma scores, and greater durations of LOC or PTA reflecting more severe injuries. However, for young children it can be difficult to assess PTA due to the need for retrospective reported memory loss.

There are few specific measures for assessing the severity of other forms of ABI, and those that exist (e.g. Pediatric NIH Stroke Scale, Ichord, et al., 2011) are not yet routinely available. However, if recorded, loss of consciousness and duration of PTA can help determine the severity of non-traumatic ABI's.

In relation to developmental considerations, younger children are particularly vulnerable to more severe head trauma because the paediatric skull continues to strengthen and calcify throughout childhood (Geddes, Hackshaw, Vowles, Nickols, & Whitwell, 2001). They also have a larger head relative to body size, which further increasing vulnerability to head injury from traumatic forces, as well as heightening the risk of upper spinal injury (Margylyes & Coats, 2010; Medana & Esiri, 2003). Finally, in childhood (and adulthood) cumulative mild injuries (such as repetitive mild sports concussion) can also be associated with severe neurocognitive outcomes (Reddy et al., 2008).

#### **1.2.4 Outcomes following pABI.**

Injury to the growing brain is different from an injury acquired in adulthood. Adult ABI is typically associated with a more predictable and stable long-term recovery path (Satz, 1993); however injury to the immature brain leads to impairments that may change in nature and severity over time (Gill, 2003).

The developing brain is ‘plastic’ and continues to form after birth based on learning and experiences (Johnston, Nishimura, Harum, Pekar, & Blue, 2001). Indeed, neuroscientists have identified five key stages of neurodevelopment between birth and early adulthood (Savage, 1999), with the most significant brain growth occurring from birth to the age of 6 years, whereby rapid neurogenesis, refining of synaptic connectivity and the myelination of axons take place (Johnston, 2004). Structurally, different regions of the brain also mature at varying points across development. For instance, fronto-temporal areas mature at two key phases, in the first and second years of life, and then late adolescence into adulthood (Savage, 1999). Consequently, injuries sustained within this evolving context present a complicated picture. Recovery is varied and influenced by factors such as age and developmental level at the time of injury (Anderson, Morse, Cattropa, Haritou, 2004).

Given the developing brain’s capacity for growth and regeneration (i.e. ‘plasticity’ or ‘functional reorganisation’) researchers have traditionally claimed that a child is more resilient to brain injury and less susceptible to lasting impairments, an effect known as the ‘Kennard principle’ (Kennard 1938; 1942; Lenneberg, 1967; Smith, 1983). There is evidence this may be the case for difficulties caused by select focal lesions such as hemiplegia (Maegaki et al., 1997) or acquired language difficulties (Chapman, Levin, Waneck, Weyrauch & Kufera, 1998; Vargha-Khadem,

Issaacs, & Muter, 1994). However, a number of recent studies have consistently demonstrated that cerebral trauma in childhood is associated with persisting functional deficits (Anderson, Brown, Newitt, & Hoile, 2009; 2011), particularly if damage is diffuse or impacting on pre-frontal regions (Pickard & Stewart, 2007). This is commonly referred to as the ‘plasticity versus vulnerability argument’ (Anderson, Spencer-Smith, & Wood, 2011).

Furthermore, emerging longitudinal data indicates that the extent of an injury to a child’s brain may only become evident over time. This has been referred to as ‘neurocognitive stalling’ (Chapman, 2007), whereby usually after a year-post injury the development of subsequent milestones is slowed, causing individuals to ‘lag’ behind their same-aged peers. Factors contributing to this stalling effect may include limited opportunities for skill attainment before the injury; difficulties developing or acquiring new skills and increased demands for new learning after the injury (Chapman et al. 2009; Savage, 2007). Importantly, difficulties often become most apparent during adolescence when the disrupted maturation of the frontal lobes (which have a protracted developmental trajectory) may begin to highlight the impact of brain injury on developing executive functions (Sowell, Thompson, Holmes, Jernigan & Toga, 1999; Teichner & Golden, 2000). Therefore, the developing brain appears to be more, rather than less vulnerable to the effects of brain injury (Ylvisaker 1998; Mahone & Slomine, 2007).

#### ***1.2.4.1 Neurocognitive and behavioural consequences.***

Given the potential for deficits to emerge over time, it is not surprising that pABI can lead to a range of long-term cognitive, emotional and psychosocial sequelae depending on the nature and location of injury. Frequently reported

impairments include problems with speed of processing (Babikian & Assarnow, 2009); attention (Anderson, & Pentland, 1998); general intellectual functioning (Anderson, Catroppa, Morse, Haritou, & Rosenfeld, 2005); executive and self-regulatory skills (Sesma, Slomine, Ding, & McCarthy, 2008); and communication (Ewing-Cobbs, et al., 2011; Ylvisaker & Feeney, 2007). Furthermore, pABI is associated with an increased risk of behavioural problems (Yeates et al., 2002); compromised academic performance (Catroppa et al., 2009); mental health difficulties (Max et al., 1997; 1999; 2000); and significantly poorer social outcomes, including an increased risk of engaging in criminal behaviour (McKinlay, Horwood, & Fergusson, 2010; Williams, Giray, Mewse, Tonks, & Burgess, 2010).

Functional outcomes however, do not always correspond to the severity of injury, and several factors are known to contribute to recovery. These include injury related variables such as the nature of injury and the age and cognitive level of the child at injury, individual factors such as personality type and premorbid abilities (Anderson et al., 2011), and environmental factors including family support and sociodemographic factors such as economic disadvantage (Donders, 2007).

#### ***1.2.4.2 Memory impairments.***

Despite the extensive consequences of brain injury, problems with memory are one of the most highly reported neurocognitive impairments after ABI, in both children (Catroppa & Anderson, 2002, 2007; Lajiness-O'Neill, Erdodi, & Bigler, 2010) and adults (Wilson, 2002b).

Memory can be defined as the ability to encode, store and retrieve information after a delay (Wilson, 2002). Many different forms and models of memory exist depending on factors such as the amount of time information is stored;

the type of information to be recalled; the degree of consciousness involved; and whether the memory represents events from the past (retrospective) or for the future (prospective). Models often distinguish between short (or working memory) and long-term memory systems. Working memory allows the temporary storage and manipulation of information (Logie, 1994; Baddeley, 1997), whereas long-term memory enables storage of information over time (Squire, 1992; 1994). Long-term memory can be further separated into declarative (or explicit), which requires conscious thought and includes memories for facts (semantic memory) and autobiographical episodes (a form of episodic memory); and non-declarative (or implicit memory) which does not involve conscious thought, and includes procedural knowledge such as skills and habits (Gathercole, 1998). Given the broad construct, it is not surprising that memory supports many cognitive processes including language and the ability to learn and understand new information, which are unsurprisingly central for independent functioning.

Historically, the memory literature (in both children and adults) has largely focussed on declarative or explicit memory and retrospective memory especially (Ellis & Freeman, 2008; Squire, 1994; Tulving, 1985). In contrast, the study of prospective memory has been relatively neglected; the adult literature has only gained increased attention in recent years, whilst paediatric PM research remains in its infancy (see Shum, Levin & Chan for a review, 2011). However, PM failures have widespread negative consequences impacting upon areas such as independent living, employment and social relationships (Shum & Fleming, 2009). Therefore, it seems highly important to investigate this aspect of memory further, particularly in a paediatric sample. Thus, PM which is the focus of this thesis will be discussed in detail below. Given the minimal paediatric research in this area, models and theories

drawn from the adult literature will be discussed first, before considering child developmental studies.

### **1.3 Prospective Memory**

PM is often defined as remembering to carry out intended actions in the future (Ellis, 1988; 1996). Prospective memory tasks can be event-based and elicited by an external cue (e.g. give a message to a friend when you see them), or time-based where time alone acts as the cue (e.g. remember a meeting at 3.00pm). Typically, successful performance requires actions to be carried out without specific reminders, and without the structure of highly practised tasks that have become largely automatic (e.g. adding milk and sugar to tea), and as such these skills are central to independent functioning across the lifespan (Ellis & Freeman, 2008). Time-based PM is characteristically harder than event-based PM as no obvious cues are provided, resulting in a greater need for self-initiated processing (McDaniel & Einstein, 1993; McFarland & Glisky, 2009).

#### **1.3.1 Theoretical models.**

Since the mid-1990's a growing body of research has proposed models for the stages and components of PM (Raskin, 2009). It is now generally accepted that PM is not a discrete cognitive or neural construct, but rather the outcome of a series of processes that include encoding of an intention, retention over a delay period, retrieval at the relevant time or place and initiation of the appropriate actions needed to carry out the intention. In addition, meta-cognitive skills are needed to monitor and evaluate the outcome (Ellis 1996; Ellis & Freeman, 2008). Across these processes episodic RM (defined above as the recall and recognition of past

information) is assumed to be involved in the retention of an intention (Cockburn, 1996). In contrast, the planning, encoding and monitoring of an intention, along with the instigation of a required action are associated with executive functioning (Kliegal, Martin, McDaniel & Einstein, 2002). RM is mostly mediated by medial temporal and hippocampal brain structures (Zola & Squire, 1991) and executive functioning is supported by the prefrontal cortex (Fuster, 1993).

Given the dependence on many components, it appears there may be several reasons to perform poorly on a PM task. For those with memory loss, failure to act on an intention is primarily linked to an inability to remember the content. However, for many individuals, the failure to act on an intention is often not due to a complete inability to remember it, but rather a failure to adequately attend or monitor it (Fish, Wilson & Manly, 2010a). Importantly, the more distinct processes (and underlying brain systems) that contribute to a function, the more vulnerable that function is to brain injury and this may well account for why PM difficulties are so commonly reported across neurological conditions (Fish, et al., 2010a).

### **1.3.2 Prospective memory retrieval.**

Despite agreement over the broad process analysis (Ellis, 1996), theoretical accounts differ in the extent to which executive functions are involved in the retrieval of an intention in the relevant context (Kliegel, Altgassen, Hering, & Rose, 2011; Martin et al., 2007). One conceptual view known as the preparatory attentional and memory process (PAM) model (Smith, 2003; Smith & Bayen, 2004), states that retrieval of intentions can only happen when executive resources such as attention and working memory are directed towards monitoring the environment for the prospective target (e.g. searching for the presence of a post-box if the intention is



to post a letter). Consistent with this, experimental data has shown ‘monitoring costs’ including interference with the speed and accuracy of on-going activity (e.g. a lexical decision task) when participants were expected to also perform a PM task during the experiment or after a delay (Smith, 2003; Smith, Hunt, McVay, & McConnell, 2007). Furthermore, dividing attention during PM tasks has been associated with impaired performance (Marsh, Hancock & Hicks, 2002), thus suggesting effortful processing is required to remember a future action.

However, on-going tasks do not always affect PM performance (e.g. Einstein & McDaniel, 2005; Scullin, McDaniel, & Einstein, 2010). To account for this, multi-process theory argues that PM retrieval can be supported by different processes that may include monitoring (i.e. preparatory attentional resources), and automatic mechanisms (McDaniel & Einstein, 2000). Here, automatic processing refers to the notion that an intention can spontaneously ‘come into mind’ at an appropriate moment without effort, such as when triggered by an associative cue (e.g. simply passing a post box).

In line with this theory, many studies have shown that the degree to which monitoring is involved depends on various characteristics such as the nature of the prospective task, the types of cues, and an individual’s personality (Winograd, 1988). Specifically, monitoring strategies are more likely to be employed if an intention is important (Kliegal, Martin, McDaniel & Einstein, 2004), if target events are less noticeable (e.g. time-based rather than event-based; Guynn, 2008), if on-going tasks are attentionally demanding (Mahy & Moses, 2011), and if the PM task does not involve processing key elements of the PM cues, such as related words (Harrison & Einstein, 2010). Low mood has also been found to reduce the accuracy of monitoring in time-based PM tasks (Kliegal et al., 2005). In addition, variables

such as greater daily activity, and less day to day structure or routine have been shown in some studies to reduce PM strategy use (Phillips, Henry, & Martin, 2008).

### ***1.3.2.1 Motivation.***

To some degree, all PM tasks have a motivational component (i.e. some 'want' or 'wish' driving completion). Despite this, empirical research exploring PM and motivation is relatively limited (Phillips et al., 2008). However, building on the cognitive models discussed above, Penningroth and Scott (2007) propose a motivational-cognitive model of PM that incorporates motivational variables into a theoretical understanding of PM performance. The authors highlight the importance of goals (defined as one's mental representation of an aim), and predict better PM performance for tasks that are personally relevant to an individual's goals. Consistent with this, study findings suggested that goal-relevant PM tasks were reported as more important, in particular when involving social interactions (Penningroth, Scott, & Freuen, 2011). Furthermore, strategy use to support encoding of an intention was more frequent for goal-related PM tasks; the contents of a goal-related PM task were retrieved from memory earlier than non-goal related PM tasks; and goal relevant PM tasks were more frequently carried out (Penningroth & Scott, 2007). Thus, findings support the notion that motivational factors impact on all stages of a PM task including PM retrieval (Penningroth & Scott, 2007).

### **1.3.3 Frontal lobe involvement in prospective memory.**

Although the above models make differing use of automatic and monitoring processes at retrieval, it is clear that prospective memory is supplemented by a number of executive processes including planning, monitoring and attentional

control. Consequently, the frontal cortex is predicted to play a key role in prospective remembering (Burgess et al., 2008; O'Connor, Manly, Robertson, Hevenor & Levine, 2004). Indeed, some have argued that PM is principally a frontal lobe function (West, 1996). Consistent with this, single-case and group studies have reliably reported PM deficits in adults with frontal lobe lesions (e.g. Shallice & Burgess, 1991; Katai et al., 2003), across a range of neurological conditions including Parkinson's disease (Kliegel, Altgassen, Hering & Rose, 2011), schizophrenia (Wang et al., 2008), multiple sclerosis (Rendell, Jensen & Henry, 2007), and dementia (Huppert & Beardsall, 1993).

Neuroimaging studies have repeatedly shown activation of frontal areas during experimental PM tasks (see Burgess, Gonen-Yaacovi, & Volle, 2011; Burgess et al., 2008 for reviews). For instance, Burgess, Quayle and Frith (2001) observed greater activity in the rostral prefrontal cortex (specifically area BA 10) when adults anticipated PM cues, regardless of whether they were presented, suggesting this area is involved in the maintenance of an intention. Recent data also implicates involvement from the right polar prefrontal region (specifically BA10), in time-based, but not event-based PM (Volle, Gonen-Yaacovi, de Lacy Costello, Gilbert, & Burgess, 2011).

Neuropsychological data have also highlighted the importance of frontal systems in PM. For example, McDaniel, Glisky, Rubin, Gynn and Routhieux (1999) categorised older adults into high and low frontal functioning and high and low hippocampal functioning based on neuropsychological test performance. They found that poor PM was associated with low frontal functioning, but not hippocampal functioning, suggesting PM performance is better predicted by executive functioning rather than RM. Elsewhere, Flemming et al., (2008) found

that executive function impairment was associated with poorer PM performance in a sample of adults with severe TBI. The frontal lobe involvement in PM is interesting, given that areas in the prefrontal cortex (particularly, the ventrolateral, dorsolateral and anterior regions) are thought to contribute to other memory processes such as working memory, encoding of episodic memories and episodic memory retrieval (Baldo & Shimamura, 2002; Fletcher & Henson, 2001).

#### **1.3.4 Executive functioning theory and PM.**

Given the involvement of the frontal lobe regions in PM, and the close relationship between PM and executive functioning (Martin, Kliegel, & McDaniel, 2003), models of executive functioning that are pertinent to PM are considered below.

Historically, Luria (1966) was one of the first to link the frontal lobes to planning, problem-solving and self-regulatory abilities. Building on this, the Norman and Shallice (1986) Supervisory Attention System (SAS) model offers a more detailed account of behavioural control and everyday action slips. The authors propose that actions are organised in a two-tiered framework. Typical daily activities including habits or procedural tasks are coordinated largely at an automatic level, and rely on the activation of pre-existing schema. However, these schema are in competition and only the most strongly activated at the time emerges (which is known as the 'contention scheduling process'). In contrast, in novel, less predictable, or dangerous situations where actions need to be considered more thoroughly, the SAS exercises control over lower level schema and enables the situation to be dealt with (e.g. through a change in the course of action). Adding to this, Shallice and Burgess (1996) breakdown the SAS into processes including

generating and implementing plans (by creating a new schema for action), and monitoring and evaluating courses of action. In relation to PM, Fish, Manly & Wilson (2010a; 2010b) highlight similarities between the SAS and the multi-process model (McDaniel & Einstein, 2000).

The theory of goal neglect (Duncan, 1986; 1995; Duncan, Burgess, & Emslie, 1995; Duncan, Emslie, Williams, Johnson, & Freer, 1996; Duncan et al., 2000) is also relevant to PM. Duncan (1986) stated that the majority of behaviour is directed by goals, and that appropriate actions are coordinated by these (in a way somewhat analogous to the motivational-cognitive model of Penningroth & Scott, 2007). Therefore, goal-focussed behaviour is a key executive functioning skill. However, following frontal lobe damage goal-directed behaviour is disturbed and ‘goal neglect’ occurs when an individual may have intact knowledge and recall of a task, but be unable to hold it in mind or carry it out. More recently, this effect has also been reported in preschool children whose executive function systems are in the early stages of development (Towse, Lewis, & Knowels, 2006).

Duncan’s theory of goal neglect has guided the development of a prominent executive functioning rehabilitation technique called Goal Management Training (GMT; Robertson, 1996). GMT involves teaching individuals to stop, pay attention to the current situation, outline their goals and then to mentally review and monitor whether goals have been attained (Levine et al., 2000; Levine et al., 2007). The errors from goal neglect have been defined as comparable to a PM slip (Fish et al., 2010a; 2010b), and as such, researchers have begun to evaluate whether GMT is also helpful when considering the rehabilitation of PM difficulties (Fish et al., 2007).

### **1.3.5 Development of PM in neurologically healthy children.**

There are few developmental studies of PM in children, and existing research has generated several inconsistent results, thought to be linked to methodological differences in studying PM in childhood. Factors thought to contribute to discrepant findings across studies include a failure to adequately control for confounding variables such as poorer comprehension and recall of task instructions from younger children, and the level of task interest or task difficulty (Kvavilashvili, Kyle, & Messer, 2008).

Despite this, there is an overall developmental trend for older children to demonstrate better PM performance than younger children (Einstein, McDaniel, Marsh & West, 2008). This is consistent with the protracted maturation of the frontal lobes which continues well into adolescence and early adulthood (Gogtay et al., 2004). The trend is also linked to developmental improvements in other frontally guided areas of cognition such as attentional and executive systems which show considerable advances between ages 3 to 12 years (Marlowe, 2000), and the development of other memory systems including working memory and RM (including episodic and semantic memory), which show significant changes from infancy to around 7 years, and more steady improvement into adolescence (Gathercole, 1998).

#### ***1.3.5.1 Early childhood.***

Event-based PM skills have been observed in pre-schoolers, although the earliest age and pattern of event-based PM task performance has varied across studies. For instance, a naturalistic study by Somerville, Wellman and Cultice (1983) found that 2 year olds performed as well as 4 year olds when asked to remind their

mother of tasks (e.g. to buy sweets) over a two week period. However, a small sample, lack of statistical analysis and failure to control for task interest could confound these findings (see Kliegel & Jager, 2007). More consistently, studies have begun to show the emergence of PM skills at 3 years of age (Kleigel & Jager, 2007; Gujardo & Best, 2000). Some studies have found a significant age effect on performance, such as 5 year olds remembering to press a key more often than 3 year olds (Gujardo & Best, 2000), and better PM performance between ages 3 and 6 years in a task involving putting an item in a box after a cue (Kleigel & Jager, 2007). However, age-effects in early childhood have often been difficult to find. For example, across several studies no age-effects have been seen between 4 and 5 year olds (Kvavilashvili, Messer & Ebdon, 2001; Mahy & Moses, 2011), or 7 to 10 year olds (Smith, Bayen, & Martin, 2010).

#### ***1.3.5.2 Mid-childhood through to adolescence and young adulthood.***

More reliable age effects have been observed across mid-childhood through to adolescence. On event-based PM laboratory tasks, 12-13 year olds have been shown to perform better than 8 to 9 year olds (Shum, Cross, Ford, & Owsnworth, 2008), and young adults aged 22 years have shown better PM performance compared to teenagers aged 13 years (Wang, Kliegel, Yang, & Liu, 2006). In a wider developmental study, children aged 7-10 years achieved fewer PM targets than adolescents aged 13-16 years, or young adults aged 18 to 21, although here adolescents and young adults performed equivalently (Ward, Shum, McKinlay, Baker-Tweeney, & Wallace, 2005). Similarly, in a large cross sectional internet study both PM and RM improved between ages 8 to 17 years, but interestingly, whilst PM performance in teenagers was equal or better than adults, RM

performance continued to increase during adulthood until between ages 20 to 30 years (Maylor & Logie, 2010). Delaying or interrupting an event-based PM task has also been associated with poorer performance in children below 12 years of age (Rendell et al., 2009; Shum et al., 2008).

In contrast, time-based PM seems to be established later than event-based PM. Studies have shown that it begins to develop around the 7 to 12 year range (Kerns & Price, 2001). It is thought to emerge later because the on-going monitoring of time necessitates greater executive functioning resources (Wang et al., 2006; Mantyla, Grazia Carelli & Forman, 2007). In one seminal study, 10 to 14 year olds were asked to remember to take cupcakes out of the oven after exactly 30 minutes, whilst being distracted by a computer game (Ceci & Bronfenbrenner, 1985). The task was conducted in both laboratory and home environments. All performed well in the laboratory, but at home age effects were observed where 10 year olds performed more poorly than 14 year olds. Interestingly, participants employed different time monitoring strategies across settings. In the laboratory, children monitored the cupcakes throughout the task with an increase towards the end. However, in the home environment children checked the cupcakes at the beginning and end of the time period, but rarely in the middle. Overall, lateness was linked to poorer time monitoring, although participants demonstrated little conscious awareness of their monitoring strategy use in the PM task (Ceci & Bronfenbrenner, 1985). Higher motivation in the laboratory condition has been proposed to explain the differences in performances across settings (Kvavilashvili et al., 2008).



### ***1.3.5.3 PM across adulthood.***

Although a detailed discussion of the development of PM in adulthood is beyond the scope of this thesis, a summary is included here for completeness. As above, variability in PM performance and age-related differences has been observed across studies. However, in laboratory research a general trend for PM skills to decline in a linear direction from middle age to older adulthood has been observed, thought to be linked to age-related changes in frontal lobe functioning (Maylor & Logie, 2010; McFarland & Glisky, 2009). Older age has been associated with greater declines in time-based, rather than event-based PM. However, this has been hypothesised to be due to internal time-monitoring impairments as opposed to PM per se (Park, Hertzog, Kidder, Morrell, & Mayhorn, 1997; Jäger & Kliegel, 2008). In contrast, in naturalistic settings older adults have frequently demonstrated equal or better PM performance to younger adults (Kliegel, Jäger, & Phillips, 2008; Schnitzspahn, Ihle, Henry, Rendell, & Kliegel, 2011). Variables such as individual motivation, task importance, strategy use, and less daily activity in older adults have been thought to moderate this effect (Einstein et al., 2008; Schnitzspahn et al., 2011). Thus, age differences in adulthood also appear to be linked to many factors including the type of PM demands (time-based or event-based), and the task context and setting (e.g. naturalistic or laboratory).

### **1.3.6 PM in children with ABI.**

As discussed above, few studies have formally investigated the effects of pABI on PM. A comprehensive review by Shum et al., (2011) reported 5 experimental studies that had investigated PM in children with brain injury (McCauley et al., 2010a; McCauley et al., 2010b; McCauley, McDaniel, Pedroza,

Chapman & Levin, 2009; Ward, Shum, McKinlay, Baker, & Wallace, 2007; McCauley & Levin, 2004). In addition, there have been 2 preliminary studies (McCauley & Levin, 2000; 2001), one interview study (Ward, Shum, McKinlay, Baker-Tweney, & Wallace, 2004), and one further study by McCauley et al. (2011).

The early preliminary studies explored PM abilities in a small sample of children with severe TBI aged 6 to 16 years (McCauley & Levin, 2000, 2001). Children with TBI performed more poorly on an event-based PM task than similar-aged neurologically healthy children. However, given the small sample-size, and large age-span it is difficult to draw firm conclusions from this data. Building on this, both adolescents with TBI and their parents reported PM problems in daily life in the interview study, and often PM impairments impacted significantly on independent functioning (e.g. ability to be left alone; Ward et al., 2004).

More recently, experimental data has begun to clearly highlight paediatric PM difficulties that are comparable to those reported in the adult brain injury literature (e.g. Mathias & Manfield, 2005; Groot, Wilson, Evans, & Watson, 2002). For example, McCauley and Levin (2004) compared data from 10-19 year olds with mild or severe TBI, at least 5 years post-injury, to those of children with orthopaedic injuries. Participants were presented with different colour words on a computer screen and were asked to decide which semantic category words were from (fruit or furniture). During this activity, the PM task involved noting out loud when a blue word appeared. Results showed significantly poorer performance on the PM task for those with both mild and severe brain injury in comparison to the orthopaedic group. Furthermore, reminding participants of the PM task enhanced performance in those with mild TBI, but not severe. However, a small sample-size reduced the robustness

of the data analyses, limiting the generalizability of findings, particularly in relation to any severity of injury effects.

Advancing on this, Ward et al. (2007) analysed PM performance of 45 children and adolescents with TBI (age 7 to 19 years) against 45 non-brain injured controls. The prospective task involved identifying italic words whilst completing a lexical decision task. Those with TBI demonstrated poorer PM skills, and performance reduced further when the on-going task became more cognitively demanding. Importantly, adolescents with TBI were most adversely affected by the increased cognitive demand, suggesting that disrupted pre-frontal development in those with TBI (which would normally mature throughout adolescence and thus be less noticeable in childhood), had impacted on performance in comparison to same-aged controls. This study is one of the first to provide fairly strong evidence to highlight the crucial role the prefrontal cortex plays in the development of PM. However, it is unclear how well the experimental task is matched across age groups, which may confound the age-effects observed (Kvavilashvili et al., 2008). In addition, the laboratory-based setting does not help determine how PM works in less controlled contexts and everyday settings (Ward et al., 2007).

Elsewhere, studies have evaluated the effect of financial rewards on event-based PM performance after TBI (McCauley et al., 2009; McCauley et al., 2010b; McCauley et al., 2011). Whilst completing an assessment battery, children and teenagers were asked to respond with a phrase 'please give me three points' each time they were asked 'let's try something different.' Each correct response was awarded either a dollar or penny (high versus low motivation conditions). Higher monetary incentives improved PM task performance in those with mild, moderate and severe injuries who were at least one year post-injury (McCauley et al., 2009;

2010b, 2011). However, those with severe injuries in the more acute phase of recovery (e.g. 1 to 2 months post-injury) did not benefit from higher monetary reward (McCauley et al., 2010b; 2011). These studies highlight the importance that motivation plays in PM following pABI. However, a failure to assess RM skills does limit the interpretation of findings, and as above, the laboratory based-task makes it hard to generalise these results to real-world settings where different levels of incentive may impact on PM task motivation (e.g. social reinforcement).

Finally, Magnetic Resonance Imaging (MRI) data from children and adolescents in the first few months after closed head injury highlighted a reduction in cortical thickness in prefrontal and temporal areas, which in turn was associated with poorer event-based PM performance (McCauley et al., 2010a). Although this study is the first to begin to investigate the neuroimaging of PM following pABI, future research using larger samples and newer types of imaging (e.g. diffusion tensor imaging, DTI) has been recommended to help better understand key neural pathways and regions involved (McCauley et al., 2010a).

### ***1.3.6.1 Summary of PM in children with ABI.***

Overall, findings suggest that PM impairments are prevalent after pABI. Behavioural and neuroimaging data indicate the involvement of the prefrontal lobes in PM, which are commonly affected by brain injury. As with adults, the conditions of a PM task (e.g. cognitive-demand) and individual factors (e.g. motivation level) appear to moderate PM achievement. Given the documentation of PM impairments after pABI, literature highlights the need for regular clinical assessment of PM difficulties in this population, as well as the need for further evaluation of rehabilitation strategies, beyond monetary incentives in a laboratory setting.

#### **1.4 Assessment of PM**

Taking into account the widespread nature of PM impairments, it is important to diagnose PM difficulties in clinical practice in order to accurately inform treatment. However, very few PM measures exist for an adult population, and even fewer have been designed for children (Shum & Fleming, 2009). In general, there have been four main approaches to the assessment of PM. These include the use of specific standardised PM tests; the assessment of separate processes involved in the stages of prospective remembering such as intention formation, storage and retrieval; the use of real-world tasks and the use of experimental tasks aimed at capturing one's ability to activate an intention after a delay (Fish et al., 2010a; 2010b).

For adults, the Rivermead Behavioural Memory Test (RBMT; Wilson, Cockburn & Baddeley, 1985) and revised editions (RBMT-E; Wilson, Clare, Cockburn, Baddeley & Tate, 1999; RBMT-2; Wilson, Cockburn & Baddeley, 2003; RBMT-3; Wilson et al., 2008) were the first standardised measures to consider PM, by including two PM subtests (involving remembering hidden belongings and asking a question when an alarm sounds). More recently, the Cambridge Prospective Memory Test (CAMPROMPT; Wilson et al., 2005) and Memory for Intentions Screening Test (MIST; Raskin & Buckheit, 1998; 2001) have been created specifically to assess PM. A handful of PM self-rating questionnaires also exist, such as the Prospective and Retrospective Memory Questionnaire (PRMQ; Smith, Della Sala, Logie, & Maylor, 2000), the Comprehensive Assessment of Prospective Memory (CAPM; Waugh, 1999), the Prospective Memory Questionnaire (PMQ; Hannon, Adams, Harrington & Fries-Dias, 1995), and the Everyday Memory Questionnaire (EMQ; Sunderland, Harris, & Baddeley, 1983; Sunderland, Harris, &

Gleave, 1984). However, the psychometric properties of these measures range in acceptability, and for many the clinical utility and ecological validity remains to be determined (Fleming et al., 2009).

For younger people, the Rivermead Behaviour Memory Test for Children (RBMT-C; Wilson, Ivani-Chalian, & Aldrich, 1991; Wilson, Ivani-Chalian, Besag, & Bryant, 1993) is the only standardised clinical tool which includes a PM test, however, normative data is not available for those above 11 years of age. The Six Parts Test from the Behavioural Assessment of Dysexecutive Syndrome for Children (BADS-C; Emslie, Wilson, Burden, Nimmo-Smith, & Wilson, 2003) is also thought to have a strong PM component (Mackinlay Charman & Karmilov-Smith, 2006). There are few specific child PM ratings scales. However, an adult everyday memory questionnaire (McGlone & Wands, 1991) has been adapted to form the Child Memory Questionnaire (CMQ) and Parent Memory Questionnaire (PMQ; Vriezen & Smith, 1996; Kadis, Stollstorff, Elliot, Lach, & Smith, 2004). This has 28-items assessing learning, retrieval and prospective memory.

Measures to assess the cognitive processes involved in the stages of a PM task including sustained attention, executive function and the retention of information over a delay are more readily available for both adult and child populations, and have better established psychometric properties (Lezak, Howieson, Loring, Hannay, & Fischer, 2004). However, they can miss PM failures that are due to problems integrating different cognitive skills (Fish et al., 2010a; 2010b).

Real-life PM tasks such as asking an individual to remember to make a phone call, send a postcard, or complete a diary are well used methods in rehabilitation settings for both children and adults (Middleton, 2002; Sohlberg & Mateer, 1989). These have good ecological validity and provide a better estimate of PM functioning

outside of the clinic. However, downsides include the need for greater time commitment from the individual and service offering the assessment to allow for a more longitudinal evaluation. Scoring may lack sensitivity as there may often be only one or two opportunities to perform the task. Furthermore, the absence of normative data makes it harder to interpret performance in line with same-aged peers, which is particularly relevant for the developmental context of PM in a child and adolescent population.

Advancing on this, the application of virtual reality (VR), or computer simulated environments to the assessment of PM is currently being explored. For example, the creation of a virtual 4-bedroom home was used to assess how well adults with schizophrenia could remember to take the right medication (Kurtz, Baker, Pearlson, & Asutr, 2007). Other virtual settings have included a furniture storage unit (Sweeney, Kersel, Morris, Manly, & Evans, 2010), an office (DeLuca, Millis & Rizzo, 2007), a board game designed to mimic daily life (Rendell & Henry, 2009), and a virtual shopping task (Kinsella, Ong, & Tucker, 2009).

In the paediatric literature, a video-game like task has been used to assess time-based PM in neurologically healthy children, and those with Attention Deficit Hyperactivity Disorder (ADHD). The task requires individuals to ‘drive’ a car and remember to re-fill the fuel tank when the fuel gauge points to low (Kerns, 2000; Kerns & Price, 2001). A virtual reality task known as JAAM, which assess one’s ability to remember to complete tasks required to set up an office meeting (e.g. arranging coffee, getting out tables), is also in the process of being adapted for a paediatric sample (Jansari, Agnew, Akesson, & Murphy, 2004; Jansari et al., 2009). Although these are promising methods that have been applied to clinical populations,

the reliability and validity (including real-world predictive validity) remains to be evaluated (Knight & Titov, 2009).

Finally, across most empirical studies in neurologically healthy adults and children, experimental tasks have been used to evaluate PM skills (e.g. Kliegel & Jager, 2007; McFarland & Glisky, 2009). Typical experimental paradigms involve giving instructions for a PM task that is to be completed later, using a filler activity (to act as a delay), and then carrying out an experimental task (i.e. ongoing activity), and it is during this that the participant must remember to carry out the PM task (Kvavilashvili, et al., 2008). However, there are several methodological limitations with this paradigm, particularly for developmental research. PM failures could be due to forgetting the initial PM task instructions (especially in young children); it is also difficult to set up an ongoing activity that has equivalent task difficulty across age groups (Kvavilashvili, et al., 2008). In addition, these tasks often have poor face and predictive validity, and have seldom been used with clinical populations (Kliegel Altgassen, Hering, & Rose, 2011).

In summary, there is a need to assess PM in clinical populations. However, to date, few reliable and valid indicators of PM are available in clinical or research settings, and the assessment of PM in children and adolescents is particularly under-established (Ward et al., 2007).

### **1.5 How Can we Rehabilitate PM Impairments?**

Cognitive rehabilitation aims to restore or compensate for cognitive problems that have resulted from neurological damage (Wilson, 2002a; Sohlberg & Mateer, 2001). At a neural level, restoration approaches assume that treatment can stimulate



neural recovery or regeneration, whereas compensation infers that deficits can be overcome by neural reorganisation or substitution (Dixon, Garrett & Backman, 2008).

Given that PM difficulties are common following ABI, with widespread functional consequences, it seems important to find evidence for effective rehabilitation techniques. However, as discussed above, literature has largely used experimental paradigms to investigate the construct of PM (Raskin, 2009), leaving the rehabilitation of PM difficulties a relatively under-researched area. Recently, Fish et al. (2010a), Raskin and Sohlberg (2009), and Thone-Otto and Walther (2008) have reviewed the emerging PM rehabilitation literature in adults. In addition, Shum et al., (2011) included the appraisal of five child studies in a review of PM research relevant to both children and adults with closed head injury. Nonetheless, compared to adult brain injury research, significantly less is known about the impact of pABI on PM, or the most appropriate rehabilitation approaches. In particular, very few PM specific interventions for children with ABI have been published. Therefore, it seems essential to develop and evaluate PM treatment programmes for this population (Catroppa & Anderson, 2009).

Theoretically, taking into account the multi-componential nature of PM (i.e. the involvement of memory, attentional and executive resources) it seems likely that a range of interventions may be necessary depending upon the reason for the memory failure. In line with this, approaches to PM rehabilitation in adults include those aimed at remediation or restoration of function (e.g. by training and practice of cognitive skills) and those aimed at compensation (e.g. by finding alternative means to bypass problems). More recently, meta-cognitive methods aimed at enhancing self-awareness and self-regulation, and mixed approaches combining compensatory

and meta-cognitive strategies have also been utilised (Evans, 2006; Raskin & Solberg, 2009).

Given the dearth of literature pertaining to cognitive rehabilitation for pABI, the adaption and generalisation of empirically supported adult-based treatments have been strongly recommended (Catroppa & Anderson, 2009; Limond & Leeke, 2005). Although this seems an appropriate direction for future research with important clinical implications, there are differences between adult and pABI groups that need to be considered. Specifically, a child's injury needs to be understood within a developmental framework as factors such as the nature and severity of injury, the level of pre-injury skills acquired, and the family and social context will affect outcomes (Van't Hooft, Andersson, Sejersen, Bartfai & Von Wendt, 2003). Indeed, given the potential for a child's deficits to evolve over time, specific rehabilitation techniques may be more effective at certain stages (such as restoration at earlier stages when neuronal plasticity is predicted to be at its greatest, Van't Hooft & Norberg, 2010). Taking this into account, it is generally agreed that paediatric neuropsychological interventions should be: developmentally (and age) appropriate; targeted at improving functioning in real-world settings; tailored to an individual's needs over a longitudinal time period; sensitive to family and school contexts and grounded in scientific theory (Galvin & Mandalis, 2009; Spevack, 2007; Ylvisaker, 1998).

### **1.5.1 Literature review.**

To evaluate the effectiveness of rehabilitation approaches to PM following ABI, and to ascertain which interventions may be appropriate for a paediatric population, a literature review was conducted. The electronic databases AMED

(1985 to date), EMBASE (1980 to date), MEDLINE (1950 to date) on OVID, and PsycINFO (1806 to date) on OCLC, were searched between November 2009 and November 2011. Search strategies combined variants of the terms ‘acquired brain injury’ AND ‘rehabilitation’ AND ‘prospective memory’. Searches were supplemented by reviewing references of retrieved papers and hand searching key journals (including Neuropsychological Rehabilitation, Neuropsychologia, Brain Injury, Brain Impairment, Child Neuropsychology and Developmental Neurorehabilitation), until November 2011.

For the purpose of this thesis, from the adult literature, articles pertaining solely to the assessment of PM and to interventions for other types of memory impairments (e.g. retrospective loss or generic memory groups) were excluded, as were studies with individuals with degenerative neurological conditions (see Fish et al., 2010a). Given the lack of publications related to pABI rehabilitation, articles from the child literature were included if they evaluated PM less directly (e.g. in an assessment format or secondary outcome measure).

The research reviewed below is grouped according to intervention type in line with theoretical approaches to cognitive rehabilitation discussed above, and then organised chronologically. Evidence from adult rehabilitation studies, followed by applications to pABI are discussed under each approach.

### **1.5.2 Restoration.**

Repetitive training of PM has been the focus of several rehabilitation studies. Sohlberg, White, Evans and Mateer (1992a) described cases of two participants with ABI. Each individual received between 4-6 hours a week of repetitive training, over a course of 5-months. Participants were trained to remember to carry out simple

event based tasks (e.g. clap hands when experimenter stands), and time based tasks (e.g. blink in 3 minutes) over increasingly spaced intervals. Both showed improvements in PM task accuracy over the course of the study. This effect was replicated in a controlled experimental single-case study, however only limited generalisation to everyday tasks was observed (Sohlberg, White, Evans & Mateer, 1992b). Raskin and Sohlberg (1996) further investigated effects of similar PM training in two individuals with TBI. Again, participants' ability to carry out actions over extended periods improved following training, and there was some transfer to both naturalistic and everyday tasks as assessed by a phone call task and relative-rated diary of prospective memory achievements. However, treatment carryover effects were seen in a second baseline phase reducing credibility of the treatment effect.

More recently, Umeda, Nagumo, and Kato (2006) compared effects of prospective memory training in two amnesic patients: one with lesions in the medial temporal lobe, and one with lesions to the medial frontal lobe. The intervention itself involved participants memorising every-day actions and completion times, and correctly reporting the action at the appropriate time cue, over a course of 12 weekly sessions. Self and family reported scores on an everyday memory questionnaire did improve after the training in both cases. However, the frontal lesion patient showed less marked prospective memory improvement across sessions, raising the question whether training may not be as beneficial to those with executive difficulties.

Taken together, these studies suggest that repetitive training may have some positive effect on PM in adults. However, the evidence for transfer of gains beyond training is not yet convincing, and the time commitment required remains a challenge in clinical settings. Moreover, the small number of participants and

limited control conditions in the studies above do restrict the interpretation of findings, and further research is needed to fully demonstrate the efficacy of this approach.

### ***1.5.2.1 Evidence in children with ABI.***

To date, no researchers have specifically investigated the effects of PM training in a paediatric sample. However, several studies have evaluated the remediation of attention, learning and memory more broadly. Galbati, et al., (2009) administered 6 months of attention-specific training comprising sustained and selective attention training and metacognitive strategies to 40 children aged 6 to 18 years with attentional problems following TBI. In comparison to TBI controls, those who participated in training demonstrated improvements in attention skills and adaptive functioning (including the ability to complete daily living tasks).

Evidence also supports the use of CogMed, a computerised working memory training package, which involves repetitive practice of working memory tasks designed to target skills such as focussing, planning and holding information in mind (Pearson Education, Upper Saddle River, NJ). Training requires 30 to 45 minutes of daily practice over 5 weeks, and different versions of the package exist for pre-schoolers, school-aged children and adults. The package has been evaluated across a range of paediatric presentations including ABI and ADHD. Results have shown positive effects on working memory and improvements in some school tasks such as maths skills (e.g. Bergman-Nutley et al., 2011; Holmes et al., 2010). However, there has been very limited transfer and generalisation beyond the specific tasks practised (Diamond & Lee, 2011). For example, no observable improvements have been found in problem solving, impulsivity, or class-room behaviour (Klingberg et al.,

2005; Thorell, Lindqvist, Bergman, Bohlin, & Klingberg 2008; Holmes, Dunning & Gathercole, 2009; Holmes et al., 2010). Therefore, at present, there is little evidence to suggest that working memory training could directly improve PM.

Elsewhere, the Amsterdam Memory and Attention Training for Children (AMAT-c; Hendricks & van den Broek, 1996), was originally developed as a 20-week cognitive training programme focussing on attention (sustained and selective), memory (episodic memory training, and encoding strategies), metacognitive strategies (e.g. raising awareness of techniques) and repetition. There are two sets of material, one for those aged 8 to 12 years, and one for those 13 years onwards. In a pilot study (Van't Hooft et al., 2003), three children with ABI aged 9 to 16 years completed 30 minutes of AMAT-c training per day for 20 weeks at school or home. Results showed significant gains on tests of sustained and selective attention and some improvements on test of memory (including the RBMT which has a PM subtest).

Subsequently, the package has been evaluated more rigorously in a randomised controlled trial (RCT; Van't Hooft, et al., 2005). Here, 38 children with ABI aged 9 to 16 were randomly allocated to receive AMAT-c or 30 minutes of interactive activity. Training was completed daily over 17 weeks. Those who received AMAT-c showed significant improvements in sustained and selective attention, verbal working memory and everyday memory (including RBMT performance,  $p < .0002$ ) in comparison to the control group. Gains were also maintained at six-month follow up (Van't Hooft et al., 2007). More recently, pilot studies have made attempts to evaluate the AMAT-c fully in school settings (Sjo, Spellerberg, & Kihlgren, 2010, and with the use of a parent coach to support generalisation of learning (Van't Hooft & Norberg, 2010). Consistent with previous

findings both studies showed improvements in attention learning and working memory. However, PM was not assessed directly (as the RBMT was not used), and although Sjo et al., (2010) included a measure of executive functioning (the Behaviour Rating Inventory of Executive Functions, BRIEF; Gioia, Isquith, Guy, & Kenworthy, 2000), no positive gains were observed in skills linked to PM (e.g. initiation, planning, and organising).

Training in attention and metacognitive skills has also been applied to paediatric brain cancer survivors. Butler et al. (2008) randomised 161 participants to 20 sessions of cognitive training, or a wait-list control condition. Those who received training showed improved academic abilities (maths and language) and parents reported improved attention in daily life. However no changes were seen on neurocognitive outcome measures (including working memory and verbal recall), and again PM was not measured explicitly.

Overall, the literature suggests that training can improve children's attention and memory functioning after ABI. However, existing studies are generally of moderate or low methodological quality, and issues such as small samples, lack of control conditions and an absence of effect sizes make it difficult to determine the strength of the AMAT-c and other cognitive training (Ross, Dorris & McMillan, 2011). The inclusive training packages make it hard to evaluate which are the active components of the intervention, for instance, improvements could be due to increased strategy use (due to metacognitive skills training). Also the time-intensive nature of repetitive training, may limit the use of these interventions, particularly in those with reduced motivation or less family support. Studies have included an expansive age range of participants across the developmental span. However, issues such as age, age at injury and time-post injury require greater research, specifically

in relation to at what stage in brain development training may be most beneficial (Johnson, 2004). Furthermore, as discussed in the adult literature, the generalisation and transfer of training beyond test-specific situations remains to be determined. Therefore, as PM was rarely assessed or considered explicitly in this literature, it is impossible to be clear of the impact of AMAT-c, CogMed, or other training packages on PM, in experimental or real world settings.

### **1.5.3. Compensation**

Compensatory approaches are frequently used in cognitive rehabilitation settings (Wilson, 2004) and have been the focus of a growing number of PM studies. Internal strategies such as rehearsal and imagery are useful methods to improve the remembering and learning of information. However, in isolation they are less effective at helping someone recall a delayed intention at a particular time (Wilson, 2010). Therefore, external aids have been more commonly used to compensate for prospective memory problems (Fish, Manly & Wilson, 2008).

External aids can be classed as passive or active (Herrmann, Brubaker, Yoder, Sheets, & Tio, 1999). Passive aids are those which retain the content of an intention and therefore support the retrospective memory aspect of a prospective task (e.g. to-do lists and pill boxes). However, effective use requires the ability to remember to check the aid (Thone-Otto & Walther, 2008). In contrast, active aids are those which prompt retrieval at the relevant time. This can include devices which alert an individual to an intention, but not the specific content (e.g. alarms, kitchen timers), and combined strategies that also include details of the intended action (e.g. an electronic diary, or a reminder from another person).



***1.5.3.1 Non-electronic aids.***

Traditionally, various non-electronic aids have been used to support prospective remembering, including notebooks, diaries and white-boards (e.g. Sohlberg & Mateer, 1989; Evans, Wilson, Needham, & Brentnall, 2003). For example, McKerracher Powell and Oyebode (2005) compared the use of an enhanced and standard memory notebook in one individual with ABI. They found the modified notebook led to a systematic improvement in the participants' ability to complete weekly prospective tasks, and highlighted the importance of adapting memory interventions to suit an individual's needs. However, most studies evaluating non-electronic aids are anecdotal or small number single-case designs, and this does limit the generalizability of findings, particularly given the diverse sequelae of brain injury (Tate et al., 2008).

***1.5.3.2 Electronic aids.***

As technology has advanced, more attention has turned to electronic aids (see Kapur, Glisky & Wilson, 2004; & LoPresti, Mihailidis & Kirsch, 2004 for reviews). NeuroPage, a portable paging system has the strongest evidence of effectiveness as demonstrated in single case designs (Evans, Emslie & Wilson, 1998; Wilson et al., 1997; 1999), and a large RCT (Fish, Manly, Emslie, Evans, & Wilson 2007; Wilson, Emslie, Quirk & Evans, 2001; Wilson, Emslie, Quirk, Evans & Watson, 2005). Here, pre-programmed text reminders are sent to a pager worn by the memory-impaired individual, at the appropriate time (e.g. take medication now). Across all studies, people with memory and planning problems following ABI showed improvements in achieving everyday activities. For example in the RCT, 143 patients with ABI were included, and out of these 84% were significantly more able

to complete their everyday goals (such as keeping appointments), in comparison to the pre-treatment baseline phase. Indeed, on average, target task achievement increased by 30% (Fish et al., 2008). Moreover, some participants continued to recall and implement daily tasks after the pager was removed, although maintenance was less apparent in those with poorer executive functioning (Wilson et al., 2001; Fish et al., 2008).

Despite these beneficial outcomes, NeuroPage has disadvantages. It is highly specific in its use and requires a reminder to be programmed by an external person, which leaves a time delay and reduces flexibility. There is also no way to adjust a message if a task needs to be completed at a later time, or to confirm if an intention has been realised (Thone-Otto & Walther, 2003). Therefore, this single-step system is not practical or appropriate for every prospective situation.

Consequently, several other electronic aids have been evaluated including voice organisers (Van Den Broek et al., 2000; Yasuda et al., 2002) and palmtop computers (Kim, Burke, Dowds, Boone & Park, 2000), as well as more interactive systems that can adapt at different stages of a prospective task, such as the Planning and Execution Assistant Training (PEAT; Levinson, 1997) which is a palm sized reminding device that amends plans and intentions throughout the day. These studies indicate that a range of more flexible systems can support the retention and achievement of behavioural goals. However, there have been concerns that complex electronic devices may not be acceptable to all individuals such as those with more severe cognitive impairments (McKerracher et al., 2005), and that new interventions may become redundant given the pace of technological development (Fish et al., 2010a).

In this respect, mobile phones now have an advantage over other compensatory aids in that they are widely used in everyday life, making them a familiar and socially acceptable tool, more likely to enable continuous support (Jacucci et al., 2009). However, comparatively few studies have evaluated the use of mobile phones to assist prospective remembering after brain injury. Stapleton, Adams and Atterton (2007) programmed specific reminder messages (e.g. feed dog) into the mobile phones of five adults with everyday memory problems following TBI. Across participants, reminders led to an increase in the number of target behaviours achieved independently. Elsewhere, Wade and Troy (2001) sent reminder messages via a computer system to the mobile phones of five individuals with memory, planning and organisation problems following ABI. Results showed this led to greater achievement of weekly target behaviours (e.g. attending appointments) for all participants.

Despite consistent evidence supporting the use of electronic aids to facilitate the retrieval of an intention at the appropriate time (e.g. Wilson et al., 2001), a significant proportion of this rehabilitation research is of weak methodological quality (Tate et al., 2008), with the use of single-subject designs in the absence of rigorous experimental controls (e.g. Wade & Troy, 2001), statistical analysis of effects (e.g. Van Den Broek et al., 2000), or attention to generalisation into an individual's life (e.g. Yasuda, 2002). Therefore, it is difficult to determine how best to compensate for PM difficulties in more interactive and flexible ways; who is most likely to benefit from which type of external aid, and whether aids are more effective when dovetailed with other strategies.

### *1.5.3.3 Evidence in children with ABI.*

A small number of studies have attempted to evaluate the efficacy of external aids to help bypass memory problems after paediatric ABI. Some of the most robust evidence can be seen from the NeuroPage trial described above (Wilson et al., 2001). A subgroup of 12 children and adolescents aged 8 to 17 years, with neurological deficits were included in the original study (Wilson et al., 2009). Consistent with the adult data, the children showed a significant increase in their achievement of prospective target behaviours (such as completion of homework, or feeding pets), with pager reminders. However, as discussed above, the need to pre-programme specific reminders does limit the flexibility of the aid.

Several other forms of compensatory aids have been utilised with a paediatric population. Flannery, Butterbaugh, Rice and Rice (1997) found that messages shown on a computer aid (e.g. 'catheterize now') increased independent self-care task completion, in an adolescent with spina bifida and hydrocephalus. Kerns and Thomson (1998) trialled the use of a memory notebook, which included a to-do list, daily calendar and checklist with a 13 year old who was experiencing functional memory problems after an intracranial tumour. Results showed an increase in independent task achievement, such as school attendance and homework completion, and that the aid was still used effectively at 2 year follow-up. In addition, the use of mobile phones to send individuals specific reminders to increase goal-directed behaviour has been advocated for younger people with brain injury, given their familiarity with this technology (Culley & Evans, 2009). Svoboda, Richards, Polsinelli, and Guger (2010) used a smartphone to increase achievement of independent tasks (e.g. appointments, chores, social activities) in an 18 year old with severe memory problems following a brain tumour. In addition, Adlam, Gracey,

Prince and Humphrey (2011) used mobile phone alarms to successfully improve PM performance (e.g. remembering to feed a rabbit) in a 16 year old male with TBI.

However, to the author's knowledge, few other studies have systematically evaluated the impact of mobile phones on PM. Finally, a handful of studies have reported the use of compensatory memory aids such as photographic cues (Feeney & Ylvisaker, 2003), and diaries (Ho, Epps, Parry, Poole & Lah, 2011) in joint-use with other strategies. However, taking into account the multi-componential nature of these interventions they are discussed below in Section 1.5.7.

Although there is some evidence to support the efficacy of compensatory aids for PM problems, the small number of participants and case-report nature of the majority of data makes it hard to generalise to individuals of different ages, or those with different types or severity of brain injury. Across studies, PM difficulties have not been assessed clinically, making it hard to be clear about the nature or extent of participants' PM problems. Although some studies report changes in behavioural measures (e.g. Wilson et al., 2001), few report clear objective PM outcomes such as standardised ratings or experimental measures (Cicerone, Azulay & Trott, 2009). In addition, all compensatory aids require some awareness of deficits, and some degree of adjustment to be willing to use an external support, which can be challenging in a paediatric population (e.g. given the importance of peer group belonging; Wilson, Donders & Nguyen, 2011).

### **1.5.4 Meta-cognition.**

Elsewhere, evidence has been growing to support the use of meta-cognitive strategies which aim to target the executive functioning aspects of a prospective task (e.g. helping one monitor their thinking). Goal Management Training (GMT; Levine

et al., 2000) is one intervention developed to improve self-regulation and achievement of goals in those with executive dysfunction (Duncan 1986). The training focuses on the mental stages involved in achieving an intention. Individuals are taught to stop current actions, define appropriate goals, and divide these into sub-goals if necessary; rehearse the steps required and then review and monitor outcomes. A randomised trial compared a brief session of GMT against motor skills training in 30 adults with TBI. The GMT was associated with improved ability to plan and solve problems that mimicked real life. A single case study also highlighted functional benefits following GMT that included more efficient meal preparation (e.g. by remembering to follow all the recipe instructions; Levine et al., 2000).

Other research has begun to explore the ability of external cueing to support appropriately timed action. For example, Manly, Hawkins, Evans, Woldt and Robertson (2002) conducted a study to investigate the effects of brief auditory alerts on future task performance in participants with ABI. Despite a relatively small patient group a matched control group was included, and the intervention (auditory-cues associated with instructions to ‘think about subsequent tasks’) was presented in a randomised, counterbalanced order to minimise potentially confounding variables. In the alerted condition, those with ABI performed equally to controls; however, without alerts those with ABI attempted fewer tasks and were slower. Findings suggest that the non-specific cues may help intentions ‘come into mind,’ and have a positive effect on goal-directed behaviour.

Building upon this, Fish et al. (2007) found that a strategy which enhanced self-monitoring led to improved PM performance in real-world settings, in 20 adults with acquired brain injuries. Participants were asked to remember to make four phone

calls at set times each day from a mobile phone. Next they were sent text message cues reading 'STOP' at random times across several days, and were taught to briefly monitor their current goals and behaviour (which included the phone call task) on receipt of the message. Results showed significantly better phone call task performance on days with text message cues in comparison to days without. The study utilised a robust within-subjects design which controlled for error variance associated with individual differences. It also minimised interference from potentially confounding variables such as task novelty effects and retrospective memory errors, allowing us to be more certain of the interventions effects. Therefore, the data suggests that supporting self-monitoring by providing occasional non-specific reminders can improve an individual's ability to act on an intention.

Advancing further on this, a recently completed Randomised Controlled Trial (RCT), assessed whether brief GMT and automated cueing could increase the realisation of participant's own goals (Manly, personal communication, 2011). The study known as the Automated Intention Monitoring (AIM) trial included 60 adults with ABI. Individuals were randomly assigned to a GMT and cueing group, or a placebo condition involving psychoeducation and visuo-spatial task practice. After 3-weeks the groups crossed over, so that the placebo group received the intervention. Consistent with Fish et al., (2007), the GMT encouraged individuals to pause and mentally review their goals and intentions, and to associate this technique with the phrase STOP. Again, individuals were asked to remember to make four phone calls per day, and text messages containing the STOP phrase were sent to participants' mobile phones at random times over a 3-week period. However, in this study, self-reported goal-attainment was recorded by the researchers on a daily basis. Preliminary findings (Manly, personal communication, 2011) revealed a significant

effect of cueing on total goal achievement. An interaction was also observed between condition and phase, in that benefits to the number of goals achieved were only evident when participants were receiving text message cues. Thus, the study provides the strongest empirical evidence to date, in support of the use of cueing to facilitate monitoring behavioural attainment. Importantly, it is the first to show a transfer of cueing effects to patients' own goals and longer-term functional gains (e.g. return to work; Gracey et al., 2012; Hardy et al., 2010). However, anecdotal reports (Manly, personal communication, 2011) suggest that for some the intervention had minimal impact. Therefore, it is important to further examine individual factors influencing response to this intervention (e.g. age, severity of injury, motivation).

Finally, it is important to note that in contrast to the above literature, Sweeney et al. (2010) did not find a positive effect of auditory alerts on PM performance. Here, a sample of 17 adults with ABI aged 18 to 65 years completed a VR furniture moving task. PM tasks included checking the front door every 5 minutes for the arrival of the removal van (time-based PM), labelling cabinets containing glass as fragile when they appear (event-based PM), and closing the front door when entering the storage room (activity-based PM). Auditory alerts were played intermittently during the task, and participants were instructed to use these as reminders to 'think about what they are currently doing, and the aims goals and rules of the task.' However, PM performance did not differ significantly across alerted and non-alerted conditions. The authors consider that their sample may have more severe executive impairments in comparison to previous studies (e.g. Manly et al., 2002; 2004). The removal task is also more complex, involving different instructions, categories, and sub-tasks, and the authors suggest that in these types of



situations more comprehensive GMT (as administered by Fish et al., 2007, and Gracey et al. 2012; Hardy et al., 2010) may be required Sweeney et al., (2010). Therefore, this study indicates that the impact of cueing and self-monitoring is likely to be moderated by variables such as injury severity and PM task complexity.

### ***1.5.4.1 Evidence in children with ABI.***

Although several studies have attempted to apply executive functioning or metacognitive strategies to children with brain injury, few have directly evaluated their impact on PM. Catroppa, Anderson and Muscara (2009a) piloted a six session executive functioning intervention for three adolescents with TBI. The programme involved psychoeducation about brain injury and discussions of ways to develop executive skills, such as staying on track and using reminders. After the intervention, all participants showed improvements on a planning task, and one showed an increase in rate of independent daily task achievement as reported on a questionnaire (suggesting a benefit on PM performance). However, the absence of an experimental design reduces internal validity and limits the conclusions that can be drawn. The inclusive nature of the intervention makes it hard to be sure about which aspects may be responsible for treatment effects. Furthermore, any gains to PM are tentative as they are based solely on qualitative reports.

Marlowe (2000) has identified the need to teach step-by-step problem solving to children with executive difficulties including the skills of highlighting a goal; following steps to act on an intention; and monitoring behaviour throughout. Consistent with this, Suzman, Morris, Morris and Milan (1997) evaluated the efficacy of problem-solving training in five children aged 6 to 11, with ABI, using multiple-baseline single-case designs. Children received a training programme

which included self-regulation skills (e.g. 'Stop and Think'), metacognitive skills (e.g. to draw on past experiences to solve problems) and training to increase awareness of reasons for successful task completion. Participants showed improved performance on a computerised problem solving task, and some were more able to plan and organise in a classroom setting. However, the generalisation of effects to everyday PM tasks remains to be evaluated.

An interesting study by Selznick and Savage (2000) used self-monitoring training and auditory cues to improve on-task academic behaviour in three 14 year old males with ABI. To increase self-monitoring, participants were trained to record time spent on or off task during maths activities. Auditory cues were played every 45 seconds and participants were also instructed to use the cue as a prompt to self-monitor. Results indicated a significant increase in on-task behaviour, and although not explicitly measuring PM, the authors argue that self-monitoring can lead to prospective behaviour change in adolescents with ABI (Selznick & Savage, 2000).

Elsewhere, training in martial arts and mindfulness (a metacognitive skill aimed at promoting self-monitoring) has been shown to improve executive functioning in neurologically healthy children (Diamond & Lee, 2011). Lakes and Hoyt (2004) compared 5 to 11 year olds who participated in Tae-Kwon-Do training against those who completed other physical exercise. The Tae-Kwon-Do included practice to focus on the present moment, self-monitor and plan (e.g. by asking questions such as 'what should I be doing?'). The Tae-Kwon-Do condition showed improvements in cognitive and emotional self-regulation. More recently, Flook et al., (2010) allocated 64 participants aged 7 to 9 years to a mindfulness awareness practice condition which involved training in attention regulation, and increasing awareness of body sensations and the environment, or a silent reading condition.

Mindfulness practice led to improvements on the BRIEF (Gioia et al., 2000), including gains on monitoring, planning and organising scales. Although mindfulness studies may have potential, the transfer of gains to goal-directed behaviour remains to be determined. In addition, the suitability of mindfulness training for a clinical pABI population needs to be evaluated (McMillan, Robertson, Brock & Chorlton, 2002).

More recently, Krasny-Pacini et al., (2011a; 2011b) conducted a pilot study to investigate the application of GMT to children with everyday problems in executive functioning following ABI. Four individuals aged 9 to 14 years, completed a 15 week course of adapted GMT which involved exercises and games to increase self-monitoring and the mental review of one's goals, and to promote the steps to achieving these (Krasny-Pacini et al., 2011a). To promote maintenance and generalisation, parents and school teachers were provided with ways to apply the strategies in home and school settings (e.g. cooking tasks and school exercises). Following training, all participants showed improvements on a PM task which involved sending three text messages per week. In addition, all showed gains on measures of executive functioning in real life contexts (either the Children's Cooking Task, Chevignard et al., 2008; or the BRIEF, Gioia, et al., 2000). The results from this well-controlled experimental study are the first to indicate that GMT can promote PM and executive function performance in children with ABI. However, the multi-componential nature of the GMT package, makes it hard to be clear about which is the most effective aspect of the intervention. In addition, the uptake of involvement from parents and teachers was limited, making it harder to promote the transfer and generalisation of GMT (Krasny-Pacini, personal communication, 2011).

### **1.5.5 Mixed/Other.**

Fleming, Shum, Strong and Lightbody (2005) piloted a mixed intervention aimed at increasing self-awareness of memory deficits and enhancing organisational skills and the use of compensatory aids such as a notebook or electronic diary. Three adults with TBI were included in the study and all showed improvement on formal measures of PM and diary use following training. However, the small sample size and lack of control conditions makes it difficult to draw clear conclusions. Also two participants were less than four months post-injury, and their performance may have been confounded by neurological recovery. Subsequently, a more rigorous randomised controlled trial has examined the effects of combined self-awareness and compensatory training in comparison to each component with an active control, and an active control only (Shum, Fleming, Gill, Gullo & Strong, 2011). Retraining as described above (Raskin & Sohlberg, 1996) was utilised as the active control for compensatory PM training, and interventions were delivered to 45 participants with TBI over 8 weekly sessions lasting up to 2 hours. Those in the compensatory training conditions showed improvements in standardised assessments of PM and diary use, although limited generalisation was observed by relatives. Conversely, self-awareness training did not enhance PM either alone or in combination. But, as expected, given the relatively brief treatment time, retraining was not associated with benefits to PM performance over the 8 weeks. This provides some evidence in support of compensatory training for PM deficits, rather than repetitive training. However, given limitations with the data which included high attrition, small numbers in each group (11 or 12), and differences in severity of injury between conditions, it is possible that the efficacy of additional self-awareness training may be seen in future studies (Shum et al. 2011).

*1.5.5.1 Evidence in children with ABI*

Feeney and Ylvisaker (2003) used a single-case reversal design to examine the effects of a cognitive behavioural programme in two children aged 5 and 6 with challenging behaviour following TBI. The programme comprised the use of routine and structure to support executive functioning, photographic cues to direct children to the appropriate task, behavioural management strategies (e.g. positive reinforcement), and cognitive strategies including a 'goal-plan-do-review' which supported individuals to identify goals, plan steps to achieve these goals and then reflect and review the outcome. Results showed a quantitative reduction in aggressive behaviours for both, although amount of schoolwork completed did not increase significantly. Extending this, Feeney and Ylvisaker (2006) repeated the intervention with two other young children with behavioural problems following TBI. Again findings showed a decrease in the frequency of challenging behaviours. However, here results also demonstrated an increase in the amount of schoolwork achieved, (which could be seen as comparable to a PM task). Strengths of these studies included the use of a strong experimental design, the replication of findings across studies, and the context-specific nature of the intervention (i.e. delivered directly in school). Nonetheless, participants' PM was not assessed or measured and it remains to be seen whether this combination of interventions which included training around planning and the executive review of behaviour, can enhance the achievement of PM tasks more generally and in different settings.

Elsewhere, Ho et al., (2011) evaluated the efficacy of self-instructional and diary training on everyday memory, as measured on the Child and Parent Memory Questionnaire (Kadis et al., 2004), which includes PM items such as 'forgetting to pass on a message'. Fifteen children with ABI age 11 to 17 years completed six

weekly sessions. The intervention covered the internal steps needed to complete a task (e.g. what is needed to be done, what strategies are needed to achieve it, how to try it out and monitoring completion), and specific diary training, such as where and how to use the diary (e.g. how to use the diary notes section, planner and address section). Results showed a decrease in everyday memory difficulties as reported by both children and parents, and an increase in participant diary use. However, a lack of control conditions limits the strength of the data; for instance, it is possible that diary use may have increased spontaneously. In addition, a failure to fully characterise participants' cognitive functioning at baseline (including an absence of assessments of working memory, executive function and PM) makes it difficult to ascertain who may respond more readily to this programme.

Finally, as discussed in Section 1.3.6, higher financial incentives have been shown to improve event-based PM performance in a laboratory task in children aged 6 to 19 years with TBI (McCauley et al., 2009; 2010b; 2011). However, those with severe injuries in the more acute phase of recovery (e.g. 1 to 2 months post-injury) have consistently not benefited from higher monetary reward (McCauley et al., 2010b; 2011). Furthermore, although these findings have implications for rehabilitation, more research is needed to evaluate whether such gains can transfer to clinical and real-world settings and enhance participants' everyday PM functioning.

### **1.5.6 PM rehabilitation: Summary and conclusions.**

The evidence-base for the rehabilitation of PM problems following ABI in both children and adults has been described above. Overall, a modest number of papers met search criteria for adults, and only a handful formally evaluated the impact of an intervention or technique that may improve PM in children (Krasny-

Pacini et al., 2011a; 2011b; McCauley et al 2009; 2010b; 2011), highlighting a scarcity of research in this area. Methodological issues across studies are considered separately below for the adult and child literature. Theoretical and clinical implications are then discussed, followed by the conclusions drawn from the rehabilitation literature.

### *1.5.6.1 PM rehabilitation in adults.*

Most studies suggested positive gains to PM functioning following intervention, and this was seen across restorative, compensatory, meta-cognitive and mixed approaches. In particular, there is growing high-quality evidence to support the use of metacognitive strategies that are aimed at the executive functioning aspect of a PM task (Fish et al., 2007; Gracey et al., 2012; Hardy et al., 2010).

However, methodological issues do hinder the interpretation of findings. For example, in the adult literature reviewed above the majority of studies used single-subject designs, and of these, four studies were uncontrolled or only used AB procedures (baseline, followed by treatment), which does not give a clear evaluation of treatment effects (Barker, Pistrang & Elliot, 2007). In general, single-case designs are considered weaker evidence in intervention research due to limitations with external validity (Cicerone et al., 2009). Although there is more robust evidence for the use of compensatory electronic aids (e.g. Wilson et al., 2001), many studies across other rehabilitation approaches had flaws, such as unreliable baseline sampling, or an absence of statistical analysis, limiting the empirical evidence in support of PM interventions. Also, some authors failed to provide adequate information about the interventions, making it hard to further replicate and evaluate specified techniques.

PM deficits and treatment outcomes were assessed in different ways across studies. There was limited standardised assessment of PM, and other cognitive variables related to PM functioning (e.g. attention or RM), and poor reporting of reliability and validity of measures. Outcome measures were often restricted solely to behavioural targets (e.g. PM task achievement), and failed to capture other potential intervention effects (e.g. psychosocial impact). Typically, studies provided detailed descriptions of participants, with clear inclusion and exclusion criteria. However, there was great variety in time-post injury and aetiology, and factors such as spontaneous recovery may confound treatment outcomes (Evans 2006). Also sample sizes were small, limiting generalisability of findings. Furthermore, many studies did not assess maintenance over time, or generalisation of treatment gains to other settings or behaviours. As such, the ecological validity, and longer-term effectiveness of interventions are hard to determine.

### ***1.5.6.2 PM rehabilitation in children.***

Very few PM-specific studies exist in the paediatric research. General limitations across the literature included little use of randomised or controlled designs, small sample sizes and the inclusion of a wide participant age range (e.g. 8 to 19), with varying times since injury (e.g. acute and chronic), which makes it hard to determine the effectiveness of treatment approaches, or at which developmental stage they may be most appropriate (Limond & Leeke, 2005). In relation to PM, only a minority of studies assessed participants' PM at baseline, or pre and post treatment. In addition, few included objective PM outcome measures (e.g. PM task achievement), making it impossible to be clear about the efficacy of treatment for paediatric PM impairments.



Despite this, across rehabilitation approaches several studies show promise for children with PM problems after ABI (although there is a need to interpret with caution). There is growing evidence to suggest that attention and aspects of memory can be improved by repetitive training (Galibati et al., 2009; Van't Hooft et al., 2003; 2005; 2007), however, whether such gains can generalise to PM, or functioning in real-world settings is yet to be determined. There is also evidence to support the use of compensatory aids for PM problems, and this line of research may increase as technology becomes more commercially available (e.g. smartphones, Svoboda et al., 2010). However, as discussed above, such aids often require specific reminders to be programmed, and are not always appropriate for situations requiring more spontaneous prospective remembering (e.g. posting a letter when you walk past a letter box). On a different note, there are an increasing number of studies investigating the use of metacognitive strategies in paediatric ABI rehabilitation. Initial findings suggest that improvements in self-monitoring may lead to prospective behaviour change (e.g. Krasny-Pacini et al., 2011a; 2011b). In turn, this could offer the potential for a more flexible PM strategy. However, many questions remain to be clarified, such as whether this effect can be replicated reliably, if injury type, severity, or developmental age impacts upon the acceptability of the intervention, and whether PM improvements can be maintained and generalised to everyday functioning. Finally, there is some evidence to support the use of combined strategies (e.g. compensatory and metacognitive; Ho et al., 2011), although again, potential benefits to PM performance need to be evaluated more thoroughly.

### *1.5.6.3 Theoretical context.*

As outlined in Section 1.3.1, although PM involves a series of cognitive processes, there is thought to be significant frontal-lobe involvement, and theories of executive functioning (e.g. goal-neglect; Duncan, 1986) have been drawn upon to help better understand PM. These theories infer that after brain injury a failure to act on an intention is often a result of poor self-monitoring (as opposed to difficulties recalling an intention; Burgess & Robertson, 2002). Conceptual frameworks derived from the experimental literature also demonstrate the importance of executive resources (e.g. attention and working memory) in the retrieval of intentions generally (e.g. PAM model, Smith, 2003), and if a PM task is more demanding, or if it involves a long-delay (e.g. multi-process theory, McDaniel & Einstein, 2000). Although these theoretical accounts place differing emphasis on the degree of executive involvement (e.g. PAM versus multi-process theory), it has been argued that in everyday settings, PM tasks are more complex (e.g. requiring non-routine actions), and therefore will require the involvement of executive attentional and monitoring processes (Fish et al., 2010b).

Consistent with this, theoretically driven intervention studies in the adult (e.g. Evans et al., 1998; Fish et al., 2007; Gracey et al., 2012; Hardy et al., 2010; Manly, et al., 2002) and child literature (e.g. Selznick and Savage, 2000; Krasny-Pacini et al., 2011) have begun to demonstrate that supporting individuals to self-monitor and keep their goals in mind can improve their ability to complete intended tasks. Such intervention approaches may be particularly pertinent for children and adolescents with ABI, as executive functioning skills have yet to develop fully (Hanten & Levin, 2008).

However, researchers, (e.g. Umeda et al., 2006) have highlighted how different elements of PM tasks may involve independent neural bases and that remembering content of PM intentions may involve medial-temporal lobe regions, rather than pre-frontal areas. Indeed, clinical literature suggests that although some participants appear to benefit strongly from executive focussed interventions (e.g. Gracey et al., 2012), for others they have minimal impact (Manly, personal communication, 2011). Therefore, it is possible that cognitive models of associated functions may also need to be drawn upon, depending upon the reason behind an individual's PM failures (Kinsella et al., 2009).

### ***1.5.6.4 Clinical context.***

The review suggests that there are a number of potential techniques that may help reduce PM difficulties following adult and childhood ABI. In contrast to many other cognitive functions, PM may be an area suitable for remediation approaches (Wilson & Kapur, 2008). However, the lack of rigorous scientific evidence makes it hard to formulate clear practice recommendations, particularly for children, and much remains to be learned about which individuals are likely to benefit from which approach.

Despite this, many studies employed simple strategies (e.g. electronic aids or diaries), that were trialled in everyday clinic settings. Therefore, current practice options may be to implement interventions in rehabilitation settings and conduct clinical, experimental-validation to guide future research initiatives (Levine et al, 2000). However, there are many cases when simple reminders may not be practical because they require details in advance about a certain task (e.g. the time or location).

Encouraging evidence supports the use of external cues to modulate the initiation of actions, in combination with training to mentally review one's goals (Fish et al., 2007; Krasny-Pacini et al., 2011a; 2011b). This simple technique could offer a more flexible approach to help enhance independence and the achievement of individualised goals.

Finally, the review also highlights gaps in the systematic assessment of PM functioning. Given the need for assessment to inform and guide intervention planning this also seems an important area for future consideration.

### ***1.5.6.5 Conclusions.***

In conclusion, research investigating PM rehabilitation for adults and children with ABI is in its infancy. Although several well designed studies exist, these are often limited to small numbers of participants. More methodologically sound research is needed to determine the effectiveness and efficacy of different rehabilitation interventions. There is extremely limited data in the paediatric literature, and modification of adult-based interventions is recommended (Catroppa & Anderson, 2009).

## **1.6 Summary, Aims and Rationale for the Study**

PM problems are common after pABI, and are associated with widespread negative consequences. Despite this, very few studies to date, have investigated the assessment or rehabilitation of PM deficits in adolescents with ABI. To address this gap in the literature, the aims of the current study were to: (1) adapt a strategy used by Fish et al. (2007), which has shown to be effective for adults with PM impairments; (2) to pilot this intervention programme with adolescents with reported

PM problems in everyday life following ABI in childhood; (3) to gather feedback from adolescents and families in relation to experiences of taking part and the acceptability of the intervention; (4) to explore factors associated with better or worse response to the strategy; and (5) to explore the association between standardised tests of cognitive functioning and performance on the real life prospective phone call task.

This design used by Fish et al. (2007) examined the effects of brief GMT and external content-free cueing (in the form of text messages) on PM task performance. In this pilot study, the procedure involved completing a PM task of making three phone calls per-day at specific times for 3 weeks. After one week of calls participants received training to ‘stop and think’ for a moment, and were taught to use the phrase ‘STOP’ to cue them to mentally review tasks and goals. Six text messages reading ‘STOP’ were sent to participant’s mobile phones at random times on 5 of the 10 following working days.

## **1.7 Research Questions and Hypotheses**

### ***1.7.1 Research questions.***

To address the above aims, the following research questions are given:

- 1 a). The primary research question was to investigate whether brief GMT and content-free cueing (in the form of text messages) could improve the execution of a prospective memory phone call task in adolescents (12-17 years of age) with ABI.
- b). Secondary to this, using PM telephone task performance, the study assessed whether the initiation of an action (i.e. number of calls made) was associated with the accuracy of the actions (i.e. accuracy of call times).

In addition to the primary research question, two exploratory research questions were proposed:

- 2) To find out what is the relationship between neurocognitive test performance on measures of retrospective memory, attention, executive functioning, general intellectual ability, age of injury and current age and response to the intervention in an adolescent sample.
- 3) To find out what is the relationship between standardised neurocognitive test scores (on measures of retrospective memory, prospective memory, attention, executive function, general intellectual ability), and performance on the naturalistic prospective memory telephone in an adolescent sample

### **1.7.2 Main hypotheses.**

#### ***1.7.2.1 Hypothesis 1.***

In line with PM and executive functioning theory, and consistent with findings from adult alerting strategy studies (e.g. Manly et al., 2004; Fish et al., 2007; Gracey et al., 2011), and a preliminary paediatric GMT study (Krasny-Pacini et al 2011a; 2011b), hypothesis 1 predicted that adolescents with ABI would show significantly better performance on a prospective memory phone call task on days with text message cues in comparison to days without text message cues. Improved performance was predicted in relation to both the number of calls made (proportion scores) and accuracy of call timings (composite score).

#### ***1.7.2.1 Hypothesis 2.***

PM tasks may involve both the initiation of an action at a specific time, or at some point within a more flexible temporal interval (Ellis, 1988). To represent this,

the telephone task has two scoring systems; one to assess whether an action has been initiated (proportion of calls), and one to evaluate how well an intention was remembered at a specific time (composite score). There is obvious overlap between both scoring systems. However, research with adults with ABI found that those who were more accurate in their timing also remembered to make more calls (Fish et al., 2007). This result remained when all reasons for late or missed calls (e.g. forgetting to take mobile phone) were included in the analyses. Therefore, it was of interest to analyse if this effect was observed in adolescents too. In keeping with previous research (Fish et al., 2007) hypothesis 2 anticipated that adolescents who made a higher proportion of calls would also be more accurate in the timing of those calls.

### **1.7.3 Supplementary hypotheses.**

#### ***1.7.3.1 Hypothesis 3.***

As discussed earlier (see Section 1.3.1 ) several cognitive processes are involved in prospective memory and relationships have been found between prospective memory and cognitive domains including attention, retrospective memory, executive functioning and general intellectual functioning (e.g. Contardo, Black, Beauvais, Dieckhaus & Rosen. 2009; Groot et al., 2002; Martin et al., 2003). Given the studies' developmental context, cognitive performance after pABI has also been associated with younger age of injury (e.g. Anderson et al., 2005). Furthermore, PM performance itself is known to be positively correlated with age in childhood and adolescence (Aberle & Kleigal, 2010). Therefore, hypothesis 3 predicted that neurocognitive test performance on measures of retrospective memory, attention, executive function and general intellectual ability, age of injury,

and current age, would be associated with an individual's change in PM performance in response to the intervention (i.e. the degree of the cueing effect).

#### ***1.7.3.2 Hypothesis 4.***

Finally, given limitations with the current standardised assessment of PM in children and adolescents (see Section 1.4), an additional aim of the study was to explore the relationship between performance on standard neurocognitive test scores, behavioural questionnaires and actual prospective memory performance on the real world telephone task. The first week of calls (where no intervention was present), provided useful data to show how well an individual performed a PM task in a more naturalistic setting, over a more longitudinal time-frame (i.e. a more ecologically valid measure of PM). Although, there can be a poor association between standardised neurocognitive tests and real-life performance, especially in the assessment of executive functions (Chevignard et al., 2008), some adult (Fleming et al., 2008; Groot et al., 2002; Martin, Kleig et al., 2003) and child literature (Ward et al., 2007) has shown positive correlations between PM task performance and standardised executive and RM assessments. Therefore, in line with this research, hypothesis 4 stated that neurocognitive and behavioural test performance on measures of general intellectual ability, RM, PM, attention, and executive functioning would be associated with week 1 telephone task performance.



## **Chapter 2**

### **Method**

This Chapter outlines the study design, selection criteria and recruitment procedure. Next, the characteristics of the study sample are described and details of the prospective memory intervention are provided. Following this, details are given about the measures and procedures employed. Finally, ethical considerations are discussed and a data analysis plan is outlined.

#### **2.1 Design**

A randomised alternating treatment, single-case series design (Barlow & Hayes, 1979) was used to examine the effects of brief GMT and external content-free cues (in the form of text messages) on prospective memory task performance. Participants were asked to make three phone calls a day to a voicemail service at set times, for a 3-week period excluding weekends. Target call times were generated quasi-randomly with a distinct set for each individual, and calls were at least 1 hour apart. Consistent with previous studies (Fish et al., 2007; Krasny-Pacini et al., 2011a, 2011b), participants were given a written record of their call times to increase the likelihood that any omissions were a result of prospective, rather than retrospective memory failures. However, individuals were asked not to explicitly use other reminders (e.g. electronic aids) and parents were asked not to prompt their child to ensure this did not confound the effects of the intervention. The total number of calls made and accuracy of call times were recorded to provide a controlled measure of prospective memory.

Following a one-week period of calls to reduce task novelty, participants were given training to associate text messages to cue them to mentally review their

goals. Over the next two weeks participants were sent six text alerts on 5 of the 10 working days. In keeping with previous research (Fish et al. 2007), texts were sent on randomly selected days to control for confounds such as practice, task novelty and after-school activity. Similarly, text message times were generated randomly (between the hours of 8am and 7pm); but were not sent within 30 minutes of a specified call time or 15 minutes of another text. For each individual, task performance was compared between cued and un-cued days (i.e. intervention versus no intervention) to determine the efficacy of the intervention for each participant.

Single-case methods are often employed to evaluate neuropsychological interventions (Crawford & Garthwaite, 2011; Wilson, 2006) and strengths of this study design included clear target behaviours to measure intervention success, multiple sampling of the behaviour to differentiate treatment response from no-treatment behaviours, and the opportunity to replicate effects across subjects to strengthen the validity of findings (Tate et al., 2008). Given the paucity of research in this area it is commonly accepted that new approaches should be tested first with a small number of individuals using strong experimental designs (Beeson & Robey, 2006).

## **2.2 Participants**

### **2.2.1 Sample size.**

Ten adolescents aged between 12 to 17 years who had sustained an ABI were recruited into the study, although only seven completed the full treatment protocol (see Section 2.2.5 for a description of the sample). Given the preliminary nature of this project, sample size was estimated by taking into account both pragmatic issues (e.g. the time-intensive rehabilitation protocol) and the wish to replicate results

across subjects to increase the credibility of findings. Despite the relatively small sample size, it is important to note that the single-case randomisation does allow valid conclusions of efficacy to be drawn for each participant (Todman & Dugard, 2001). Furthermore, several studies in this area (e.g. Catroppa et al., 2009; Krasny-Pacini et al., 2011a; 2011b; Stapleton et al., 2007) have evaluated treatments using less than ten participants.

### **2.2.2 Inclusion criteria.**

Inclusion criteria for the study were that young people:

- a) Had sustained a brain injury prior to recruitment and had recovered sufficiently to be medically and cognitively stable so that secondary medical factors such as brain swelling had resolved (Noppens & Brambrink, 2004).
- b) Had everyday prospective memory and organisational problems as reported by clinicians or relatives (e.g. often forgetting to pass on a message).
- c) Were able to speak and read basic level English, and were willing and able to use a mobile-phone.

Where available, severity of injury was characterised according to the Glasgow Coma Scale (GCS; Teasdale & Jennett, & 1974) and coma or post-traumatic amnesia duration (Bigler, 1990). However, an explicit time post-injury for inclusion in the study was not defined because the literature is less clear about a period of spontaneous recovery in children due to ongoing brain maturation. For instance, it is thought that residual impairments are not static but that children may ‘grow into’ deficits gradually throughout childhood (Anderson, et al., 2004).

Given the poor ecological validity of many standardised memory and executive tests (Burgess et al., 2006), in keeping with previous studies (e.g. Manly et al., 2002;

Fish et al., 2007), the presence or absence of prospective memory difficulties was based on observations and qualitative reports of participants in their daily lives, rather than standardised criteria (Burgess et al., 2006).

### **2.2.3 Exclusion criteria.**

Participants were not included if they had:

- A pre-injury diagnosis of developmental delay, neurological disorder, learning or intellectual disability, attentional disorder, or significant mental health difficulty (e.g. major depression), as these factors are known to be associated with impairments in the cognitive processes involved in prospective memory (e.g. working memory and executive function; Altgassen, Williams, Bolte, & Kliegel, 2009).
- Sensory-motor or severe perceptual deficits preventing use of a mobile-phone.
- Severe aphasia including reading deficits leading to insufficient understanding of written instructions.
- Dense amnesia preventing retention of training information.

Identifying if participants had any of the above pre-existing conditions was established through discussions with parents at initial contact and clinicians involved in the recruitment stages. Medical notes were also consulted in some instances.

The additional limits were defined to include only those who were cognitively and physically able to complete study tasks (e.g. using a mobile phone), so as to minimise any risk of potential distress.

#### **2.2.4 Recruitment.**

Participants were recruited from brain injury services across the United Kingdom (UK) including the Cambridge Centre for Paediatric Neuropsychological Rehabilitation (CCPNR), Addenbrooke's Hospital, The Children's Trust, Tadworth and via health professionals who were members of the local Child Brain Injury Trust (CBIT). Several charities also supported the recruitment process including the Encephalitis Society, Headway, Childhood Stroke Support and Different Strokes.

Recruitment sites were sent information letters (Appendix A) and senior clinicians within services were asked to approach eligible participants, introduce the study and pass on information sheets (Appendix B). Those who expressed an interest were asked to fill out a form giving permission to be contacted by the research team, which was completed and returned to the researcher (Appendix C). Telephone contact was made to check that the study selection criteria were met and to arrange an initial meeting to discuss the project.

Some participants were recruited through media advertisements placed on charity website pages. The advertisement stated the age and nature of participants required (aged 12 - 17 years, with an ABI), and gave a brief synopsis of the study (Appendix D). The researcher's contact details were provided and individuals or families were asked to respond for further information. Those who responded to an advertisement were sent two sets of information sheets (adolescent and parent versions; Appendix B) in the post and were approached by the researcher via telephone or email to arrange a meeting to discuss the study further and assess eligibility for participation.

### **2.2.5 Sample characteristics.**

Fourteen individuals were identified as potential participants by recruitment sites and charities (Encephalitis Society = 4; Addenbrooke's Hospital = 1; CCPNR = 5; Childhood Stroke Support = 4). One further individual responded to an online media advertisement ([www.differentstrokes.co.uk](http://www.differentstrokes.co.uk)). Of these, one family chose not to participate after receiving further information and four individuals did not meet the study inclusion criteria. Reasons for exclusion included a premorbid history of developmental delay ( $n = 2$ ), severe retrograde memory difficulties ( $n = 1$ ) and significant global cognitive impairment ( $n = 1$ ).

Of the remaining ten individuals, three dropped out of the study, after initial assessment ( $n = 1$ ), or after the first week of calls ( $n = 2$ ), but still consented for their data to be used for comparison purposes (see Appendix E). Reasons for dropout included illness and school pressure ( $n = 1$ ), other hospital appointments ( $n = 1$ ) and loss of motivation ( $n = 1$ ). In total, seven children and adolescents (5 boys and 2 girls) aged 12 to 17 years (Mean = 13) completed the study. Table 1 provides demographic and injury-related information for study completers. Three individuals had sustained a TBI and four had experienced a CVA. In keeping with previous research (e.g. Ho, et al., 2011), for those who survived a TBI, severity of injury was determined by lowest Glasgow Coma Scale (GCS; Teasdale & Jennett, 1974), length of post-traumatic amnesia (PTA; Brown & Nell, 1991), or loss of consciousness obtained from medical records (LOC; Greenwald, Burnett & Miller, 2003). Full GCS, PTA and LOC criteria can be seen in Appendix F. In the absence of such data, injury severity was left unclassified. For all participants, the location of damage was determined by findings from structural neuroimaging scans (CT/MRI) as reported in medical records. For research purposes, in keeping with previous

neurodevelopmental studies (e.g. Hanten, Zhang, & Levin, 2002; Kolk, Ennok, Laugessaar, Kaldoja, & Talvik, 2011), location of damage was summarised by lesion side (hemisphere), then primary areas of focal damage including lobe (e.g. frontal, temporal, parietal) and internal neural structures (e.g. basal ganglia, cerebral artery). For reference, a more detailed description of neuro-radiology findings can be seen in Appendix G.

At the time of the study all participants lived at home with parents. Five were attending mainstream school; one attended college and one had left formal education aged 16 as a result of the injury. Rehabilitation activity since the injury ranged from single-discipline input to involvement with specialist interdisciplinary rehabilitation teams. Participants were not involved in additional rehabilitation for memory, attentional or executive difficulties during the study, although three individuals were participating in other forms of therapy including Speech and Language Therapy (SALT), Physiotherapy and Cognitive Behaviour Therapy.

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table 1 Demographic and injury-related characteristics of sample

Case	1	2	3	4	5	6	7
Sex	M	F	M	M	M	M	F
Age at testing (years)	12.42	12.66	12.66	14.66	16.41	17.41	17.75
Age at injury (years)	0.42	9.58	11.66	12.17	14.66	16.58	16.66
Time since injury (months)	144	37	12	30	21	10	13
Nature of injury	Traumatic RTA – Passenger	Non- traumatic CVA – Ischaemic	Non- traumatic CVA – Ischaemic	Non- traumatic CVA - Ischaemic	Traumatic c RTA - Bicycle	Non- traumatic CVA - Ischaemic	Traumatic c RTA – Pedestrian
GCS (lowest)	-	-	-	-	15	-	7
PTA	-	-	-	-	3 hours	-	6 weeks
LOC	-	-	-	-	3 minutes	-	-
Severity	-	-	-	-	Mild/Moderate	-	Severe
Abnormal CT/MRI	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Primary lesion side	Right	Left	Left	Left	Right	Left	Right
Primary lesion site	OCC	CA; CC; PWM	CA; TEMP- PAR	CA	FR	CA; BG; IC; I; FR; PAR	FR; CC

*Note.* CVA = Cerebral vascular accident; RTA = Road traffic accident; GCS = Glasgow Coma Score; PTA = post-traumatic amnesia duration; LOC = Loss of Consciousness duration; CT = Computerised Tomography; MRI = Magnetic Resonance Imaging; OCC = Occipital; CA = Cerebral artery; CC = Corpus callosum; PWM = Periventricular white matter; TEMP-PAR = Temporal-parietal; FR = Frontal; BG = Basal ganglia; IC = Internal capsule; I = Insular; PAR = Parietal; - information unknown.



### **2.3 Prospective Memory Intervention**

After the first week of calls participants attended a training session based on a form of brief Goal Management Training (Levine et al., 2000; Fish et al., 2007; Manly, personal communication, 2011). The training material was adapted to make it applicable to adolescents by using simplified language, including more non-verbal material and age-appropriate examples (e.g. forgetting to do homework).

The training package included an educational explanation of prospective memory and a discussion of the many ways that everyday tasks or goals involving prospective memory can go wrong, such as by attention slips or distractions that prevent us from holding tasks in mind. Short-term memory was compared to an erasable ‘mental blackboard’ that allows us to hold in mind information that we intend to do (on a mental blackboard), but that things can become easily rubbed off and forgotten at the relevant moment. The importance of defining specific goals, keeping things in mind, and routinely checking the mental blackboard was emphasised (Levine, et al., 2007). The strategy of stopping for a moment to review goals and tasks on the 'mental blackboard' was discussed and demonstrated with use of a story.

Participants were given the mnemonic ‘Stop, Think, Organise, and Plan,’ and were reminded that doing these things for a moment can help prevent prospective memory slips. Importantly, participants were asked to use the mental review technique over the following two weeks whenever they received a text message reading ‘STOP!’. Vanishing cue techniques (e.g. using sentences that were gradually decreased until recall was successful; Wilson, 1999), and Errorless Learning (e.g. asking participants not to guess, and to say that they did

not know an answer instead of giving a wrong answer; Baddeley & Wilson, 1994) were used to promote retention of the STOP strategy.

Material was presented to participants in a PowerPoint format on an HP Pavillion Packard Bell laptop computer with a monitor measuring 35cm x 20cm. The training was interactive and participants were invited to draw on their own experiences and engage in exercises that highlighted the topics being discussed. For example, participants were asked to practise using their mental blackboard to help them remember to say 'Pink Elephant' after a 10 minute delay. In addition, a game that involved doing three activities (a word search, coin sorting and writing a list of common surnames) in the space of two minutes was used to illustrate how a 'STOP' cue can be utilised to help plan, organise and monitor performance. Auditory beeps were played randomly during the task and participants were instructed to use the cue to stop and briefly 'think about what you are doing' and 'what the task rules' are, to help them keep the task goals in mind.

Participants received handouts and completed a short quiz at the end of the session to ensure adequate comprehension of material (see Appendix H).

### **2.4 Measures**

A summary of the characterisation measures including the neurocognitive profile battery, everyday executive functioning and memory (PM and RM) assessments, and the study outcome measures (telephone task performance) are described below.

#### **2.4.1 Background assessment.**

For all participants, demographic information including age, history of injury, daily routine, current use of memory aids and familiarity with using mobile phones was recorded (Appendix I).

#### **2.4.2 Neurocognitive measures.**

A neurocognitive test battery was administered to characterise participants' cognitive profile and to explore hypotheses 3 and 4. Test selection was informed by models of executive function (Supervisory Attention System; Norman & Shallice, 1986) and prospective memory (Multi-process model; Einstein & McDaniel, 2005). It assessed general intellectual ability and facets of memory, attention and executive function. These neurocognitive measures were not repeated as outcomes of the intervention.

##### ***2.4.2.1 General intellectual functioning.***

A short version of the Wechsler Intelligence Scale for Children Fourth Edition (WISC-IV UK; Wechsler, 2003) was used to estimate current intellectual ability. Four subtests including Similarities (SI), Vocabulary (VC), Block Design (BD) and Picture Completion (PCm) were administered to derive a prorated Full Scale IQ score (FSIQ). The sum of the scaled scores for the Verbal Comprehension Index (VCI) subtests (SI and VC), and the Perceptual Reasoning Index (PRI) subtests (BD and PCm) were multiplied by  $3/2$  using Table A.7 in the WISC-IV Administration Manual (Wechsler, 2003). FSIQ scores were calculated by averaging the prorated VCI and PRI scaled scores and multiplying this by 10 (i.e. the total number of FSIQ subtests).

Short-form versions of the WISC-IV are widely used to obtain an estimate of IQ in clinical and research domains (Crawford, Anderson, Rankin & MacDonald, 2010; Garrood, Wright & Scott, 2011; Mandalis, Kinsella, Ong, & Anderson, 2007) and research shows that prorated VCI and PRI Indexes are both significantly correlated with actual index scores (all  $r$  values  $\geq .90$ ; Glass, Ryan, Bartels & Morris, 2008).

Excellent standardisation data exists for children age 6 to 16 years 11 months and overall the WISC-IV has good psychometric properties such as high internal consistency ( $r = .97$ ) and test-retest stability ( $r = .89$ ; FSIQ; Wechsler, 2003). Furthermore, the WISC-IV is recommended to be used with children with average or below average ability at the extreme ends of the age range (e.g. 16 years 11 months, Sattler & Dumont, 2004).

All selected subtests have adequate reliability and validity. For example, Similarities has reliability coefficients of .86, and is a good measure of general intelligence (66% of variance can be ascribed to  $g$  in a factor analysis); Vocabulary has reliability estimates of .89, and correlates well with the Verbal Comprehension Index ( $r = .91$ ); Block Design has reliability coefficient .86, and correlates highly with the Perceptual Reasoning Index ( $r = .81$ ); and Picture Completion has reliability coefficients of .84 and correlates more highly with Block Design than other subtests ( $r = .54$ ; Sattler & Dumont, 2004).

#### ***2.4.2.2 Verbal memory.***

Verbal memory was assessed with the Stories subtest from the Children's Memory Scale, which is standardised for those up to 16 years, 11 months (CMS; Cohen, 1997). Participants were asked to remember two short stories. For both

stories the number of correctly recalled story and thematic units were scored immediately and after a delay. A recognition trial was also included. The Stories subtest has good split-half reliability (subtest average coefficients = .78; Cohen 1997) and good inter-rater reliability (subtest average coefficients = .99). Moreover, the CMS as a whole has good internal consistency (coefficients between .88 - .93; Cohen, 1997) and good convergent validity correlating adequately with other verbal memory measures (e.g. Wechsler Memory Scale, 3<sup>rd</sup> Edition, Wechsler, 1998).

### ***2.4.2.3 Prospective memory.***

The Appointments subtest from the Rivermead Behavioural Memory Test (RBMT; Wilson, et al., 1985) was used to give a standardised estimate of time-based PM. Participants were required to remember to ask two questions when an alarm sounded after 20 minutes. The RBMT has high test-retest reliability ( $r = .78 - .85$ ) and good construct validity supported by correlations with self-reported memory errors ( $r = .71 - .75$ ; Wilson, et al., 1985). Although normative data only exists for adolescents 11-14 years the test has proved sensitive to everyday memory deficits shown by children up to 17 years (e.g. Adlam, Vargha-Khadem, Mishkin, & de Haan, 2005).

### ***2.4.2.4 Attention.***

Sustained attention and response inhibition were measured using the Walk, Don't Walk subtest from the Test of Everyday Attention for Children (TEA-Ch, Manly, Robertson, Anderson, & Nimmo-Smith, 1999). Participants were required to learn to discriminate two tones and record each time one sounds, but

not the other. Specifically, the Walk, Don't Walk subset has good test-retest reliability ( $r = .73$ ; 71% percentage agreement, Manly et al., 2001). It has been associated with a sustained attention factor (0.46; Manly et al., 1999), and shown to correlate significantly with the Trails B (a test of inhibition and speed) and Matching Familiar Figures Test (a measure of visual search abilities;  $r = .30$  and  $.20$  respectively; Manly et al., 1999; Manly et al., 2001; Baron, 2001). It is standardised for those up to age 15 years, 11 months.

#### ***2.4.2.5 Executive functioning.***

The Six Part Test from the Behavioural Assessment of the Dysexecutive Syndrome for Children (BADS-C; Emslie et al., 2003) was selected to assess planning, organisation, and multi-tasking skills. Participants were asked to follow a set of rules and attempt some of six tasks within 5 minutes. The Six Part Test has excellent inter-rater reliability ( $r = .92$ ), and correlates significantly with family-reported measures of executive difficulties ( $p < .01$ ; Baron, 2007) suggesting good ecological validity. The BADS-C is normed up to 15 years, 11 months (Wilson et al., 2003).

#### ***2.4.2.6 Developmental considerations.***

Unfortunately, the above tests lacked normative data for those in the 16-17 age range. However, in an attempt to ensure valid assessment across the developmental span, equivalent adult versions of measures were used for participants above the test age limit (Sowell et al., 2010). In these instances, the Wechsler Adult Intelligence Scale Fourth Edition (WAIS-IV; Wechsler, 2008), or Wechsler Adult Intelligence Scale Third Edition (WAIS-III; Wechsler, 1997)

were used in place of the WISC-IV, the Lottery subtest from the Test of Everyday Attention (TEA; Robertson, Ward, Ridgeway, & Nimmo-Smith, 1994) was used as an alternative to the Walk Don't Walk subtest, the Modified Six Elements from Behavioural Assessment of Dysexecutive Syndrome (BADS; Wilson, et al., 1996) was used in place of the BADS-C, Six Parts Test. Finally, the Logical Memory parts I and II from the Wechsler Memory Scale Third Edition (WMS-III, Wechsler, 1997) were substituted for the CMS Stories.

#### ***2.4.2.7 Practice effects.***

To control for practice effects (i.e. the potential for test performance to improve as a result of experience with a measure rather than alterations in cognitive functioning), standardised assessments were not repeated with an individual if they had been administered in a clinical or research setting within a year (Sirious et al., 2002). In instances where recent assessments had been completed, permission was obtained to use these scores to characterise the individuals' cognitive profile at baseline.

#### **2.4.3 Behavioural questionnaires.**

Given concerns with the degree to which neurocognitive test results reliably predict real-life functioning (e.g. Chevignard et al., 2008; 2009), questionnaire assessment of executive and memory difficulties was completed to further characterise the sample.

#### ***2.4.3.1 Everyday executive functioning.***

The parent-rated version of the Behaviour Rating Inventory of Executive Functions (BRIEF; Gioia et al., 2000) was administered to measure executive skills in participants' daily lives. This 86-item questionnaire assesses the frequency of behaviours over the last 6-months on a 3-point scale (never, sometimes, and often). The BRIEF yields scores across eight subscales including, Inhibit, Shift, Emotional Control, Initiate, Working Memory, Plan and Organise, Organisation of Materials, and Monitor. Subscales fall across two broader indices of Behaviour regulation and Meta-cognition. The BRIEF has good internal consistency ( $r = .80-.98$ ; Gioia et al., 2000) and test-retest reliability ( $r = .81$  to  $.98$ ), with average correlations of  $.81$  for parent clinical scales over a 2-week period (Gioia & Isquith, 2004). Importantly, it has also been shown to have adequate construct and criterion validity in the assessment of children with brain injury (Donders, DenBraber & Vos, 2010).

#### ***2.4.3.2. Everyday prospective and retrospective memory.***

Self and informant versions of the Prospective and Retrospective Memory Questionnaire (PRMQ; Smith, et al., 2000) were used to evaluate the efficiency of PM in everyday life (Appendix J). This is a 16-item instrument, with eight items assessing PM failures and eight assessing retrospective difficulties. Standardisation in adults aged 17 to 94 years shows good internal consistency (Self Prospective and Retrospective scales,  $r = .84$  and  $.80$ , respectively; Crawford, Smith, Maylor, Della Sala, & Logie, 2003). Similarly, the informant rating version has demonstrated adequate internal consistency ( $r = .92$ ,  $.87$ , and  $.83$  for the Total, Prospective and Retrospective scales; Crawford,



Henry, Ward & Blake, 2006). Although the scale has not been validated fully with adolescents, previous studies have used both self and informant versions with those under 17 years (e.g. Heffernan, Clark, Bartholomew, Ling, & Stephens 2010; Kliegel & Theodor, 2007), the items are generally age appropriate, and its use here to better characterise the sample, is exploratory.

#### ***2.4.3.3. Prospective memory log (PML).***

In keeping with the study by Svoboda et al. (2010), parents were asked to keep a log over a 7-day period to record the frequency of prospective memory slips made by their child (Appendix K). Through discussion with the researcher each individual's typical weekly prospective tasks or events (e.g. feeding a pet) were recorded. Parents were asked to monitor successful completion of chosen tasks on the checklist provided. Tasks were awarded 2 points if completed spontaneously, 1 point if completed with a prompt (e.g. a parent reminder) and 0 points if not completed. For the purposes of comparison across individuals, final scores were summed as percentages.

#### **2.4.4 Outcome measure.**

##### ***2.4.4.1 Primary outcome measure (Telephone task).***

Participants were asked to make three telephone calls per day from a mobile phone to an answer-phone for 3 weeks, not including weekends. Individuals were asked to leave their name after the answer machine tone. The date and time of the call was noted automatically by the machine.

To examine hypothesis 1 two scoring systems were used. First, the proportion of calls made each day (out of three) was recorded. Therefore, across

the duration of the study, the maximum number of calls per participant was 45 (15 in week 1; 15 across cued days; and 15 across un-cued days).

Second, in line with the study by Fish et al. (2007), a more sensitive scoring system was used that accounted for the accuracy of call timing on a 6-point scale. However, based on findings from the pilot study, here, points were awarded for calls made within 1 hour of a set time (as opposed to only within 30 minutes) to allow for developmental adjustments (see Section 2.7 below).

Therefore, 6 points were awarded if calls were made within 10 minutes of the scheduled target time; 5 points within 20 minutes; 4 points within 30 minutes and so forth. Zero points were given for omissions. For each individual, the maximum daily composite score was 18, and across the 3 week period the total possible score for each participant was 270 (90 in week 1; 90 across the cued condition; and 90 across the un-cued condition).

#### ***2.4.4.2. Feedback form.***

At the end of the study participants were asked to complete a feedback form designed for the study to assess the feasibility and acceptability of the intervention. Eleven questions on a 10-point Likert scale (0 = Not at all; 10 = Very), assessed experiences of taking part such as how easy it was to include the phone calls in daily routine, whether training helped individuals carry out other goals or intentions, levels of motivation, effort, and importance given to the telephone task, and how much difference the 'STOP' strategy made to individuals. Furthermore, open qualitative feedback was obtained about experiences of taking part, differences noticed and whether any additional prompts or reminders were used during the study (Appendix L).

## **2.5 Ethical Considerations**

Ethical issues involving children in research are considered below in line with documents from the Royal College of Paediatrics and Child Health (RCPCH, 2002), British Psychological Society (BPS, 2004), and Medical Research Council (MRC, 2004). Ethical approval to conduct the study was obtained from the Cambridgeshire 4 Research Ethics Committee (REC) prior to commencing the project (REC No: 10/H0305/62; Appendix M), along with authorisation from the appropriate Research and Development organisations (Cambridgeshire & Peterborough NHS Foundation Trust; Cambridgeshire Community Services; Addenbrookes Hospital; The Children's Trust; Appendix N).

### **2.5.1 Consent and coercion.**

Parents were given an information sheet detailing the purpose of the research, and nature and duration of each procedure (Appendix B). Adolescents received a specially designed information sheet outlining the study aims and tasks they would be asked to complete (Appendix B). There was a different version for those aged 16 to 17, and those below 16 years (Appendix B). Information was presented to adolescents in an appropriate way to facilitate comprehension and retention of information and support them to give informed consent (e.g. using visual stimuli and reading content aloud). The researcher met with families to answer questions and no time limit was imposed on participants to decide whether to take part. Adolescents were asked to repeat information in their own words to ensure they had understood the purpose of the research and what taking part involved.

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

For participants below 16 years, informed and voluntary written consent was obtained from parents on behalf of their child (Appendix O) and written assent was obtained from adolescents (Appendix P). Participants aged 16 or 17 years were asked to give their own written consent to take part, although parents were given information sheets for their reference (Appendix Q). Adolescents who were unable to consent or assent for themselves were not included. This was judged by the research and academic supervisors in consultation with clinicians, teachers or relatives who knew the adolescent well. For instance, those with dense amnesia or language difficulties to a degree which prevented comprehension and retention of study material and subsequent decision making were not included. Factors which may temporarily affect capacity to consent such as fatigue, medication and pain were also taken into consideration (Department of Health, 2001).

Consent was also obtained for permission to view hospital medical records to gain more information about the severity and nature of brain injury, and to notify each participant's GP that they were involved in the study.

It was made clear to participants that they could withdraw at any time from the study without giving reason, and that this would not prejudice any future treatment they might receive. Adolescents below 16 years were assured that they had the right to withdraw even if their parents had consented for them to participate.

All participants received a £10 book voucher as a small gift for taking part and costs incurred (e.g. phone credit) were reimbursed. Participants were asked to return all mobile phones supplied by the researcher after the study.

### **2.5.2 Confidentiality.**

Data were coded anonymously and stored in accordance with the Data Protection Act (1998). Participant contact details were stored in a locked filing cabinet. Other paper data generated throughout the study (e.g. questionnaires, neuropsychological tests) was coded and stored in a separate location away from participant names and contact details. Electronic data were stored on a password protected computer and transfer of this occurred with an encrypted memory stick. For the prospective memory task participants were required to make daily phone calls and leave short messages on an answering machine. This machine was located in a locked office and voicemail messages were erased daily. The automated system used to send text messages stored details securely and did not pass personal information onto third parties (<http://neuropage.nhs.uk>).

### **2.5.3 Managing risk and distress.**

Although participation involved time commitment from participants and their families over a number of weeks, the protocol was piloted with three neurologically healthy individuals (see Section 2.7 below) to ensure that it was feasible and developmentally appropriate. Participants were made aware of what was involved at the start and were reminded they were free to withdraw at any time. To further minimise burden, call times were scheduled within the constraints of individuals' daily lives and participants were not asked to make calls at times that were difficult (e.g. during school) or potentially dangerous (e.g. during a physical exercise class). Also careful selection criteria were defined to involve only those who would be cognitively and physically able to complete these tasks (e.g. not those with dense amnesia).

It was considered possible that adolescents may not use the study mobile phones responsibly (e.g. by using credit for personal calls). Therefore, responsible and safe mobile phone use was discussed at the start of the study and parents were asked to oversee this. Participants were informed that extensive misuse of mobile phones or phone credit may result in exclusion from the study. This is documented in participant information sheets. The researcher remotely monitored participant mobile phone use online (<https://www.youraccount.orange.co.uk>). However, no one was excluded from the study for this reason.

Steps were taken to ensure that participants did not feel disappointed with their performance on tasks. During neuropsychological testing participants were assured that ‘nobody gets every question right’ and standardised discontinuation criteria were applied. Individuals were given frequent breaks to reduce fatigue and maximise performance. In the case that psychological distress was reported or arose during the study, the researcher had a plan to discuss options with the academic supervisor and intervene if necessary by referring to relevant organisations (e.g. GP, mental health service). However, such actions were not required during the study.

Finally, the researcher conducted home visits during data collection. To minimise risks to the researcher the Cambridgeshire and Peterborough NHS Foundation Trust lone worker policy was followed (CPFT, 2008). The researcher informed others in the research team of the location and time of appointments, and made arrangements to report back on safe return.

## **2.6 Procedure**

### **2.6.1 Consent and background assessment.**

Subsequent to the recruitment procedure described above (Section 2.2.4) the researcher met with adolescents and parents who had made contact to discuss the study further and determine if the child met the inclusion criteria. The researcher read through the information sheet with potential participants and they were given the opportunity to ask questions. If parental consent and adolescent assent were given (or adolescent consent for those aged 16 or 17) an interview (with participant and a parent) was arranged to obtain background information (e.g. about current routine and history of injury) and to complete the BRIEF and PRMQ. Parents were also asked to complete the prospective memory log to monitor their child's memory slips in everyday life. Next a neurocognitive testing appointment was arranged with the adolescent alone. Participants completed the assessment battery in one meeting which lasted up to 2 hours with breaks. Initial sessions and all those following took place at the participant's home.

### **2.6.2 Prospective memory telephone task.**

Next, the researcher met with participants and a parent again (for approximately 1-hour) to introduce the telephone task. Participants were asked to make three short phone calls per day from a mobile phone to a voicemail service over the next week, excluding weekends. A set of call times (out of school hours) was established quasi-randomly for each individual, and calls were required to be at least 60 minutes apart from each other. Calls were scheduled in collaboration with participants and their families, and times that were difficult or

inconvenient (e.g. a regular after-school activity) were excluded from the randomisation options.

Errorless learning and vanishing cue techniques were used to help participants learn call times during this meeting (Wilson, Baddeley, Evans, & Shiel, 1994). Each call time was presented gradually and one digit at a time was removed (e.g. 10:50, then 10:5\_). Call times were presented in both analogue and digital format and were displayed in either 12 hour or 24 hour format, depending upon participant preference. Participants were asked not to guess the answers and to only respond if they knew the correct time. At the end of the session participants were able to repeat all three call times correctly. They were also given an A4 size written record of call times (Appendix R), and a credit card sized reminder to minimise any retrospective memory failures. Participants were asked not to use other aids to remind them of the call times, and parents were asked not to prompt or remind their child.

Participants were asked to start the telephone task over the following 5 days. Six individuals used their own mobile phones to make calls (although phone credit for study calls was provided). However, one individual was provided with a mobile phone and credit for study calls for the duration of their involvement. Errorless learning and vanishing cue techniques were also used to instruct these individuals how to use simple functions on a mobile phone.

At the end of each day the researcher briefly telephoned or texted the participant to monitor their experiences of participation, discuss reasons for any missed calls and check phone-credit levels. All participants were willing to be contacted daily by the researcher.



### **2.6.3 Intervention.**

The first week of calls was to enable participants to become accustomed to the task and minimise any novelty or practice effects. After the baseline period participants attended the GMT session. All sessions were conducted on an individual basis in a quiet room. Each session lasted approximately 1 hour.

At the end of the session participants were asked to continue with the telephone task for the following two weeks (excluding weekends). However, on half of these days, selected at random for each individual, they received six text messages reading 'STOP!' The texts were sent from NeuroPage (<http://neuropage.nhs.uk>) a computer automated system. The date, time and wording of the messages were emailed to the NeuroPage administrator who inputted these onto the system. Participants were not told which days they would be receiving text messages. Again, at the end of each day the researcher telephoned or texted the participant to discuss any omissions.

### **2.6.4 Debrief.**

Following protocol completion, the researcher met with each participant and their parent. Individuals and families were thanked for their participation and feedback was sought. On average participants were in the study for 6 weeks.

## **2.7 Pilot Study**

In line with good research practice (Lancaster, Dodd & Williamson, 2004), prior to commencing the procedure above, a pilot study was carried out with two neurologically healthy children aged between 11 and 17 years, and one

adult. The purpose was to ensure that the telephone task protocol was acceptable and feasible and that the adapted GMT was developmentally appropriate.

A convenience sampling method was used to recruit pilot study participants. Ethical procedures described above were also followed for the pilot study (e.g. obtaining informed consent, ensuring confidentiality; Appendix S) and participants received a £10 book voucher for taking part. The pilot study procedure included making three phone calls per day from a mobile phone for a week (excluding weekends), receiving the GMT, then continuing to make phone calls for two weeks (excluding weekends) and receiving content-free text messages on half these days. One individual in the pilot study just participated in the GMT session. Feedback was sought from participants and families. The achievability of making three calls per day, the optimum number of text message cues to send, and ease of understanding training material were considered.

Adjustments to the training following the pilot study included presenting the material on a laptop to increase participant interaction and incorporating exercises to explicitly practise using the mental blackboard and STOP technique. For the telephone task, the composite scoring system used by Fish et al. (2007) was extended to award points for calls made within 1 hour of a set time (as opposed to only within 30 minutes), so as to reflect the general trend for children to perform less proficiently on time-based PM tasks than adults (Voigt, Aberle, Schönfeld & Kliegel, 2011; Yang, Chan, & Shum, 2011). A summary of data collected in the pilot study can be seen in Appendix T.

## 2.8 Overview of Analysis

For each participant, data distributions were graphed and inspected visually for homogeneity of variance and patterns of responding across conditions. Tests of normality (Skewness, Kurtosis, Shapiro-Wilk) and homogeneity of variance (Levene's test) were carried out on raw cued and un-cued proportion and composite scores for each individual (Appendix U). Parametric test assumptions were not violated for six participants' single-case composite score data, and group level composite and proportion data. However, given the small sample size ( $N = 7$ ) and low power to detect significant departures from normality (Todman & Dugard, 2001) non-parametric analyses were employed throughout (Bryman & Crammer, 1990). Statistical analysis was deemed appropriate for this single-case study because there were at least 10 data points per participant, and randomisation of treatment conditions had been used (Backman, Harris, Chrisholm & Monette, 1997; Tate et al., 2008).

Week 1 phone calls were to reduce task novelty and were not part of the intervention analysis. To test hypothesis 1, Mann-Whitney  $U$  tests were utilised to examine the effects of cueing on telephone task performance, by comparing the proportion of calls made on cued and un-cued days over the 2-week intervention phase of the study, for each individual separately. These analyses were repeated using composite scores on the telephone task (which also incorporated timing accuracy). Because cued and un-cued days were randomly allocated across each participant and cued messages were also randomly distributed on these days, the unit of measurement (i.e. telephone calls) was independent, thus such between groups randomisation tests were considered appropriate to use (Todman & Dugard, 2001; Todman, 2002).

However, to further analyse the experimental effect at a group level, Wilcoxon Signed Rank tests were conducted to compare mean proportion and composite scores across cued and un-cued conditions. This was because for the group as a whole paired comparisons were available for each individual, making a repeated measures analysis appropriate (Howell, 2007). Alpha levels of .05 were used for all tests associated with hypothesis 1.

In keeping with good research practice standardised effect sizes were calculated to measure the strength of the treatment effect (Crawford, Garthwaite & Porter, 2010). For Mann-Whitney and Wilcoxon tests effect size measures were based on the  $Z$  statistic ( $r = Z / \sqrt{N}$ ; Pallant, 2010), where  $N$  equalled the total number of observations for each individual in Mann-Whitney analyses ( $N = 10$ ), and the total number of observations across conditions in Wilcoxon analyses ( $N = 14$ ). Interpretations were made in line with Cohen's (1988) conventions for effect sizes. (small = .10, medium = .30 and large = .50).

To test hypothesis 2, non-parametric correlations (Spearman's Rho) were used to examine the relationship between the proportion of calls made and the timing accuracy of calls. Average scores across the three study weeks were selected as a means to assess whether those who made more calls were more accurate in their timing over the course of the study. To illustrate, the sum of daily scores (e.g. proportion scores) across week 1, cued and un-cued days were divided by the total number of study days ( $n = 15$ ). Total proportion and composite scores across week 1, cued and un-cued days were calculated for each individual and the association between these was analysed. In contrast to the study by Fish et al. (2007), few calls were excluded for extenuating circumstances, and in most instances additional days were added onto the end of

the study period (see Section 3.2.2). Therefore, it was not deemed necessary to repeat these analyses with the omission data (for further discussion see Section 4.3.5).

To test hypothesis 3, Spearman's correlations were conducted to explore the relationship between an adolescent's response to the cueing intervention and scores on tests of cognitive function which assess domains known to be related to real life prospective memory (retrospective memory, prospective memory, attention, executive function and general intellectual function). Average daily proportion and composite scores were calculated across the intervention phase for each participant on both cued days (e.g. daily cued proportion scores divided by 5), and un-cued days (e.g. daily un-cued proportion scores divided by 5). Consistent with Fish et al. (2007), response to cueing was determined by the difference between these average daily telephone task scores on cued and un-cued days (cued minus un-cued scores). Age-corrected scaled scores from the initial neurocognitive battery and behavioural measures of cognitive functioning (BRIEF T-scores; raw scores from the PRMQ prospective and retrospective subscales; and percentage of tasks achieved independently on the PMD) were entered as neurocognitive correlates. In addition, the association between response to cueing, age at injury and current age was also examined.

Finally, to test hypothesis 4, Spearman's correlations were utilised to assess the relationship between week 1 proportion and composite telephone task scores and results from neurocognitive and behavioural assessments in the initial battery. Here, data from the first week of calls (where no intervention effects were present), were used to investigate how well an individual performed a more ecologically valid PM task (e.g. in a naturalistic setting, over a more longitudinal

time-frame). Average daily proportion and composite scores were calculated across week 1 for each participant (e.g. week 1 daily cued proportion scores divided by 5; and week 1 daily composite scores divided by 5). These daily average, week 1 proportion and composite scores were correlated with age-corrected scaled scores on neurocognitive tests, T-scores from the BRIEF, raw scores from the PRMQ prospective and retrospective subscales (both self and informant ratings), and percentage of PM targets achieved independently as recorded in the PML.

Given the small sample size, all correlational analyses were exploratory in nature and results are to be interpreted with caution.

One-tailed significance values were reported for hypothesis 1 because directional predictions were made about the expected difference between performance across cued and un-cued conditions. Similarly, one-tailed significance values were given for hypothesis 2, as directional expectations were made about the relationship between proportion and composite scores (Fish et al., 2007). However, given the exploratory nature of hypotheses 3 and 4, and mixed findings about the association between neurocognitive assessments and real life PM performance (e.g. Groot et al., 2002; Fish et al., 2007), two-tailed tests were reported, as clear predictions about the direction of associations were not stated. The Statistical Package for Social Sciences (SPSS, version 18) was used for all analyses.

## **Chapter 3**

### **Results**

At the start of this Chapter baseline neurocognitive scores are briefly summarised and the treatment of missing telephone task data are discussed. Next descriptive telephone data for week 1 (included to reduce task novelty); cued, and un-cued days are presented. Following this, statistical analyses of the cueing effect at both an individual and group level are reported and related to the primary hypothesis. Next, the relationship between proportion and composite scores, factors associated with response to cueing and neurocognitive correlates of PM task performance are reported and related to hypotheses 2, 3 and 4 in turn. This Chapter closes with a summary of the results.

#### **3.1 Baseline Assessment**

Neurocognitive assessment scores for the seven individuals who underwent the treatment protocol are summarised in Table 2. Estimated FSIQ scores were in the average range for most, although Participant 1 scored in the borderline range and Participant 4 fell in the superior range. Immediate and delayed verbal memory (CMS or WMS-III) was in the average range for all. On a simple test of PM (RBMT Appointment subtest) all but two individuals (Participants 1 and 6) achieved a perfect score, possibly highlighting a task ceiling effect given the restricted profile score range (0 – 2). Performance varied across tests of executive function (Six Parts Test or Six Elements Test) and attention (Walk Don't Walk or Lottery), where borderline or impaired functioning was seen for five individuals on a test of multitasking (Participants 1,

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

2, 5, 6, and 7) and for five individuals on a test of sustained attention

(Participants 1, 2, 3, 5, and 6).



PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table 2 Participant baseline neurocognitive assessment

Case	1	2	3	4	5	6	7
Measure							
FSIQ <sup>a</sup> (prorated)	78	99	88	123	87	116	91
CMS Stories <sup>a</sup>							
Immediate	11	10	15	15	10		
Delayed	12	12	12	12	12		
Recognition	8	9	9	9	9		
WMS-III <sup>a</sup>							
Logical-Memory I						9	8
Logical-Memory II						9	13
RBMT <sup>b</sup>							
Appointment	1	2	2	2	2	1	2
BADS-C <sup>a</sup>							
Six Parts Test	5	5	8	8			
BADS <sup>b</sup>							
Modified Six Elements Test					3	0	2
TEA-Ch <sup>a</sup>							
Walk Don't-Walk	5	1	3	10			
TEA <sup>a</sup>							
Lottery					3	3	9

*Note.* FSIQ = Full Scale Intelligence Quotient; CMS = Children's Memory Scale; WMS-III = Wechsler Memory Scale Third Edition; RBMT = Rivermead Behavioural Memory Test; BADS-C = Behavioural Assessment of Executive Dysfunction in Children; BADS = Behavioural Assessment of Dysexecutive Syndrome; TEA-Ch = Test of Everyday Attention for Children; TEA = Test of Everyday Attention.

<sup>a</sup>Scaled score. <sup>b</sup>Profile score.

Table 3 presents BRIEF Index scores. Across Indices, parent ratings of their child's executive dysfunction in everyday life were moderately or highly elevated ( $T \geq 65$ , Gioia et al., 2000) for all, except Participant 6 (and Participant 5 on the Behavioural Regulation Index; BRI). Consistent with qualitative reports, scores reflected clinically significant concerns with inhibiting and shifting responses, regulating emotions, sustaining working memory, planning, organising and solving problems.

Self and parent reported prospective and retrospective memory slips in everyday life are also presented in Table 3. In comparison to normative data from the general adult population, Participant 2 reported a frequency of prospective memory slips that was 2 *SD* higher than the adult self-rating normative mean ( $M = 20.18$ ,  $SD = 4.91$ ; Crawford et al., 2003); whilst parent prospective memory ratings for Participants 3, 4, 5 and 6 were all 2 *SD* higher than the proxy-rating normative mean ( $M = 18.7$ ,  $SD = 5.50$ ; Crawford et al., 2006).

Parent observations of participants' real life prospective memory function are also shown in Table 3. Examples of prospective tasks included taking items to and from school, doing homework, taking medication, caring for pets and after-school activities. Diary entries showed that all participants made functional prospective memory slips over the week preceding the start of the study. The average percentage of tasks achieved independently was 33 % (range 0 – 75), and 52 % (range 3 - 100) with a prompt (e.g. parent reminder). However, across the sample, an average of 14 % of tasks remained uncompleted (range 0- 48).

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table 3 Participant baseline questionnaire and behavioural assessment

Case	1	2	3	4	5	6	7
<b>Measure</b>							
<b>BRIEF<sup>a</sup></b>							
BRI	86	74	79	68	58	52	80
MI	75	73	80	77	82	53	68
GEC	98	75	83	76	76	52	74
<b>PRMQ<sup>b</sup></b>							
Self-T	32	52	43	33	40	46	39
Self-P	13	*30	25	20	21	29	23
Self-R	19	22	18	13	19	17	16
Parent-T	47	48	56	49	46	59	50
Parent-P	24	26	*33	*31	*30	*37	26
Parent-R	23	22	23	18	16	22	24
<b>PML<sup>c</sup></b>							
Targets achieved	0	38	75	0	47	0	71
Achieved with prompt	82	14	25	100	37	100	14
Not achieved	18	48	0	0	16	0	14

*Note.* BRIEF = Behaviour Rating Inventory of Executive Functions; BRI = Behavioural Regulation Index; MI = Metacognitive Index; GEC = General Executive Composite; PRMQ = Prospective and Retrospective Memory Questionnaire; T = Total Score; P = Prospective Memory Scale; R = Retrospective Memory Scale; PML = Prospective Memory Log.

<sup>a</sup>T-score. <sup>b</sup>Raw score. <sup>c</sup>Percentage.

\*Scores = > 2 SD from normative (adult population) mean.

## **3.2 Treatment of Data**

### **3.2.1 Testing data assumptions for analyses.**

Given the small sample size ( $N = 7$ ) and low power to detect significant departures from normality (Todman & Dugard, 2001) non-parametric (distribution-free) analyses were employed throughout (Bryman & Crammer, 1990).

### **3.2.2 Calls excluded during the study.**

To accurately compare performance across individuals, attempts were made to exclude from the statistical analysis any telephone task scores that were clearly missing for reasons other than prospective memory failures (e.g. not having access to a mobile phone). Three raters who were unaware of the cued or un-cued order of the days judged whether reasons were valid. Week 1 calls were also screened for valid omissions. During the intervention phase, most omissions were deemed suitable to include (e.g. watching TV, playing on x-box). However, Participant 2 did not have access to a mobile phone for a day (confiscated by parent), Participant 6 had a planned day trip, and Participant 7 had a scheduled outpatient hospital appointment lasting a day. Raters were consulted about the validity of these omissions during data collection and in these instances an equivalent day (cued or un-cued) was added to the end of the intervention phase for each participant. During the week 1 period, calls that conflicted with GMT sessions were excluded, resulting in the elimination of one call for Participant 1, and two calls for Participants 2 and 6. In these cases the proportion and composite scores were adjusted for the total number of calls possible. Rater agreement across these phases was 100% (see Appendix V).

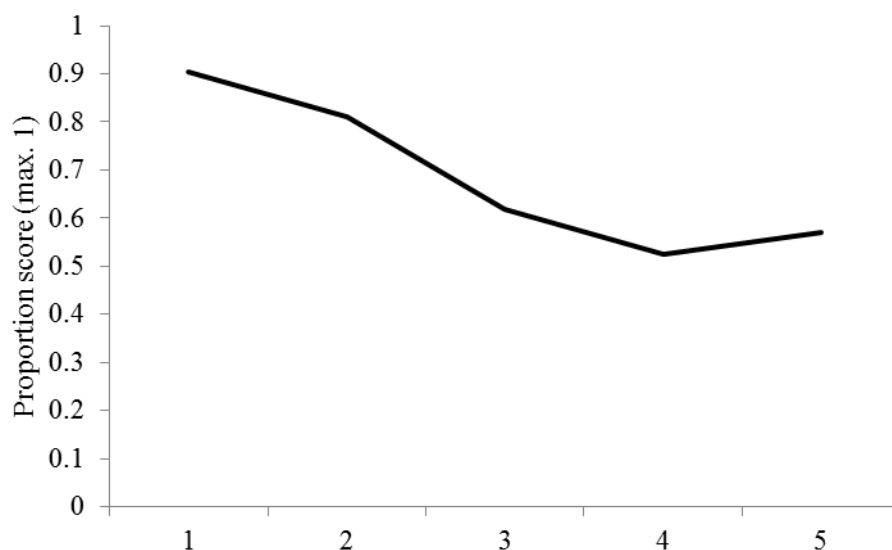
### 3.3 Telephone Task

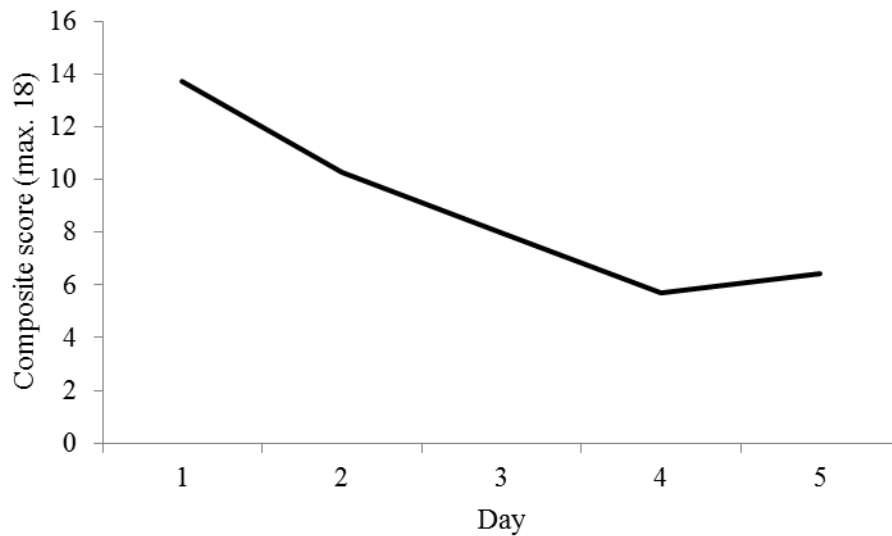
#### 3.3.1 Descriptive data.

##### 3.3.1.1 Week 1 (*pre-intervention*).

There was considerable variation in terms of week 1 telephone task performance with an average of 69% of calls achieved (range 47-100%). The average daily composite score which reflects the timing accuracy of calls was 8.82 ( $SD = 3.17$ ) out of a daily maximum of 18 points (see Section 2.4.4.1 for scoring criteria). At a group level, the participants mean daily proportion and composite scores over the 5 day baseline period are displayed separately in Figures 1a and 1b. As both figures show, in general participants demonstrated a decline in proportion and composite scores over the baseline period, possibly as a result of lessening task novelty. However, visual inspection at an individual level (see Figure 2 in Section 3.4.1.1) indicated that some did perform more consistently across the first week (e.g. Participants 3 and 4).

*Figure 1a.* Group mean week 1 telephone task proportion scores.



*Figure 1b.* Group mean week 1 telephone task composite scores.

### **3.3.1.2 Intervention phase.**

Across the intervention phase an average of 77% (range 67-93%) of calls were achieved on cued days, in comparison to only 50% (range 33-73%) on un-cued days. Consistent with this, the average daily composite score was greater on cued days ( $M = 10.60$ ,  $SD = 1.88$ ) than on un-cued days ( $M = 5.29$ ,  $SD = 2.76$ ).

## **3.4 Hypothesis Testing (Primary Hypotheses)**

### **3.4.1 Hypothesis 1.**

Research with adults with ABI have shown that content-free cueing can reliably increase prospective memory performance (e.g. Manly et al., 2004; Fish et al., 2007). However, very few studies have attempted to systematically investigate whether this strategy is effective for adolescents who have survived an ABI. Based on the existing literature, this thesis predicted that adolescents with ABI would show significantly better performance on a prospective memory phone call task on days with text message content-free cues in comparison to

days without text message cues, in relation to both proportion and composite scores.

#### *3.4.1.1 Single case analysis.*

For each participant, daily proportion and composite telephone task scores across the study are shown in Figure 2. Visual inspection suggested an improvement in task performance (in both proportion and composite scores) on cued in comparison to un-cued days for four participants (Participants 1, 2, 6 and 7).

To statistically evaluate the effect of text message cueing on telephone task performance separate Mann-Whitney *U* tests were conducted to compare the proportion of calls made over 5 cued and 5 un-cued days for each individual. As shown in Table 4, four participants (Participants 1, 2, 6 and 7) demonstrated a statistically significant effect of cueing, and as predicted made a significantly greater amount of calls on cued days (see Table 4). The effect sizes for these differences were classed as large to very large ( $r = .63$  to  $.77$ ; Cohen, 1988). However, three participants (Participants 3, 4 and 5) did not show a pattern of response consistent with the hypothesis that cueing would increase call achievement.

Mann-Whitney *U* tests were repeated to compare the composite scores of calls made over 5 cued and 5 un-cued days for each individual. When considering both timing accuracy and the number of calls made, four participants (Participants 1, 2, 6, and 7) showed a pattern of results consistent with the hypothesis, and performed significantly better on cued days in comparison to un-cued days (Table 4). Very large effect sizes were calculated for all statistically

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

significant differences ( $r = .71$  to  $.77$ ; Cohen, 1988). Three participants (Participants 3, 4, and 5) did not show a pattern of response consistent with the hypothesis (Table 4).

Figure 2. Telephone task proportion and composite scores over week 1 and randomly allocated cued and un-cued days for each participant.

### Participant 1

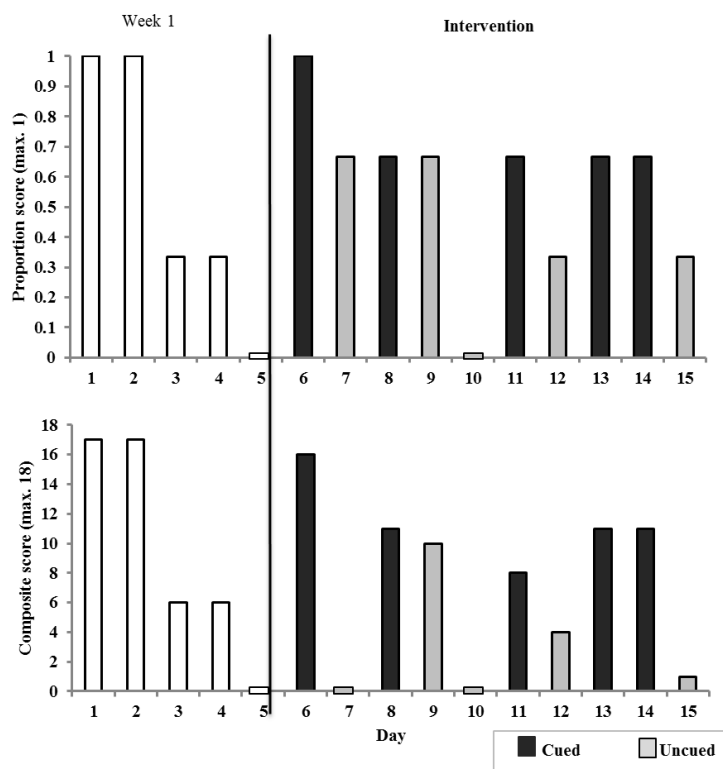




Figure 2. (Continued).

Participant 2

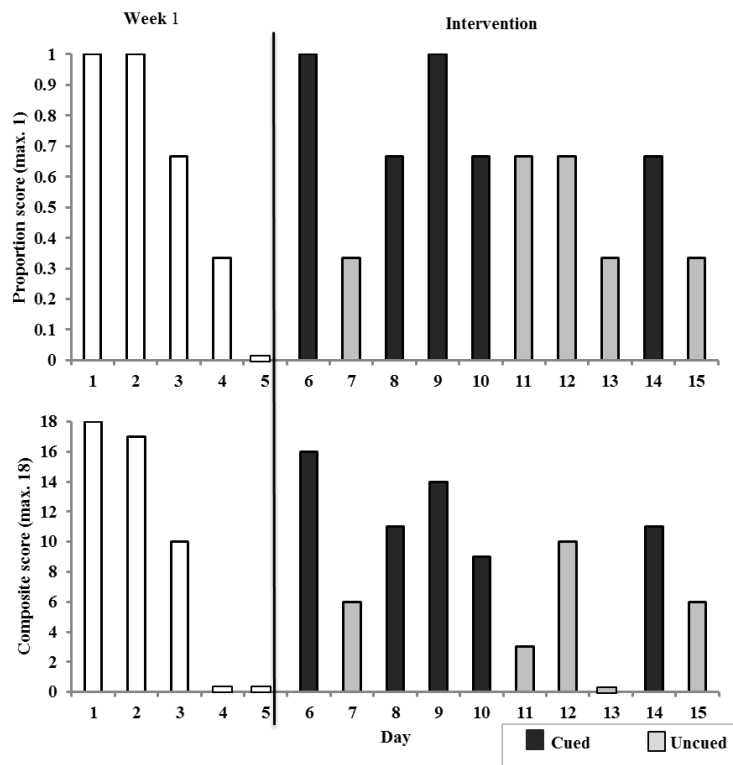


Figure 2. (Continued).

Participant 3

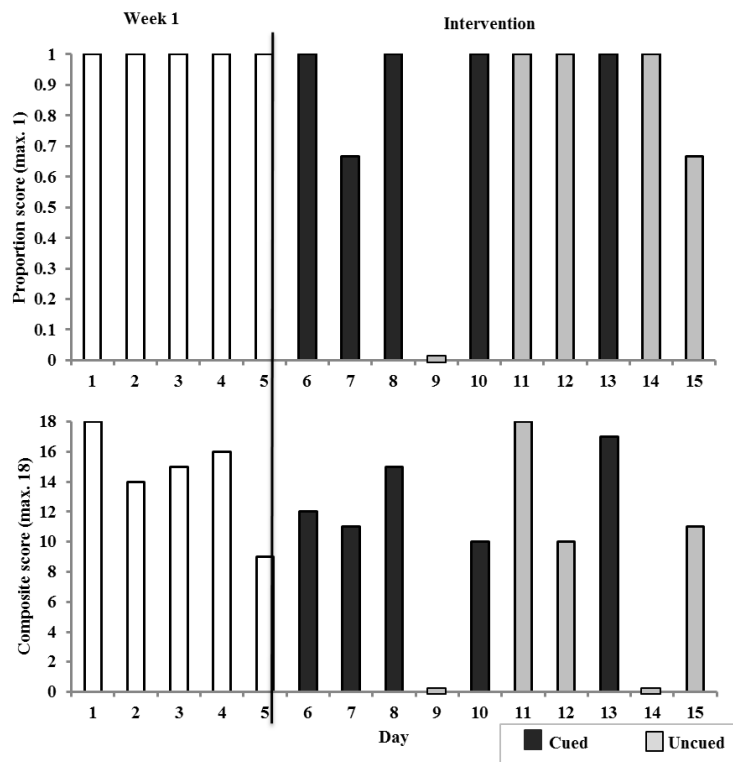


Figure 2. (Continued).

Participant 4

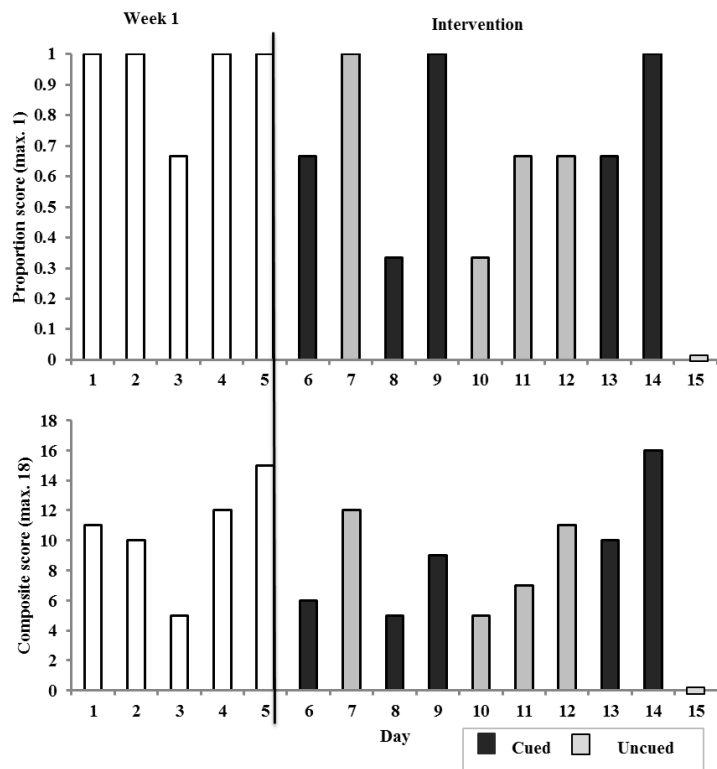
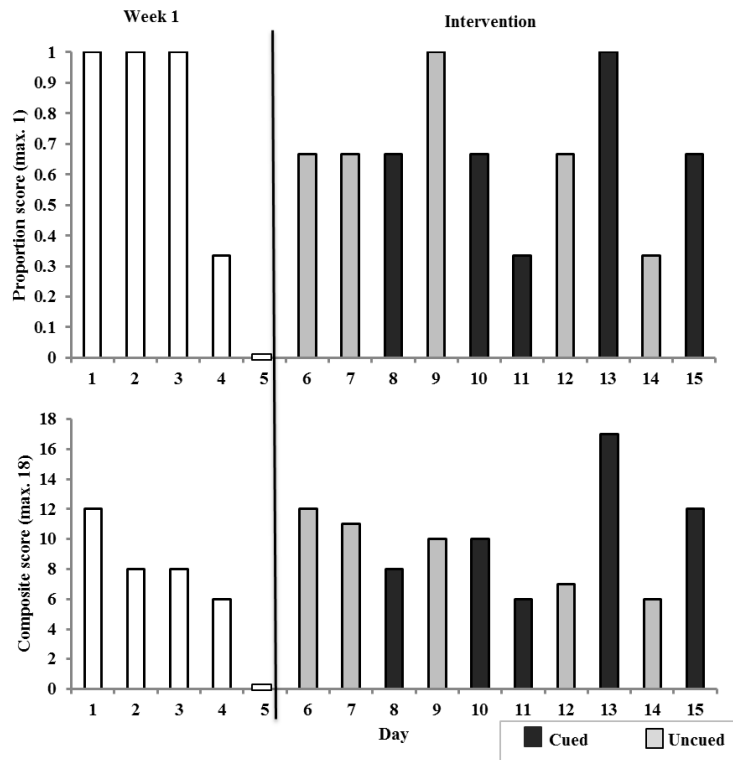


Figure 2. (Continued).

Participant 5



PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Figure 2. (Continued).

Participant 6

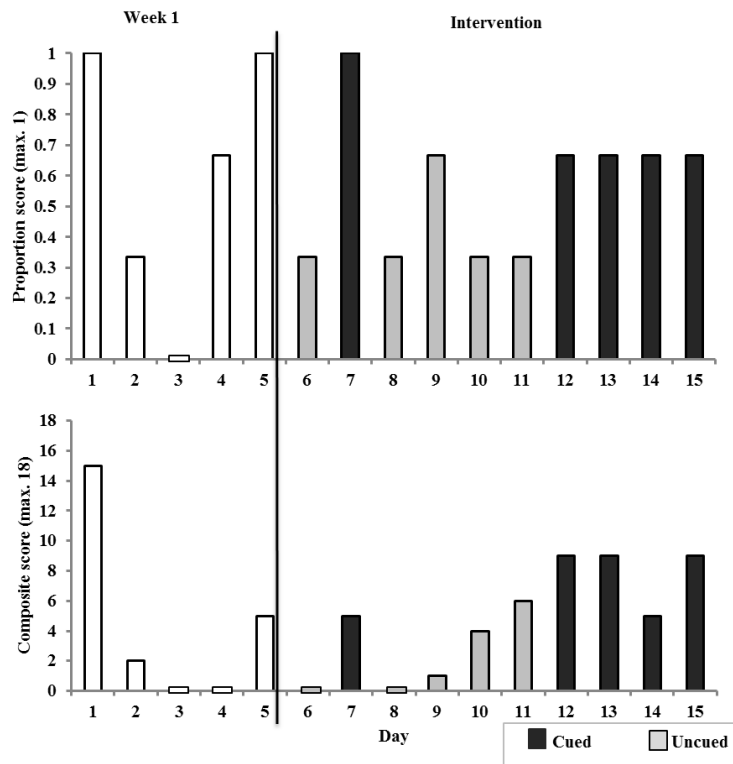
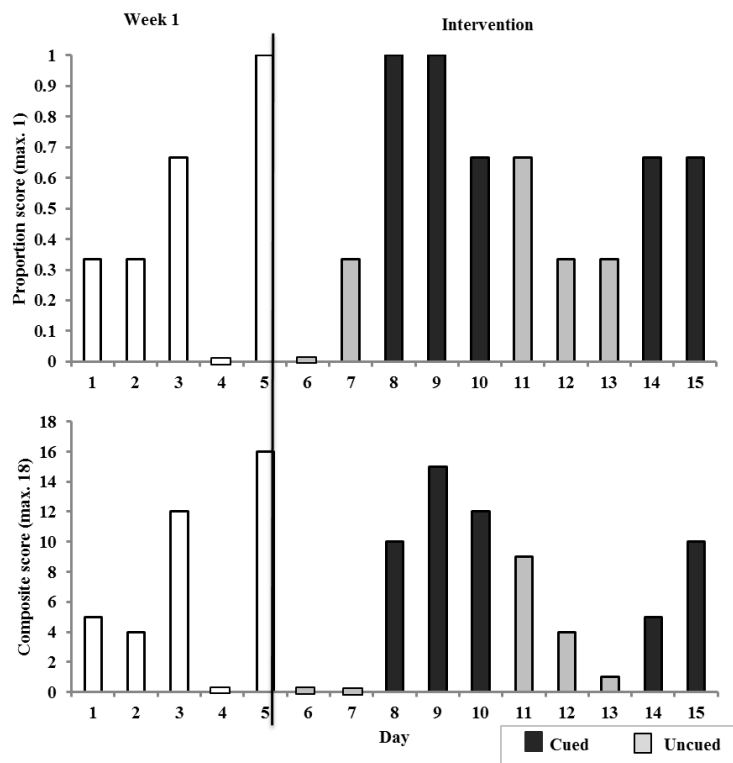


Figure 2. (Continued).

Participant 7



PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table 4 Mann-Whitney *U* analyses of proportion and composite scores across cued and un-cued telephone task conditions for each participant. Scores are median (range) values.

Case	Cued days (n = 5)	Un-cued days (n = 5)	<i>U</i>	<i>p</i>	<i>r</i>
1	.67 (.67-1)	.33 (0-.67)	4.00	.048*	-.63*
2	.67 (.67-1)	.33 (.33-.67)	3.00	.028*	-.68*
3	1 (.67-1)	1 (0-1.0)	9.50	.31	-.25
4	.67 (.33-1)	.67 (0-1.0)	9.50	.31	-.20
5	.67 (.67-1)	.67 (.33-1)	8.00	.21	-.34
6	.67 (.67-1)	.33 (.33-.67)	2.00	.016*	-.77*
7	.67 (.67-1)	.33 (0-.67)	1.50	.012*	-.76*
Composite					
Case	Cued days (n = 5)	Un-cued days (n = 5)	<i>U</i>	<i>p</i>	<i>r</i>
1	11.00 (8.00-16.00)	1.00 (0-10.00)	1.00	.008**	-.77*
2	11.00 (9.00-16.00)	6.00 (0-10.00)	1.00	.008**	-.76*
3	12.00 (10.00-17.00)	10.00 (0-18.00)	7.00	.155	-.13
4	9.00 (5.00-16.00)	7.00 (0-12.00)	10.50	.383	-.13
5	10.00 (6.00-17.00)	10.00 (6.00-12.00)	10.50	.383	-.13
6	9.00 (5.00-9.00)	1.00 (0-6.00)	2.00	.016*	-.71*
7	10.00 (5.00-15.00)	1.00 (0-9.00)	1.00	.008**	-.76*

Note. Effect size measure is based on the Mann-Whitney *Z* statistic ( $r = Z / \sqrt{N}$ ; Pallant, 2010).

\* $p < .05$ , \*\*  $p < .01$ , and a large or very large effect size; values are exact one-tailed probabilities based on the Mann-Whitney randomisation distribution (Todman & Dugard, 2001).

**3.4.1.2 Group analysis.**

To investigate the effect of text message cueing on telephone task performance for the sample as a whole, Wilcoxon Signed Rank Tests were conducted to compare mean proportion and composite scores across cued and un-cued days. For proportion scores, within-group comparisons revealed a statistically significant effect of cueing ( $z = 2.22$ ,  $p = .013$ ), with a median call proportion of .73 (range .67 to .93) on cued days and .47 (range .33 to .73) on un-cued days. The  $r$  family effect size measure ( $r = Z / \sqrt{N}$ ; Pallant, 2010) corresponded to a large degree of separation in their distributions ( $r = .59$ ; Cohen, 1988).

Similarly, when analysing composite scores a statistically significant effect of cueing was observed ( $z = 2.37$ ,  $p < .001$ ), with a median score of 10.60 (range 7.40 to 13.00) on cued days and 5.00 (range 2.20 to 9.20) on un-cued days. The effect size was again analogous to a large effect ( $r = .63$ ; Cohen 1988). At a group level, these patterns of results are consistent with the hypothesis that cueing would facilitate telephone task performance.

**3.4.2 Hypotheses 2.**

As discussed previously, PM tasks may involve the initiation of an action at a specific time, or at some point within a more flexible period (Ellis, 1988). To represent this, the telephone task has two scoring systems; one to assess whether an action has been initiated (proportion of calls), and one to evaluate how well an intention was remembered at a specific time (composite score). Research with adults with ABI found that those who were more accurate in their timing also remembered to make more calls (Fish et al., 2007). This continued

when all reasons for missed or late calls were included in the analyses.

Therefore, it was of interest to analyse if this effect was observed in adolescents too. In keeping with previous research (Fish et al., 2007) it was hypothesised that adolescents who made a higher proportion of calls would also be more accurate in the timing of those calls.

#### ***3.4.2.1 Proportion and composite score relationship.***

Non parametric correlations (Spearman's rho) were performed to analyse the relationship between average total proportion scores (reflecting amount of calls) and average total composite scores (reflecting timing accuracy), across the 3 weeks of the study. Consistent with the hypothesis, total proportion and composite telephone task scores were positively associated ( $r(7) = .89, p < .01$ , one-tailed). The size of this correlation co-efficient indicated a large strength of association between both scores (Cohen, 1988).

#### **3.4.3 Supplementary hypotheses.**

##### ***3.4.3.1 Hypothesis 3.***

A secondary aim of the study was to explore factors that may be associated with an adolescent's response to the cueing intervention. Several cognitive processes are involved in PM and relationships have been found between PM and cognitive domains including attention, retrospective memory, executive functioning and general intellectual functioning (e.g. Contardo et al., 2009; Groot et al., 2002; Martin et al., 2003). Given the studies developmental context, cognitive performance after paediatric brain injury has also been associated with severity and younger age of injury (e.g. Anderson et al., 2005).

Furthermore, PM performance itself is known to be positively correlated with age in childhood and adolescence (Aberle & Kleigal, 2010). Therefore, it was predicted that neurocognitive test performance on measures of RM, PM, attention, executive function, general intellectual ability, and age of injury, and current age, would be associated with an individual's change in PM performance in response to the intervention (i.e. the degree of the cueing effect). Severity of injury was not entered into this analysis due to the lack of available information for 5 participants (see Table 1, Section 2.25).

### *3.4.3.2 Factors associated with response to cueing.*

The relationship between these selected variables and the extent of the observed cueing effect (each individual's cued minus un-cued proportion scores, and each individual's cued minus un-cued composite scores) were assessed using Spearman's rho correlations. Daily average proportion and composite difference scores from across the intervention phase were correlated with the studies neurocognitive, behavioural, and demographic measures (see Section 2.8 and Table 5 below for a full description of variables).

For proportion scores, a negative association was reported with immediate verbal memory recall, in that poorer verbal memory was related to a larger cueing effect (Table 5). A negative association was also observed with BRIEF GEC scores. However, in contrast, poorer executive functioning was related to a smaller cueing effect (Table 5). When analyses were repeated for composite scores, the parent-rated retrospective scale from the PRMQ was positively associated with telephone task scores, whereby poorer retrospective

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

memory was related to a bigger response to cueing (Table 5). No other variables were significantly associated with proportion or composite difference scores.



PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table 5 Correlation co-efficients for relationships between cognitive and behavioural assessments of neurocognitive functioning, injury age, current age and the size of the cueing effect for daily average proportion and composite telephone task scores (cued minus un-cued). Data are Spearman's rho.

Measure	Proportion	Composite
FSIQ (WISC-IV/ WAIS-III or WAIS-IV <sup>a</sup> )	.11	-.31
Story recall immediate (Stories or Logical Memory <sup>a</sup> )	-.77*	-.42
Story recall delayed (Stories or Logical Memory <sup>a</sup> )	.18	.21
Prospective memory (RBMT Appointment <sup>a</sup> )	-.33	-.40
No. of parts attempted (BADs-C or BADs <sup>b</sup> )	-.43	-.43
No. of rule breaks (BADs-C or BADs <sup>b</sup> )	.35	.29
Attention (Walk Don't Walk or Lottery <sup>a</sup> )	-.47	-.43
GEC (BRIEF <sup>c</sup> )	-.81*	-.50
Self-P (PRMQ <sup>b</sup> )	.24	-.02
Other-P (PRMQ <sup>b</sup> )	-.38	-.66
Self-R (PRMQ <sup>b</sup> )	-.01	.20
Other-R (PRMQ <sup>b</sup> )	.73	.83*
Percentage of targets achieved independently (PML) <sup>b</sup> )	-.10	-.06
Injury age (years)	.17	-.31
Current age (years)	.22	-.28

Note. N = 7. FSIQ = Full Scale Intelligence Quotient; WISC-IV = Wechsler Intelligence Scale

for Children Fourth Edition; WAIS-III = Wechsler Adult Intelligence Scale Third Edition;

WAIS-IV = Wechsler Adult Intelligence Scale Fourth Edition; RBMT = Rivermead Behavioural

Memory Test; BADs-C = Behavioural Assessment of Executive Dysfunction in Children; BADs

= Behavioural Assessment of Dysexecutive Syndrome; GEC = Global Executive Composite;

BRIEF = Behaviour Rating Inventory of Executive Functions; PRMQ = Prospective and

Retrospective Memory Questionnaire; P = Prospective Memory Scale; R = Retrospective

Memory Scale; PML = Prospective Memory Log..

<sup>a</sup>Scaled score. <sup>b</sup>Raw score. <sup>c</sup>T-Score; \*p<.05, two tailed.

***3.4.3.4 Hypothesis 4.***

Given the limitations with the current standardised assessment of PM in children and adolescents (see Section 1.4), an additional aim of the study was to explore the relationship between performance on standard neurocognitive test scores, behavioural questionnaires and PM performance on the real world telephone task. In keeping with previous literature (e.g. Fleming et al., 2008; Groot, et al., 2002; Martin, et al., 2003; Ward et al., 2007), it was hypothesised that neurocognitive and behavioural test performance on measures of general intellectual ability, RM, PM, attention, and executive functioning would be associated with week 1 telephone task performance.

***3.4.3.5 Neurocognitive and behavioural correlates of week 1 telephone task performance.***

Relationships between these selected variables were explored using Spearman's rho. Daily average proportion and composite telephone task scores from across week 1 were analysed with the studies neurocognitive and behavioural measures (see Section 2.8 and Table 6 below for a full description of variables).

A positive association was observed between average week 1 proportion scores and immediate verbal memory recall (Table 6), in that better verbal memory scores were related to making a greater proportion of calls. BRIEF, GEC scores were also related to week 1 proportion scores; however, poorer executive dysfunction (as reflected by higher BRIEF-GEC scores) was associated with making a higher proportion of calls (Table 6). No other variables were significantly associated. For composite score analyses the same

relationships between immediate verbal memory recall and BRIEF-GEC scores were observed, whilst again, no other variables were significantly correlated (Table 6).

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table 6 Correlation co-efficients for relationships between cognitive and behavioural assessments of neurocognitive functioning and daily average week 1 proportion and composite telephone task scores. Data are Spearman's rho.

Measure	Proportion	Composite
FSIQ (WISC-IV/ WAIS-III or WAIS-IV <sup>a</sup> )	.67	-.07
Story recall immediate (Stories or Logical Memory <sup>a</sup> )	.84*	.78*
Story recall delayed (Stories or Logical Memory <sup>a</sup> )	-.02	.63
Prospective memory (RBMT Appointment <sup>a</sup> )	.40	.32
No. of parts attempted (BADs-C or BADs <sup>b</sup> )	.42	.39
No. of rule breaks (BADs-C or BADs <sup>b</sup> )	-.14	.22
Attention (Walk Don't Walk or Lottery <sup>a</sup> )	.79	.05
GEC (BRIEF <sup>c</sup> )	.82*	.71**
Self P (PRMQ <sup>b</sup> )	.05	-.29
Other P (PRMQ <sup>b</sup> )	.65	-.09
Self R (PRMQ <sup>b</sup> )	-.09	-.09
Other R (PRMQ <sup>b</sup> )	-.51	.24
Percentage of targets achieved independently (PML <sup>b</sup> )	.19	.19

*Note.* N = 7. FSIQ = Full Scale Intelligence Quotient; WISC-IV = Wechsler Intelligence Scale for Children Fourth Edition; WAIS-III = Wechsler Adult Intelligence Scale Third Edition; WAIS-IV = Wechsler Adult Intelligence Scale Fourth Edition; RBMT = Rivermead Behavioural Memory Test; BADs-C = Behavioural Assessment of Executive Dysfunction in Children; BADs = Behavioural Assessment of Dysexecutive Syndrome; GEC = Global Executive Composite; BRIEF = Behaviour Rating Inventory of Executive Functions; PRMQ = Prospective and Retrospective Memory Questionnaire; P = Prospective Memory Scale; R = Retrospective Memory Scale; PML = Prospective Memory Log.

<sup>a</sup>Scaled score. <sup>b</sup>Raw score. <sup>c</sup>T-Score;

\*p<.05, \*\* p<.01, two-tailed.

### **3.5 Participants' Qualitative Feedback and Evaluation of the Intervention**

After the intervention, feedback was obtained from participants and family members. A manipulation check indicated that no additional prompts or reminders (e.g. provided by parents) were used to help individuals complete the task. Furthermore, all participants reported that they had mobile phones with them every day during the study.

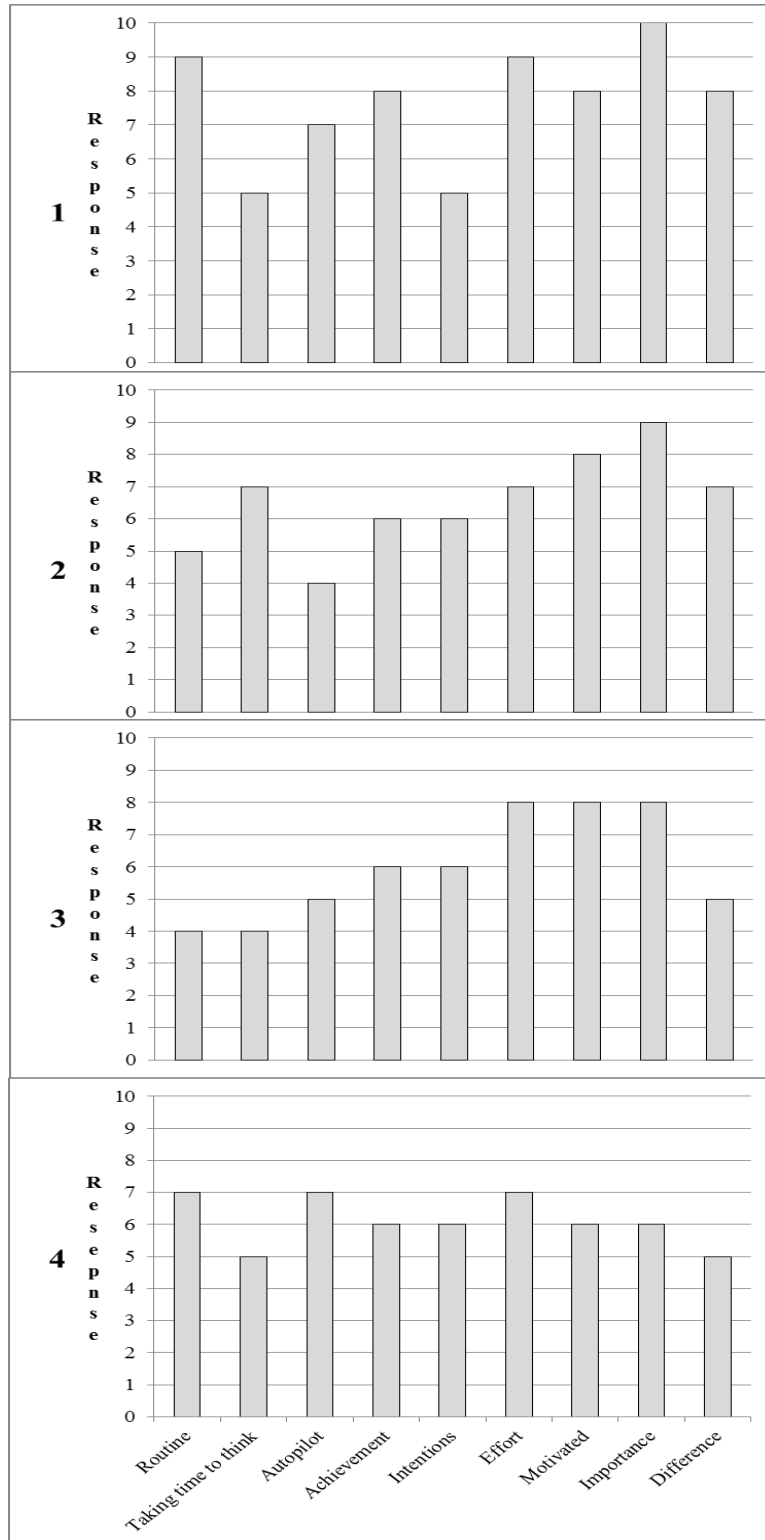
#### **3.5.1 Questionnaire evaluation.**

Questionnaire evaluation revealed that most found it moderately easy to incorporate the phone calls into their daily routine (Figure 3). Over the study, the frequency that individuals reported taking time out to think about prospective tasks ranged from low to moderate, whilst subjective experiences of functioning on autopilot mode (e.g. acting without consciously thinking) ranged from not at all to a lot. All but Participant 6 reported achieving the majority of tasks they had wanted to during the study. In addition, five participants (1, 2, 3, 4 and 5) reported a moderate to high generalisation effect of the training in helping them to carry out goals and intentions other than the phone calls. All individuals except Participant 7 described placing moderate to high levels of effort, motivation and importance on the telephone task. Finally, closed question responses indicated moderate to high differences in daily PM functioning from using the STOP strategy for all, except Participant 7.

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Figure 3. Questionnaire feedback from participants about their experiences of the GMT and content-free cueing. For item responses 10 = very, 0 = not at all.

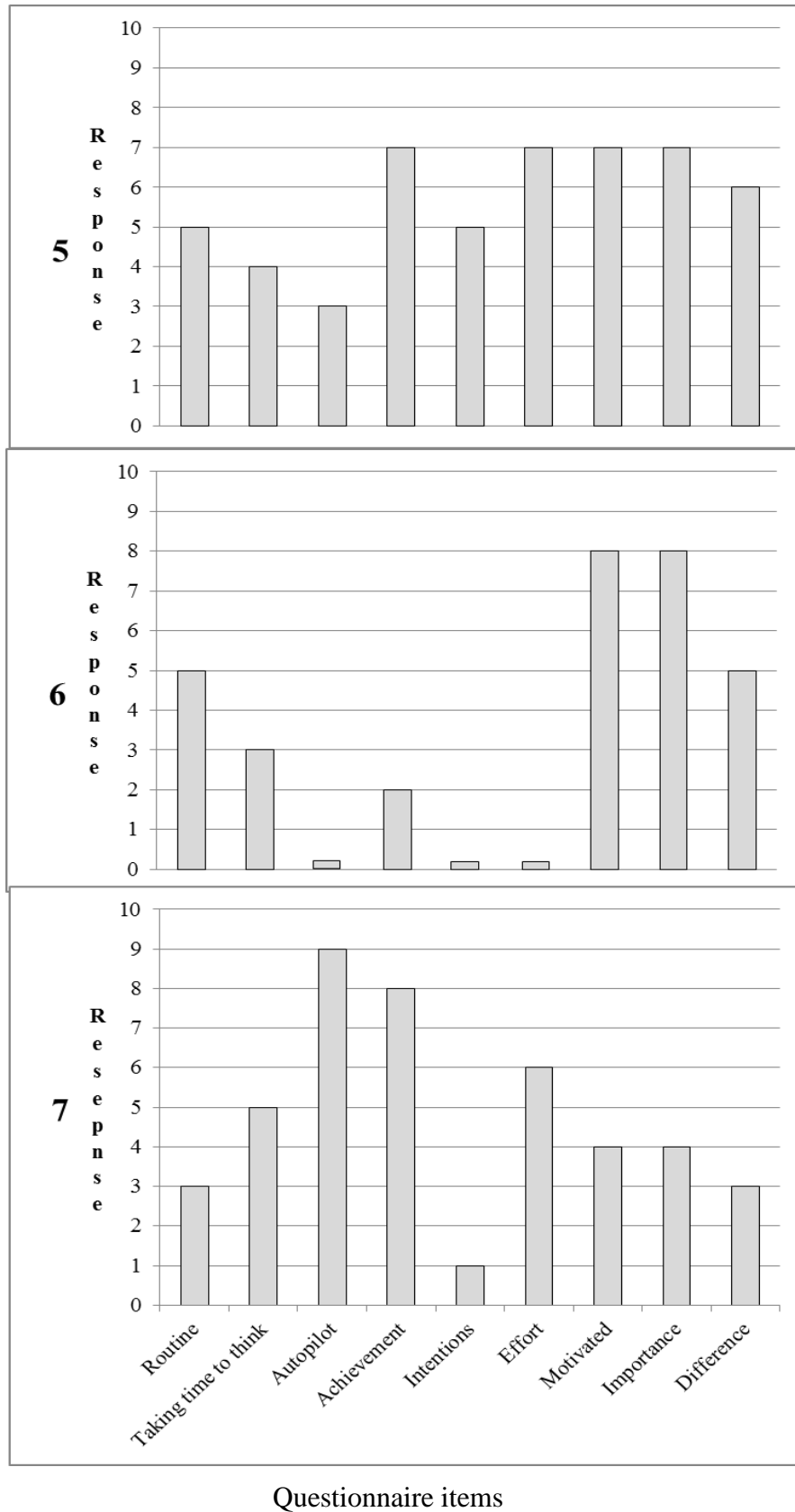
Case



Questionnaire items

Figure 3. (Continued).

Case



### **3.5.2 Qualitative feedback.**

Open qualitative feedback (Table 7) highlighted a variety of different experiences of taking part, ranging from finding the task easy or fun to finding it more difficult or annoying. Feedback indicated that all participants actively used the ‘STOP!’ strategy as a mental review technique, and that content of mental reviews had included the phone call task, therefore suggesting that the task was engaged with and well understood. In relation to the impact of the intervention two participants felt there had not been much difference to them (Participants 1 and 6), despite both benefiting at a statistical level. In contrast, the remaining five individuals described several positive gains from the intervention, such as feeling better able to hold intentions in mind and noticing an increased success in achieving other functional and personally relevant goals, such as feeding a pet.



Table 7 Qualitative feedback from participants about their experiences of the GMT and content-free cueing.

Case	What were your experiences of taking part?	How did you use the 'STOP' strategy?	What difference did you notice (if any)?
1	'It was different and fun'	'I thought about what I had to do'	'Not much'
2	'To begin with the texts were a bit annoying'	'I did what it told me and spent a few minutes thinking about what I needed to do'	'A bit; If I was watching TV I remembered to do homework a bit more and put my splint on, and remembered to take my coat'
3	'It was quite difficult to remember the call times'	'I used it to concentrate hard to remember the calls'	'I started to remember a lot of things – it helped me find and plan what I needed to do'
4	'Ok, easy'	'I used it to notice the time of day and when I had to call'	'Got me more focused'
5	'Ok'	'I reminded myself of things I needed to do'	'I got more done that I was supposed to – like housework and feeding the lizards'
6	'Text messages got a bit annoying'	'I thought about the calls at the time I got the text'	'No difference'
7	'It was easy at the beginning, I sometimes got confused about the call time'	'I looked when my phone went off and asked if I needed to make a phone call'	'Things slipped off my mind less than usual'

### **3.6 Summary of Results**

#### **3.6.1 Background assessment.**

Although all participants reported and demonstrated functional prospective memory slips prior to inclusion in the study, scores obtained on neurocognitive and behavioural measures reflected a range in functioning. However, consistent with qualitative reports difficulties with sustained attention, multi-tasking, and other executive functioning skills were prevalent among the sample.

#### **3.6.2 Main hypotheses.**

##### ***3.6.2.1 Hypothesis 1.***

At an individual level, for four participants (Participants 1, 2, 6 and 7), support was found for the primary hypothesis, namely that content free text-message cueing would lead to improved PM telephone task performance. Similarly, when timing accuracy was taken into account, the same four participants (1, 2, 6 and 7) showed significantly better phone call task performance on cued days, consistent with hypothesis 1.

Analyses for the group as a whole revealed a statistically significant effect of cueing with higher average proportion and composite scores found on cued as opposed to un-cued days, thus providing further support for this hypothesis. Medium to large effect sizes were observed for all statistically significant results related to hypothesis 1 (Cohen, 1988).

### **3.6.2.2 Hypothesis 2.**

Consistent with findings from adult studies (Fish et al., 2007) average proportion and composite telephone task scores were positively associated, and as predicted by hypothesis 2, adolescents who were more accurate in their timing of calls also made a greater amount of calls.

### **3.6.3 Supplementary hypotheses.**

#### **3.6.3.1 Hypothesis 3.**

For responses to cueing, immediate verbal memory correlated significantly with the size of cueing effect for proportion scores, in that poorer verbal recall was linked to a larger effect. In contrast, poorer executive function (as estimated by BRIEF-GEC scores) was related to a smaller cueing effect for proportion scores.

When considering timing accuracy, poorer retrospective memory (from the parent-rated PRMQ retrospective scale) was related to a greater response to cueing (Table 5). However, there was a failure to support additional predictions made by hypothesis 3, and no correlations were found between other measures of cognition, behaviour, or developmental variables and the degree of the cueing effect.

#### **3.6.3.2 Hypothesis 4.**

For hypothesis 4, daily average week 1 proportion and composite scores were significantly correlated with immediate verbal memory recall, and higher memory scores were associated with better prospective memory performance. However, poorer executive functioning (BRIEF-GEC scores) was

also related to better task performance across the first week of the study. In contrast to other predictions made by hypothesis 4, no additional neurocognitive or behavioural variables were significantly related to week 1 performance.

#### **3.6.4 Qualitative feedback.**

At a qualitative level a range of feedback was collected. Participants appeared to engage with the STOP strategy, and most reported placing moderate to high levels of effort, motivation and importance on the telephone task. In addition, five individuals described positive gains from the intervention including an increased success in achieving other functional and personally relevant goals.

## **Chapter 4**

### **Discussion**

#### **4.1 Overview**

PM impairments are prevalent after pABI and are associated with negative functional consequences. Despite this, research into the rehabilitation of PM deficits has been relatively neglected in a paediatric population. Although prospective remembering involves several cognitive skills including attention, memory and executive functioning, growing evidence from the adult literature supports the use of strategies targeting the executive functioning aspect of PM (Fish et al., 2007; Gracey et al., 2012). Preliminary paediatric data also corresponds with this view (Krasny-Pacini et al., 2011a; 2011b; Selznick & Savage, 2000). Consistent with this research, this thesis aimed to adapt and pilot an intervention for adolescents with PM difficulties following pABI. To the authors' knowledge, this study is the first to examine the applicability of brief GMT and content-free cueing to the rehabilitation of PM deficits in adolescents following ABI.

First, this Chapter will outline the results of the current study in relation to relevant literature. Next, theoretical and clinical implications of the study will be discussed in detail. After this, strengths and limitations of the study will be evaluated and to conclude, directions for future research will be considered.

#### **4.2 Summary of Findings**

Building on work by Fish et al. (2007), this study piloted a PM intervention with seven adolescents (aged 12-17 years) with reported PM

difficulties after pABI. The results of this preliminary study are discussed and interpreted below in relation to the broader literature.

#### **4.2.1 Hypothesis 1.**

This thesis examined the effect of GMT and content-free cueing on a PM telephone task performance in adolescents with ABI. Taking into account the adult alerting literature (e.g. Manly et al., 2004; Fish et al., 2007; Gracey et al., 2012; Hardy et al., 2010), and a paediatric GMT study (Krasny-Pacini et al. 2011a; 2011b), this thesis hypothesised that adolescents with ABI would show significantly better performance on a PM phone call task on days with text message cues in comparison to days without. Improved performance was predicted for both the number of calls made (proportion scores) and the accuracy of call timings (composite score).

At a single-case level this hypothesis was partially supported, when four of the seven participants demonstrated a significant effect of cueing on both proportion and composite score measures. Analyses at a group level provided further support for this hypothesis, when both proportion and composite telephone task scores were significantly higher on cued days in comparison to un-cued days. Overall, these data are consistent with previous findings in the GMT and alerting literature (e.g. Gracey et al., 2012; Krasny-Pacini et al., 2011a; 2011b), and they provide preliminary evidence to suggest that brief GMT and content-free text message cues can improve the execution of a PM telephone task in adolescents following ABI.

Although we would expect some participants to benefit more strongly than others from the intervention given the heterogeneity of symptoms following

pABI (Limond & Leeke, 2005), it is of interest to examine why Participants 3, 4 and 5 did not show a pattern of responding that was consistent with the hypothesis. Ceiling effects could offer one possible explanation. For example, Participant 3 achieved 100% of calls in the first week, and high call achievement remained across the intervention phase leaving little opportunity for gains in the cued condition (See Figure 2, Section 3.4.1.1). However, Participants 4 and 5 did not demonstrate such high phone call success rates, and composite score measures had scope for improvement across cued and un-cued conditions for all three participants.

Alternatively, it is possible that those who did not respond to the GMT and content-free cues were more cognitively impaired in comparison to those who benefited. Indeed, it can be hypothesised that specific neurocognitive functions (e.g. working memory, attention and processing speed) need to be intact in order to benefit from GMT and cueing (Limond, Adlam & Cormak, 2011, In preparation). In line with this argument, Sweeney et al. (2010) found no PM improvement following GMT and auditory alerts in those who had more severe executive impairments in comparison to previous studies (e.g. Manly et al., 2002). In the current study all three non-responders had elevated parent-reported frequency of PM slips on the PRMQ (Table 3, Section 3.1). In addition, those who dropped out of the study at the early stages had elevated BRIEF scores (see Appendix E), and attrition could reflect systematic differences between those who did and did not complete treatment (e.g. in impairment level). However, on other neurocognitive and behavioural measures there was little to distinguish between responders and non-responders (Table 2 and Table 3,

Section 3.1). Furthermore, Participant 5 suffered a mild injury, which is less likely to be associated with severe impairments (Lajiness-O'Neill, et al., 2010).

A further possibility is that basic time estimation skills could have been impacted on PM task performance. The ability to judge temporal intervals is known to be acquired during development Piaget (1969). However, poor time estimation skills may have confounded performance on this task (Block, Zakay, & Hancock, 1999). Although time estimation skills have not been shown to not affect PM over other cognitive skills in a laboratory task (Mackinlay et al., 2009), it is possible that they may have greater importance in this study, and other more longitudinal time-based tasks. Future studies would benefit from including an evaluation of time estimation skills (Block et al., 1999).

A more speculative reason could be linked to the age of injury onset. Non responders sustained their injuries between the ages of 11 and 14 years, whereas those who responded suffered traumas earlier (e.g. less than 10 years of age) or later (e.g. aged 16 and over) in development. Several executive functioning skills (which are also involved in PM) such as working-memory, attentional shifting and goal-setting continue to mature during development, particularly between the ages of 12 and 15 years (Beauchamp et al., 2011; Horton, Soper & Reynolds, 2010). Therefore, it is possible that an injury sustained during this critical time may have disrupted these functions more severely, which in turn could have influenced these individuals' response to the studies executive focussed intervention. However, early brain trauma has also been associated with disrupted executive functioning (due to limited opportunities for skills to be established pre-injury or developed post-injury; Anderson et al., 2005; Chapman, 2007; Savage, 1999) and an evaluation of



injury age and response to GMT and cueing in a larger sample is needed to clarify this issue.

Interestingly, feedback from the non-responders (Participants 3, 4 and 5) described positive PM gains in everyday life (e.g. remembering to feed a pet), despite a failure to improve on the telephone task in the GMT/cued condition. This could reflect invalid self-reporting due to poor episodic recall, or social desirability (Sibley et al., 2010). On the other hand, it may reflect the involvement of motivation in PM performance. For example, it is possible that GMT and cueing enhanced completion of more personally relevant goals, but not the less salient telephone task (Penningroth & Scott, 2007). This is discussed further below in Section 4.3.

It is important to note that on average, pABI telephone task performance was poorer in comparison to findings with adults (Fish et al., 2007). In the study by Fish et al. (2007), participants were asked to make four telephone calls per day and an average of 85% (S.D. 22) of calls were achieved in week 1; 88% (S.D. 20) on cued days; and 71% (S.D. 31) on un-cued days. In this study, call achievement (three telephone calls per day) was numerically lower with an average of 69% (range 47-100%) of calls achieved in week 1; 77% (range 67-93%) on cued days; and 50% (range 33-73%) on un-cued days. Call timing was also less accurate in a paediatric sample. Given that maximum obtainable daily composite scores were 18 in this study and 24 in the Fish et al. (2007), in the current study, average daily composite scores only reached 49% of the maximum amount in week 1; 58% on cued days and 29% on un-cued days. In contrast, data from Fish et al. (2007) showed that average daily composite scores reached

60% of the maximum amount in week 1; 62% on cued days and 49% on un-cued days.

One possible reason for this is methodological differences across studies. Fish et al. (2007) generated participant call times throughout the day (9am-5pm). However, the current study did not schedule call times during school hours (9am-3pm), and it is possible that participants found it harder to integrate calls at the beginning and end of the day into a daily routine. Alternatively, this may reflect age differences in PM performance. Taking into account the on-going maturation of the frontal lobes into adolescence and early adulthood, and their involvement in executive abilities (Gogtay et al., 2004), the literature has reported an overall developmental trend for older children to demonstrate better PM performance than younger children (Einstein, McDaniel, Marsh & West, 2008), and young adults to show better PM performance than adolescents (Maylor & Logie, 2010; Wang et al., 2006). Statistical analyses of age-effects across the developmental span are needed to explore this trend further (see below Section 4.6).

#### **4.2.2 Hypothesis 2.**

The telephone task had two scoring systems; one to assess whether an action has been initiated (proportion of calls), and one to evaluate how well an intention was remembered at a specific time (composite score). Based on data from this procedure with adults with ABI (Fish et al., 2007), it was predicted that adolescents with pABI who made a higher proportion of calls would also be more accurate in the timing of those calls.

In line with this hypothesis, in the current study proportion and composite scores were positively associated and those who made more calls were more

accurate in their call timing. This is consistent with the body of research in the adult and child literature that has shown a direct relationship between PM responding and clock monitoring (e.g. Altgassen et al., 2009; Ceci & Bronfenbrenner, 1985; Woods et al., 2009), thus inferring that the initiation of an intended action is closely associated with timing accuracy. More frequent monitoring through the use of executive resources is thought to mediate time-based PM and better enable one to perform an intended action at the relevant target time (Altgassen et al., 2009). Given this, time-based PM tasks are thought to be harder than event-based tasks as there is a greater need for self-initiated processing (e.g. to cue oneself to act at the relevant time). Therefore, potential age-related differences in PM reported above (Section 4.2.1) could also be consistent with this (McFarland & Glisky, 2009).

### **4.2.3 Supplementary hypotheses.**

#### **4.2.3.1 Hypothesis 3.**

Previous research suggested that several cognitive, injury related and demographic variables would be associated with changes in PM performance (e.g. Contrardo et al., 2009; Aberle & Kliegel, 2010). In line with this, hypothesis 3 predicted that neurocognitive test performance on measures of RM, attention, executive function, general intellectual ability, age of injury, and current age, would be associated with an individual's change in PM performance in response to the intervention (i.e. the degree of the cueing effect).

However, this hypothesis received only partial support from three variables. For the number of calls made, poorer immediate verbal memory was associated with greater change between cued and un-cued days (i.e. benefit from

the intervention), whereas poorer executive dysfunction (parent-ratings on BRIEF-GEC) was associated with a smaller change. For the timing accuracy of calls, poorer RM (as rated by parents on the PRMQ) was associated with a larger difference between performance on cued and un-cued days. The immediate verbal memory results could be broadly consistent with multi-componential frameworks of PM that indicate a RM component to PM (Ellis 1996; Ellis & Freeman, 2008). Alternatively, it is possible that cueing enabled those with poorer immediate verbal memory to better hold in mind current information, including their intentions and goals (Quinlan & Brown, 2003; Mahy & Moses, 2011). The inclusion of a working memory measure (e.g. Digit Span, WISC-IV; Wechsler, 2003) would help explore this further. The executive function result is interesting given that the intervention is designed to enhance the self-monitoring of intentions (an executive functioning component of a PM task). As this is the first study to apply GMT and alerting in pABI, it is possible that children or adolescents with more severe executive impairments may require additional GMT, such as greater repetition and practice of self-monitoring techniques, before gains in the cued condition are evident. This would be consistent with the arguments of Sweeney et al. (2010) who found little benefit from cueing in adults with greater executive dysfunction.

However, these findings need to be considered within the methodological constraints of the current study. These results are exploratory and the small sample size and multiple comparisons limit the robustness of these analyses. Limitations with the neurocognitive battery such as the absence of appropriate normative data for 16 and 17 year olds (see Section 4.5.4 below), may have impacted on analyses involving these neurocognitive and behavioural variables.

Finally, information that was missing from the sample in regards to injury severity and location of damage (see below Section 4.5.2) may have been associated with response to cueing (Anderson et al., 2005; Yeates et al., 2002).

#### **4.2.3.2. Hypothesis 4.**

In keeping with previous adult (Fleming et al., 2008; Groot et al., 2002; Martin, et al., 2003), and paediatric (Ward et al., 2007) literature, it was predicted that week 1 telephone task performance (a more ecologically valid measure of PM) would be associated with performance on standardised measures of general intellectual ability, RM, PM, attention, and executive functioning.

This hypothesis was partially supported when a measure of immediate verbal memory was associated with higher proportion and composite telephone task scores in week 1. This result is consistent with Groot et al. (2002), and Fish et al. (2007), who found that better verbal recall was related to better PM performance. Although, given the current studies small sample size all correlational analyses should be interpreted with caution (see Section 4.5 below), this finding suggests that initial verbal recall may be important for PM in a paediatric sample, either in remembering the content of an intention, or remembering to initiate it at a relevant time (Cockburn, 1996). This could be consistent the PAM view of PM (Smith, 2003), which suggest that controlled processes are crucial for successful PM. Interestingly, there appears to be a similar relationship between verbal memory and response to cueing, and verbal memory and week 1 task performance, possibly again reflecting an important role in PM.

However, contrary to expectations, no other variables were positively correlated with week 1 telephone task performance, and conversely poorer executive dysfunction (as reflected by higher BRIEF GEC scores) was associated with better PM telephone task performance (in relation to both the number and timing accuracy of calls). This is not consistent with previous studies which demonstrate relationships between PM performance and better functioning on standardised measures of general intellectual ability (McDaniel, et al., 1999), PM (Wilson et al., 1985), attention (Groot et al., 2002), and executive functioning including attentional switching, working memory and planning (Groot et al., 2002; Mahy & Moses, 2011; Ward et al., 2007). Furthermore, the unexpected link between higher BRIEF GEC scores and better telephone task performance is not in agreement with the body of research supporting the involvement of frontal lobe processes in PM (Burgess et al 2008; 2011; Ward, 2007; West, 1996).

One possible reason for the absence of an association could be due to limitations with the predictive validity of standardised neurocognitive tests (i.e. poor ability to predict real-life performance; Chevignard et al., 2008; 2009; Fish et al 2010a). In particular, standardised tests of executive functioning typically have low ecological validity (as real life executive tasks often involve new or complex and challenging situations), and this may be relevant to the discrepant executive function findings here (Chevignard et al., 2008; 2009). In line with this, several studies including Fish et al. (2007) have failed to find an association between neurocognitive measures and more naturalistic PM or executive tasks (e.g. Catroppa et al. 2009; Chevignard et al., 2008). Alternatively, as described above, the failure to find an association could be attributed to methodological

weaknesses of the current study in relation to the small sample size and selected neurocognitive measures (see Section 4.5 below).

### **4.3 Theoretical Implications**

Several frameworks and theories have attempted to conceptualise the mechanisms underlying PM (Raskin, 2009). It has been widely accepted that the stages involved in remembering to carry out an action, from the encoding of an intention, to its timely retrieval and execution, require a range of cognitive resources (Ellis 1996; Ellis & Freeman, 2008). However, significant debate surrounds the extent to which specific cognitive skills are utilised in PM, and subsequently which brain areas recruited (Martin et al., 2007). Given that the ability to bring to mind an intention at an appropriate time or place is a crucial component of successful PM, the degree to which executive functions are involved in PM retrieval has been the focus of the majority of theorists (Kliegel et al., 2011). This has particular relevance to PM in the context of pABI, as not only are executive systems continuing to develop throughout childhood and adolescence; they are also commonly disturbed following brain injury (Mahy & Moses, 2011). Moreover, an understanding of these mechanisms holds obvious importance in guiding the development of interventions for children and adolescents with PM impairments.

In the current study, the findings of improved telephone task performance on cued days in comparison to un-cued days at a group, and at an individual level for four out of the seven adolescents, offer some support for executive functioning models of PM such as PAM (Smith, 2003; Smith & Bayen, 2004) and multi-process theory (McDaniel & Einstein, 2000; Einstein & McDaniel

2005). The PAM model proposes that executive and attentional resources are required for prospective remembering; either in monitoring during the retrieval delay, or immediately before the action is to be initiated (Mantyla et al., 2007). Although the multi-process model states that PM retrieval does not always involve monitoring processes (e.g. sometimes intentions can spontaneously pop into mind), it does agree that the use of controlled processes is more likely if a task is novel or deemed as important, if there is less association between the cue and prospective task, and if on-going activities demand high attentional resources (McDaniel & Einstein, 2000; Einstein & McDaniel 2005).

In this study, individuals learnt to associate a text message cue with their goals and intentions (which included making phone calls at set times). However, as the cues carried no information other than this broad association, and they were not scheduled to occur near prospective target call times, results suggest that individuals had encoded and stored the intention (to make a phone call), but were less able to monitor and keep this goal in mind independently (Fish et al., 2010a; Manly et al., 2002; 2004). Therefore, enhanced PM performance on days when individuals were intermittently prompted to self-monitor and engage in a mental review, suggests that controlled or monitoring processes were important for successful PM in this task. When compared with previous studies (e.g. Fish et al., 2007), these findings also infer that executive monitoring processes are central to successful PM in adolescents as well as adults (Fish et al., 2007). Furthermore, because regions of the frontal lobes have been shown to be involved in strategic monitoring processes (particularly, areas in the right frontal cortex; Burgess et al., 2011; O'Connor et al., 2004), the cueing effect in the current study also provides some support for the role of prefrontal systems in



mediating PM during childhood (Ward et al., 2007; West, 1996). Nonetheless, the small sample size and limited neuroimaging data in the current study, prevents this from being confirmed explicitly (see Section 4.5.2 below).

It is also interesting to consider how these findings relate in more detail to predictions made by the multi-process model; namely that under certain conditions the retrieval of an intention to make a phone call may have required different amounts of controlled resources (Ellis & Freeman, 2008). In line with this theory, individual differences across participants may have increased or decreased the likelihood that monitoring processes were employed, which in turn may have influenced response to the intervention (Harrison & Einstein, 2010). For example, those who placed greater importance on achieving the phone call targets would be expected to rely more on strategic processes during the retrieval phase, and therefore may have demonstrated greater engagement with the intervention (Ellis & Freeman, 2008). This may also bear relevance to individuals in this study who reported improved PM performance for personally relevant goals, in the absence of measurable gains on the telephone task. Consistent with the multi-process view, it is possible that the self-monitoring technique was applied to personal intentions (of higher importance), but not the research task (potentially perceived as less important). Although this study was limited in its ability to explore individual factors associated with response to the GMT and cueing intervention (see below Section 4.5.6), further investigation of motivation, age, injury age, and the extent of executive impairment would help better understand the role of automatic and controlled processing in PM following pABI (Kvavilashvili et al., 2008).

While the findings discussed above offer some support for executive functioning models of PM, it is important to consider the results from Participants 3, 4 and 5, who did not show improved PM performance in response to GMT and content-free cues. Referring back to descriptive models of PM (Ellis 1996; Ellis & Freeman, 2008), there are multiple stages involved in a PM task (including intention encoding, storage, retrieval and execution), and differing involvement of cognitive resources across these, including executive processes and RM (Kliegel et al., 2011). The failure of three individuals to improve when exposed to the cueing intervention reaffirms the view that in addition to the executive framework, other cognitive resources including RM might be important in PM. For example, other reasons for poor PM performance could include reduced capacity to store an intention in RM, or difficulties at the encoding stage (due to executive, attentional, and working memory impairments), which in turn may prevent adequate memory storage (Fish et al., 2010a). Although attempts were made to minimise RM failures in this study (see Section 4.5.1 below), given the time course over 3-weeks, it is possible that for some, difficulties with episodic memory affected PM task performance (Logie, Maylor, Della Sala & Smith, 2004). Moreover, the absence of clear correlations between PM performance and standardised measures of cognitive function (including general intellectual abilities, RM and executive functioning) here, and in other studies (e.g. Ward et al., 2007) further highlights the complex nature of PM (Ward et al., 2007).

#### **4.4 Clinical Implications**

Recent advances in the literature have led to a more comprehensive understanding of the consequences and outcomes of pABI, which include a greater awareness of the long-term effects of an injury sustained in childhood (Anderson & Yeates, 2010; Limond & Leeke, 2005). Despite this, the evidence-base for appropriate interventions following pABI remains in its infancy, and guidelines for clinical practice are in the early stages of development (Ross et al., 2011; Semrud-Clikeman, 2010). PM is one area of cognition that is commonly impaired following pABI, yet very few PM-specific studies exist in the paediatric literature, and only a handful have evaluated the efficacy of PM interventions for children and adolescents (Shum et al., 2011). Therefore, whilst acknowledging the methodological limitations (see Section 4.5 below), results from the current study have important clinical implications in relation to both the assessment and treatment of PM impairments following pABI.

##### **4.4.1 Implications for the assessment of PM in pABI.**

Neurocognitive assessment is important to understand presenting difficulties and guide treatment (Sparrow, 2007). However, PM is not often routinely assessed in paediatric settings due to the limited availability of standardised paediatric measures of PM (Shum et al., 2011). In this study, all seven individuals made PM slips in their daily life (as documented by the PM log). There were also relatively high failure rates on the telephone task with average achievement ranging from 47% to 100% over the course of the study. Taken together, these findings demonstrate that PM difficulties can occur across

a range of ages (12-17 years) and forms of ABI (e.g. TBI, CVA), and as such, they highlight the importance of assessing PM abilities in pABI.

In the absence of reliable and valid PM tests, the study also explored the relationship between PM performance on the everyday telephone task and neurocognitive tests which assessed several cognitive skills involved in PM (including attention, executive function, RM). Although these analyses are tentative given the small sample size, there was only limited evidence to support the ability of standardised tests to predict real life PM functioning. This has implications for the type of tools that are used to evaluate paediatric PM functioning. Indeed, findings suggest that it may be important to include measures beyond current standardised clinical tests, which could consist of naturalistic tasks (e.g. remembering to make a telephone call at a set time), VR tasks within a controlled clinical setting, objective behavioural measures of PM (e.g. a parent-rated goal attainment), and self-report.

### **4.4.2 Implications for the treatment of PM difficulties in pABI.**

The current study found preliminary evidence to suggest that GMT in combination with content-free cueing can improve PM performance for individuals following pABI. The response to this theoretically derived intervention has several important practical implications. First, it suggests that interventions aimed at supporting the executive functioning aspect of a prospective task, which includes monitoring and bringing an intention to mind, can enhance successful task completion in children and adolescents who have sustained an ABI. Furthermore, the evaluation of this strategy over a 2-week period outside of the clinic indicates that benefits can generalise to everyday

situations. This is particularly relevant in a paediatric population, given the need for rehabilitation strategies to involve school and family contexts (Semrud-Clikeman, 2010). However, as noted in the adult literature (Levine et al., 2000), the fact that individuals who responded to the intervention obtained greater, and more accurate PM task achievement on days with cues, suggests that GMT alone does not automatically generalise to real life situations.

In addition, the use of non-specific reminders to improve the ability to act on an intention has several benefits for a paediatric sample. In contrast to other compensatory aids (e.g. NeuroPage) content-free cues do not require specific goals to be determined in advance. They therefore allow greater flexibility, which may be important for younger people who often have active and changeable lifestyles (Phillips et al., 2008). Advancing on this, content-free cueing strategies have the potential to support the attainment of a wide range of individualised goals and intentions, ranging from small everyday tasks to more complicated social activities (Brandimonte & Ferrante, 2008). In this study, five participants reported gains in real-life PM achievement (e.g. feeding a pet) and this is an important area for future research (see below, Section 4.6). In relation to more general implications, the use of mobile phones to promote self-monitoring offers a familiar, discrete, and potentially non-stigmatising way to minimise the occurrence of PM slips, which again may be particularly relevant when considering the acceptability of an intervention in an adolescent population (Ylvisaker, 1998). Moreover, the use of brief GMT and content-free cueing is relatively easy to implement in clinical settings, and amenable to being incorporated into a multi-dimensional rehabilitation programme, which is a

further advantage over more time intensive rehabilitation approaches (e.g. re-training).

Finally, it is important to remember that three individuals did not demonstrate a positive response to this executive focussed intervention. Although this could be a result of methodological limitations with the study (see below Section 4.5), future research is warranted to clarify whether more comprehensive GMT or alternative treatment approaches (see Fish et al., 2010a for a review) can improve PM functioning in these participants. This is considered below in Section 4.6.

#### **4.5 Methodological Strengths and Limitations of the Preliminary Study.**

This is, to the authors' knowledge, the first study to apply GMT and content-free cueing to adolescents with PM impairments following ABI. Given the absence of research in this area pilot studies are an important pre-cursor to the development of larger scale research that may guide clinical recommendations (Cicerone, 2008). However, pilot studies typically have several limitations, and as such the methodological strengths and weaknesses of the current study are considered below.

##### **4.5.1 Design.**

The study design had various strengths. A randomised-alternating treatment single-case design was utilised across subjects. Variables such as the schedule of phone call times, the order of cued or un-cued days, and the timing of text message cues, were randomised for each participant. This experimental control enhanced the studies internal validity and allowed an examination of the

the effects of GMT and content-free cues on PM performance systematically for each individual. The week 1 period (which is not part of the primary analysis) minimised the impact of task novelty, and reduced this as a potential confounding factor. Consistent with high quality single-case research (Tate et al., 2008), the study used objective target behaviours to measure treatment response (phone call performance), there was multiple sampling of behaviour (over two weeks) to allow differentiation of treatment response from no-treatment behaviours, and procedures were repeated across seven subjects to demonstrate the broader applicability across individuals. In keeping with Fish et al., (2007), errorless learning techniques and vanishing cues (Wilson et al., 1994) were used to teach participants the times of their three prospective phone calls, and participants were given a written record of their call times, in an attempt to minimise the chance of RM failures interfering with PM performance. Furthermore, participants were asked not to use other reminders (including parents) to support them to complete the PM task, and post-study manipulation checks indicated that this was adhered to. In addition, the use of a voicemail answerphone (rather than a 'real person') minimised social reinforcement and reduced this as a potential confound. Finally, the procedure was completed over several weeks in everyday settings, and as such, the study demonstrated better ecological validity than most paediatric data so far, which has predominantly been laboratory based (e.g. McCauley et al., 2009; 2010b).

Despite this, there are several limitations. Given the lack of reliable and valid paediatric PM measures, in combination with the poor ecological validity of many tests of executive function (Chevignard et al., 2008; 2009), inclusion into the study was based solely on qualitative reports of participants' PM

difficulties (e.g. parent, self, clinician). Although in keeping with other research in this area (e.g. Fish et al., 2007; Cattropa et al., 2009), a standardised inclusion criteria (e.g. difficulties below the average range on the PRMQ or BRIEF) may have better defined the executive and PM impairments of the sample. In addition, exclusion based on performance on standardised RM tests (e.g. impaired range on x) may have been a more systematic way to remove those who were failing PM tasks as a result of significant memory problems rather than executive difficulties. Taking this into account, it is possible that standardised eligibility criteria may have reduced the current drop-out rate ( $n = 3$ ).

While participants did not report using other aids during the PM task, it is always possible that they were reminded by the written record of call times (a RM support), as opposed to the content-free cues (an executive function support). Qualitative feedback did not suggest this was the case (e.g. some individuals filed the sheets away), but clearer guidance on the use of reminder sheets may be helpful in future studies.

As most participants were in full time education, call times were scheduled outside of school hours. However, text-message cues were sent randomly throughout the day (including before and after school), and it is possible that this resulted in more redundant cues (i.e. text messages not looked at), than in comparison to the adult research (Fish et al., 2007; Gracey et al., 2012). Nonetheless, participants' school policies allowed them to check phones at break and lunch times, and there may have been similar constraints in adult studies (e.g. in the work-place, college, or when driving) that impacted on when cues were read and responded to.



#### **4.5.2 Participants.**

A comprehensive clinical history including demographic and injury related information, and neurocognitive functioning, was provided for each participant allowing comparisons with other patients to be drawn (Cicerone et al., 2009). In addition, the broad inclusion criteria (any form of ABI, from anywhere in the UK) aimed to generate a representative sample of participants that may typically present in clinic. However, recruitment difficulties limited the number of participants that completed the treatment protocol ( $N = 7$ ), and in turn this has somewhat restricted the robustness and generalisability of findings.

For many, the severity of injury was hard to determine as often information was absent (e.g. poor reporting of GCS), or not available (e.g. limited access to hospital records). This therefore limits comparisons with others, as severity of brain injury is important to consider and is known to effect response to an intervention (Cicerone, 2008). Therefore, it is also possible that injury severity may have moderated response to the cueing intervention (Sweeney et al., 2010), yet this study is prevented from investigating this systematically. Available information regarding the location of injury was also limited and further neuroimaging data would enhance the study, given that the intervention is derived from theories of frontal lobe functioning (e.g. Duncan, 1986).

Although the single-case design allowed performance to be examined on an individual basis, the heterogeneous sample, in terms of age (12 to 17 years), time since injury (10 to 144 months), and type of injury, is a further weakness as it leaves many developmental questions unanswered, such as at what stage post-

injury, or at what developmental age this intervention may be optimally effective (Limond & Leeke, 2005).

#### **4.5.3 Intervention.**

The intervention is described clearly, allowing others to understand or replicate the treatment (Boutron, Moher, Altman, Schulz, & Ravaud, 2008). In comparison to many studies in the paediatric rehabilitation literature (e.g. Krasny-Pacini et al., 2011a; Van't Hooft et al., 2005), the intervention (brief GMT and content-free text message cues) had fewer components making it easier to evaluate the key aspects of the treatment (Cicerone et al., 2008). Delivery of GMT on a one-to-one basis enabled the training to be individualised (e.g. with examples) and paced appropriately, whilst providing the same manualised programme across participants. Furthermore, presentation of material on a laptop, and the use of interactive exercises and a quiz helped ensure comprehension of material for all participants.

However, the brief nature of the GMT is a potential weakness. Consistent with a more recent automated cueing study (Gracey et al., 2012), it is possible that GMT of a greater duration or frequency, may be a more effective way to promote self-monitoring, especially in a paediatric sample who are still developing or acquiring these metacognitive skills (Marlowe, 2000). A further weakness is the absence of involvement from parents, siblings, or teachers. Literature highlights the importance of involving family and the wider system in both child and adult rehabilitation to help promote the transfer and generalisation of treatment gains (Donders, 2007; Sjo et al., 2011; Ylvisaker, 1998). Therefore,

the intervention may have had more impact if family and teachers were involved, for example by facilitating GMT homework exercises (Ross et al., 2011).

#### **4.5.4 Measures.**

In line with good practice guides for the assessment of memory in young people (Middleton, 2002), information was drawn from several sources including psychometric tests, clinical interviews, parent and self-reports, and observations of real life functioning. Also, in contrast to many studies in this area (e.g. Ho et al., 2011) a standardised measure of PM was included (RBMT Appointment subtest), and attempts were made to formally assess key cognitive components involved in PM including, attention, RM, and executive functioning.

Furthermore, the telephone task proportion and composite scores provided an objective and quantifiable primary outcome measure (Tate et al., 2008).

However, there are limitations with the measures used. First, the RBMT Appointment subtest is a simple measure of PM and all but two individuals demonstrated a perfect score. Despite the lack of reliable and valid PM standardised assessment tools (see Section 1.4), it may have been useful to include other PM subtests from the RBMT (e.g. Belongings subtest), a PM experimental tasks (e.g. VR; Kerns, 2000), or a naturalistic PM task (e.g. remember to send an email between appointments), to obtain a more thorough controlled assessment of participants' PM (Thone-Otto & Walther, 2008).

Second, in keeping with previous research (e.g. Mandalis et al., 2007) a prorated form of the WISC-IV was used to estimate general intellectual ability. However, it has been argued that this procedure can increase the 'normative standard deviation' and therefore overestimate intellectual functioning (Tellegen

& Briggs, 1967). Recent data suggests that linear equating procedures which enable the calculation of composite scores using conversion tables provide a more reliable assessment of IQ (Crawford, et al., 2010; Garrood, Wright, & Scott, 2010). As such, it may have been more reliable to administer a short-form WISC-IV such as the seven-subtest version devised by Crawford et al., (2010). Alternatively, the Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler, 1999), which is a short measure of intellectual ability suitable for those aged 6 to 89 years, may have allowed easier comparison across participants (Anderson et al., 2009), particularly given the current study's large age span (12-17 years).

Following on from this, a difficulty which affects many developmental studies was the lack of standardised neurocognitive measures for specific ages (e.g. 16, 17 years). To overcome this, attempts were made to use alternative adult versions of measures (e.g. the TEA or BADS). However, the absence of appropriate normative data may have led to a less reliable and valid cognitive profile assessment in these instances (White, Campbell, Echeverria, Knox, & Janulewicz, 2008). In addition, slightly different aspects of a cognitive domain may have been captured across tests, such as switching and sustained attention on the Walk Don't Walk subtest (TEA-Ch), in comparison to sustained attention as measured on the Lottery subtest (TEA), making comparisons of cognition across age ranges less meaningful.

Third, despite clear primary outcome measures (PM telephone task performance), the study did not formally assess generalisation of training to participants' own goals and other areas of daily PM functioning. Advancing on the PM diary included here, goal attainment scaling (GAS; Kiresuk & Sherman, 1968; Kiresuk, Smith & Caudillo, 1994), which calculates the extent that an

individual's pre-stated goals have been achieved (e.g. on a scale of 1-5), and then allows conversion to a T-Score, would have been a more rigorous way to evaluate the transfer of the treatment to real-life PM task achievement by assessing this both pre and post intervention (Ertzgaard, Ward, Wissel, & Borg, 2011). It may also have been informative to re-administer the BRIEF and PRMQ at the end of the study as secondary outcome measures, given that improvements on the BRIEF have been seen following GMT (Krasny-Pacini et al. 2011a; 2011b). Although, qualitative feedback was obtained at the end of the intervention phase, there was no longer-term follow-up (e.g. 3-months post intervention) to examine the maintenance of gains over time, which is an additional weakness.

Finally, in the rehabilitation literature it is widely accepted that treatment outcomes should be holistic, by considering factors such as activity limitations, social participation, and psychosocial variables including mood, adjustment, and family functioning (Cicerone, 2009; Ross et al., 2011; Wilson, Gracey, Evans, & Bateman, 2009; World Health Organization, 2001). As this study was a preliminary study, caution was taken not to overburden participants with lengthy assessments. However, future studies would benefit from including a standardised assessment of mood, motivation, and fatigue, which may impact on PM task performance (Brent, 2006). In addition, given the link between family functioning and treatment outcomes following pABI (e.g. Max et al., 1998), and outcomes following paediatric GMT (Krasny-Pacini et al., 2011a; 2011b), an assessment of family functioning may help better understand responses to the intervention in future studies. In addition, the inclusion of a measure of broader social functioning pre and post intervention (e.g. the Vineland Adaptive

Behaviour Scale; Sparrow, Balla, & Cicchetti, 1984), would be useful to better characterise the sample and assess any broader transfer of treatment effects.

#### **4.5.5 Procedure.**

This single-case design allowed the procedure to be adjusted depending on upon individuals' specific needs (e.g. cognitive difficulties or developmental age). For instance phone call times were scheduled semi-randomly within the constraints of an individual's daily routine (e.g. school/college and bedtimes). This was a particular strength given the heterogeneous effects associated with ABI and developmental context of the study (Limond & Leeke, 2005).

However, there were limitations with the running of the study. All assessment and training sessions were conducted in participants' own homes, which offered less environmental control in comparison to a laboratory or clinical setting (e.g. to the effects of noise or interruption). Nonetheless, as this was constant across all study participants any potential threats to internal validity should be minimised (Barker, Pistrang & Elliot, 2007).

Consistent with the study by Fish et al., (2007) participants were telephoned daily and asked to provide reasons for late or omitted phone calls. However, this information was not always available (e.g. if participants did not answer mobiles at end of the day), and some adolescents found it hard to give specific reasons for failures (e.g. only reporting 'I was busy' or 'I forgot'). Adolescents can be highly influenced by social desirability and a wish to present themselves in a positive light (Brenner, Billy & Grady, 2003), and it is possible that this influenced some participants in this study. To enable better recording of

this data in future, it may be useful to provide alternative recording methods such as a diary to be completed alone at home, or a brief email task.

Target phone call times were not stratified across the day. Although in keeping with procedure used by Fish et al., (2007), in this study, call times were not scheduled during school hours and it is possible that target times were more predictable than in the adult study (Fish et al., 2007). Nonetheless, given that target call times were generated randomly, and each call time was not within 1 hour of another, there did not appear to be an obvious pattern to calls. In addition, most participants failed to make a significant amount of calls across the study, suggesting that the PM task was not too easy.

#### **4.5.6 Data analysis.**

Consistent with single-case designs of good methodological quality, statistical analyses have been used to evaluate the efficacy of GMT and content-free cueing (rather than visual analysis); significance levels have been clearly reported, and effect sizes to indicate the strength of the analyses have been included where appropriate (Tate et al., 2008; Kennedy et al., 2008).

Nonetheless, there are limitations. Given the small sample size ( $N = 7$ ) and number of data points ( $n = 10$ ; 5 cued and 5 un-cued), non-parametric analyses were employed throughout. However, tests based on ranked data have lower statistical power, and may have been less able to detect a treatment effect. Increasing the number of participants or data points to satisfy assumptions of normality and enable the use of parametric tests, would improve the robustness of the cueing analyses (Nichols & Holmes, 2001; Sawilowsky, 1990).

Hypotheses 3 and 4 were tested using non-parametric correlational analyses to examine the association between factors related to response to cueing and week 1 telephone task performance. Given their exploratory nature alpha levels of .05 were set. However, the number of factors being explored required multiple comparisons to be made, making the study more open to type one errors (i.e. falsely rejecting the null hypothesis). Although only five variables reached significance across these analyses, additional research with larger sample sizes and more conservative alpha levels (e.g. .01) are needed to further explore these relationships. In relation to hypothesis 3, telephone task achievement on un-cued days is likely to influence the extent of a participants' response to the cueing (e.g. those who scored highly had less chance of improvement; Fish et al., 2007). However, given the ranked data, partial correlations were not conducted to account for this third parameter and as such these initial findings should be interpreted tentatively (Pallant, 2010).

### **4.6 Directions for Future Research.**

As this was (to the authors' knowledge) the first study to investigate the effects of content-free cueing and GMT on PM performance in pABI, the findings generate several exciting avenues for future research at both a theoretical and applied level.

This single-case research offered a valuable means to adapt and evaluate an adult-based PM intervention for a paediatric group. Although the results can begin to shape our understanding regarding what constitutes an effective PM treatment approach, further studies are needed to investigate the potential efficacy of the intervention. The next phase of research would be to examine



whether the effects of content-free cueing can be replicated with a larger sample. Given the heterogeneity of the current sample in terms of age, nature and location of brain damage and time since injury, analysing or comparing more specific populations (e.g. in terms of injury severity or age), may help to further delineate the effectiveness of the intervention. Furthermore, as discussed above, a more thorough evaluation of broader psychosocial factors that have been shown to predict or moderate response to memory rehabilitation such as motivation level (McCauley et al., 2011), mood (Kliegel et al., 2005), fatigue (which could cause a global deterioration in cognitive capacity, Attree, Dancey, & Pope, 2009) and family functioning (Rivara, 1994) would be beneficial. In addition to this, the inclusion of a more comprehensive assessment of RM abilities would strengthen future PM studies, and help further evaluate the relationship between RM and PM in a paediatric sample (McCauley et al., 2010b).

On a different note, manipulating the intensity and duration of GMT may help to determine whether a more comprehensive GMT package is better able to facilitate PM gains in the context of those with a developing executive capacity. Moreover, assessing whether the involvement of family or school further enhances the intervention would be of benefit. Finally, the inclusion of structural and functional neuroimaging data would help to identify neural pathways involved in PM, and help to better understand the impact of PM rehabilitation on children's developing brain functions, in terms of plasticity and neural reorganisation (Grady, 2008; Stuss, 2011).

Following developments in the adult literature (e.g. Gracey et al., 2012; Hardy et al., 2010), another key area for future research is to evaluate whether

GMT and content-free cueing can systematically promote the attainment of more functional PM goals in children and adolescents following brain injury. This has important implications for independent living and social participation following pABI (Galvin & Mandalis, 2009), and should be the ultimate aim of any form of cognitive rehabilitation (Wilson, 1999). Although this study is encouraging in demonstrating that content-free cueing can facilitate PM performance on a real-life task in everyday settings, it remains to be seen whether this can generalise to personal goals and intentions in a paediatric sample. As discussed above (Section 4.5.4), the inclusion of a formal measure of individualised goal achievement (e.g. through goal attainment scaling, GAS; Kiresuk & Sherman, 1968; Kiresuk, Smith & Caudillo, 1994) would allow investigation of this. However, there is also the need to consider the maintenance of any cueing effects over time, both during the introduction of treatment and at follow-up (e.g. 3-6 months post-intervention; Fish et al., 2007; Tate et al., 2008). Testing the generalisation of cueing to personal goals, in a well-designed, randomised-controlled group study would provide higher level evidence, which in turn could begin to inform the development of clinical guidelines for the treatment of PM impairments (Beeson & Robery, 2006; Cicerone, 2008). This would also offer the opportunity to examine the active components of the intervention in more detail. For example, a comparison of GMT and content-free cueing, against a content-free cueing only condition, may help to determine whether changes in meta-cognition, or basic arousal are responsible for the cueing effects.

Given that few standardised paediatric measures of PM exist, promoting ways to better assess PM in clinical settings is also an important area of investigation. However, because executive skills are complex, clinic-based tests

often fail to capture impairments in everyday functioning (Chevignard et al., 2008; 2009; Slomine et al., 2002). As argued by Fish et al. (2007), the telephone task has evident ecological validity and therefore, may be a good measure of PM in both research and clinical settings. Future research should further determine the reliability and validity of this task by analysing the relationship between other tests of cognition including attention, RM and executive functioning, and injury-related variables (e.g. severity) using a larger sample. The telephone task measure could also provide a more comparable way to evaluate PM performance in longitudinal and cross-sectional developmental studies (Kvavilashvili et al., 2008).

Finally, as research into PM in pABI is in its infancy, studies are needed to advance theoretical understandings of PM in a paediatric sample, and to further characterise PM deficits in pABI (Kliegel et al., 2011). For example, varying the demands of a PM task (e.g. difficulty, number of intentions to hold in mind, and length of delay; Mahy & Moses, 2011), may help better understand the contribution of self-monitoring and automatic processes under different conditions. Further delineation of the retrospective versus prospective component of PM (e.g. across event based and time based tasks) would also be informative.

### **4.7 Conclusion**

In summary, research into PM following pABI is in its infancy (Shum et al., 2011). This study has been the first to examine the effects of brief GMT and content-free cueing on PM performance in children and adolescents with acquired brain injury. The cueing strategy led to significant improvements in

PM performance in the overall group analyses, and for four of the seven individuals at a single-case level. Qualitatively, five participants also reported gains in real-life PM achievement, such as increased success in accomplishing personally relevant goals (e.g. feeding a pet).

From a theoretical perspective, the study has provided some support for the role of executive processes in paediatric PM. Enhancing successful task completion through the use of intermittent non-specific cues implies that the ability to self-monitoring and engage in a mental review is a crucial component in prospective remembering for those with pABI (Kliegel et al., 2011). At an applied level, the findings have implications for the development of PM interventions following pABI. Content-free cueing could be used to support the attainment of a wide range of prospective tasks. Furthermore, the telephone task itself may provide an ecologically valid way to assess PM abilities. However, additional research is needed to evaluate factors that may moderate the usefulness of this intervention approach (e.g. age, injury variables, and motivation), and better predict cases where cueing may be ineffective. Furthermore, it is important to investigate whether GMT and content-free cueing can promote the realisation of children and adolescents' own goals and intentions, to begin to find ways to help young people with brain injury achieve their potential.

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## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

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## **Appendices**

Appendix A: Recruitment site letter

Appendix B: Information sheets: Parents, adolescent (16-17 years) and young adolescent (12-15 years) versions

Appendix C: Permission to contact form

Appendix D: Media advertisement

Appendix E: Data of non-study completers

Appendix F: Severity of injury classification

Appendix G: Neuro-radiology findings

Appendix: H: Brief GMT package: PowerPoint presentation, participant hand-outs and quiz

Appendix I: Participant background assessment

Appendix J: PRMQ: Self and proxy ratings

Appendix K: Prospective Memory Log (PML)

Appendix L: Feedback form

Appendix M: Cambridgeshire 4 REC approval

Appendix N: Research and Development (R&D) approval

Appendix O: Parent consent form

Appendix P: Adolescent assent form (ages 12-15 years)

Appendix Q: Adolescent consent form (ages 16-17 years)

Appendix R: Written record of call times

Appendix S: Pilot study information sheets: Parents, adolescent (16-17 years) and young adolescent (12-15 years) versions

Appendix T: Pilot study summary

Appendix U: Distribution statistics for cued and un-cued data

Appendix V: Rater agreement for phone-call task omissions

Appendix A: Recruitment site letter

Date:

Dear Sir/ Madam

**Re: Prospective Memory Research Project**

My name is Rebecca Rous and I am a student at the University of East Anglia. I am conducting a research project as partial requirement to complete a Doctorate in Clinical Psychology. Supervisors for this project are Dr Anna Adlam, and Professor Malcolm Adams, and external collaborators are Dr Tom Manly, and Dr Jessica Fish (MRC-CBU), and Dr Fergus Gracey (CCPNR).

I am writing to ask whether you know of any clients who would be suitable for, and might be interested in, helping us with our research project. After brain injury, many people have difficulties in things like planning, organisation, and remembering to act upon intentions (like remembering to pass on a message or to phone someone later that day). This research project aims to investigate whether a strategy that involves training people to mentally review their goals, and then sending text messages to participants' mobile phones to remind them to pause and review their goals can help improve future remembering.

We are looking for young people (aged 12-17 years) who have had an acquired brain injury more than a year ago, and have difficulties in everyday life with prospective memory. Potential participants must be able to speak and read English, and be willing and able to use a mobile-phone. Some examples of prospective memory difficulties in daily life are:

- Leaving things behind and having to go back for them.
- Forgetting to do homework.
- Forgetting to make a telephone call or give someone a message.
- Getting occupied by something and missing an appointment.
- Missing a television programme you really wanted to watch.

Families would need to participate in the study for around 8 weeks, and would be required to meet with the researcher on roughly 5 occasions. Participants would be asked to attend assessments, training sessions and make three phone calls over a three-week period from a mobile phone. Although this sounds like a lot of work, the time involved each day is quite small, perhaps as little as 10 minutes.

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

It is important that we do not make anyone feel as if they have failed due to not having the basic abilities required to participate in this project. Therefore we want to exclude those who have:

- Dense amnesia that prevents retention of training information.
- Sensory-motor, or severe perceptual deficits that prevents use of a mobile-phone.
- Aphasia, including reading deficits that may lead to insufficient understanding of written instructions.

We also want to exclude those who have a pre-injury history of developmental delay, neurological disorder, learning or intellectual disability, attentional disorder, or significant mental health difficulty (e.g. major depression), as these factors are known to be associated with impairments in cognitive processes involved in PM (e.g. working memory and executive function).

We have enclosed a copy of the participant information sheet, which explains what the study involves, and what would happen if someone decided to take part. To comply with the data protection act and client confidentiality we would give you these information packs to pass on to anyone you think suitable. If the client gives permission to be contacted by a member of the research team regarding the study, we would ask that their contact details, i.e. name and telephone number, be forwarded to us. Their verbal agreement is ok. Anyone who volunteers to take part is completely free to withdraw from the project at any time without needing to give us a reason. Unfortunately, if more people want to take part than we are able to measure, some individuals may not be chosen to take part.

If you have any further questions, please contact a member the research team at the address below. We greatly appreciate your help and thank you in advance.

Yours sincerely

Rebecca Rous, Trainee Clinical Psychologist  
Postal Address: School of Medicine, Health Policy & Practice School of Medicine, Health Policy & Practice, University of East Anglia, Norwich, NR4 7TJ  
Telephone: 01603 593310. Email: [r.rous@uea.ac.uk](mailto:r.rous@uea.ac.uk)

Dr Anna Adlam and Professor Malcolm Adams, (Supervisors)  
Postal Address: School of Medicine, Health Policy & Practice School of Medicine, Health Policy & Practice, University of East Anglia, Norwich, NR4 7TJ  
Telephone: 01603 593310. Email: [a.adlam@uea.ac.uk](mailto:a.adlam@uea.ac.uk) and [m.adams@uea.ac.uk](mailto:m.adams@uea.ac.uk)

Appendix B: Study information sheets

**Parent Information Sheet**  
**Prospective Memory Research Project**

My name is Rebecca Rous, and I am a trainee clinical psychologist at the University of East Anglia (UEA). We would like to invite your child to take part in a research study evaluating a strategy that may help young people remember to do things in the future. It would involve your child taking part in thinking skills training, receiving some text messages and making phone calls to a researcher on a mobile phone. This would not be during school time.

**Please read on if you would like to find out more**

Please take time to read this information. Before you agree for your child to take part you must be clear about what the project involves. You do not have to decide today, and can talk to others about the study if you wish. Please ask if anything is not clear, or if you would like more information.

**What is prospective memory?**

Prospective memory is remembering to do something in the future, like passing on a message or attending an appointment.

**What is the purpose of the study?**

An acquired brain injury is an injury that happens to the brain after birth. It could be caused by many things such as an accident or illness. After brain injury people often have problems with prospective memory, and can struggle to plan, organise and remember to do things in the future. This can be disabling and can interfere with the lives of those affected. We are interested in finding out how we can help improve people's ability to remember and carry out things they intended to do.

This study is looking at one promising strategy that involves sending text messages to participants' mobile phones to remind them to pause and review their goals.

**Why has my child been chosen?**

We are looking at teenagers between the ages of **12 and 17 years**, who have had a brain injury and have problems with prospective memory. We think your child might be the right age to take part.



### **Does my child have to take part?**

No, it is up to you and your child to decide whether to take part. If you decide not to take part we will respect your decision, and it will not affect any future healthcare that your child may receive. If you and your child do decide to take part, we will ask you to sign a consent form before your child begins the project. We will give you a copy of the form and this information sheet to keep. You are free to change your minds and not take part at any time without giving a reason. If you chose to withdraw the information you and your child have already provided will be destroyed and not used in the research.

### **What will happen if my child takes part in the study?**

If your child wishes to participate, and you give consent for them to do so, we would ask you to be involved in the study for about 8 weeks. We will come and see you at your home or a local clinic. Most meetings will last about an hour.

- We will start by asking some questions about your child's brain injury and memory. We will ask you and your child to fill out some short questionnaires.
- Another day, we will ask your child to complete tests of memory, concentration and thinking skills.
- We will ask your child to try and remember to make three mobile phone calls a day to our answering machine. This will be for 3-weeks. Calls will not be during school hours and we will discuss call times with you and your child.
- The researcher will also telephone your child quickly at the end of each day over the 3-week period to review any missed phone calls, but only if you are happy with this.
- If your child doesn't have a mobile phone we will lend them one during the study, and will pay the call charges. But we will ask that they please don't use our credit for personal calls, or they might have to stop being in the study.
- After one week, we will give your child some training about remembering to do things.
- Then, on some days we will send reminder text messages to your child's mobile phone, asking them to use the training strategy to try and remember to do the things they need to that day, including the phone calls you have been asked to make.
- At the end we will ask you and your child how you felt about the training and text messages. We will also ask you to fill out some questionnaires.

### **Expenses and payments**

We are unable to provide payment for taking part in this research. However, your child will receive a £10 book voucher to thank them. Costs incurred including travel and mobile phone calls will be covered, although we ask that credit is used responsibly. Unfortunately, extensive misuse of our phone credit may result in exclusion from the study.

### **Are there any risks to my child?**

The main disadvantage is the amount of time it will require. The project involves attending assessments, training sessions and making phone calls, and we are asking you and your child to commit to the project for about 8 weeks. Although this is quite a lot of work, the time involved each day may typically be quite small, for example perhaps as little as 10 minutes during the phone call task weeks. Also all appointments will be arranged at times that are convenient for you and your child.

Tests to assess memory, concentration and thinking skills at the start of the study, have been designed specifically for children, and used before with hundreds of other children without causing distress. However, if your child did become tired, stressed or upset in anyway, testing would be stopped immediately.

### **What are the potential benefits?**

Although the study hopes to identify effective strategies to help teenagers remember to do something in the future, we do not know yet whether these strategies are useful for younger people. Therefore, it may be best not to assume that involvement in the study will benefit you or your child personally.

### **Will my child's taking part be kept confidential?**

Information collected about you and your child during the study will be kept anonymous and safe. This means we won't write your child's name or address on any questionnaires. Information will be stored by the researcher in a locked cabinet, or on a password protected computer. When the study is finished all information will be stored in a locked drawer, at the University of East Anglia for 15 years. It will then be destroyed.

With your permission we would let your child's GP know that your child is participating in this study. The only other time we would disclose any of the information that you have given us, would be if criminal or other inappropriate behaviour was made known.

### **What will happen to the results of the study?**

After the study the results may be reported in an article or at meetings, but your child's name will not be on any reports that are written. We would be happy to send you and your child a copy of our findings if you would like.

### **Who is organising the research?**

The University of East Anglia is running and funding the study.

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

### **Who has reviewed the study?**

To protect your interests, before any research starts it needs to be checked that it is fair. This study has been reviewed and approved by the Cambridge 4 Research Ethics Committee.

### **What if there is a problem?**

If you have any questions or experience any difficulties please contact me (Rebecca Rous), or Dr Anna Adlam. Our contact details are:

University of East Anglia, School of Medicine, Health Policy & Practice, Norwich, NR4 7TJ

Telephone number: 01603 593310.

### **Further information and contact details**

For further information about the project please contact Rebecca Rous ([r.rous@uea.ac.uk](mailto:r.rous@uea.ac.uk)) or Dr Anna Adlam ([a.adlam@uea.ac.uk](mailto:a.adlam@uea.ac.uk)) at the University of East Anglia, on Faculty of Health, Elizabeth Fry Building, Norwich, NR4 7TJ, Telephone: 01603 593310. We will be happy to discuss any questions you might have.

**Thank you for taking time to read this sheet.**

## Participant Information Sheet (16 and 17 years)

### Prospective Memory Research Project

Hello! My name is Rebecca Rous. I am studying to be a clinical psychologist and I am doing a project for my course.

I would like to ask you to take part. It would involve doing some thinking skills training, getting sent some text messages and making phone calls to me from a mobile phone. This would not be in school time. We are doing this to try to help teenagers remember to do things they need to.

You can choose if you want to take part. Before you choose we would like you to read this information (or ask someone to read it for you). You can discuss this with your family, friends, doctor or nurse if you want. You can ask us as many questions as you like. You don't have to decide right now.



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

An acquired brain injury is an injury that happens to the brain after birth. It could be caused by many things such as an accident or illness. We know that brain injuries can change young people's lives and stop people from doing all the things they want.

After brain injury one thing many people have problems with is remembering to do things like passing on a message to a teacher or meeting a friend. We want to find out how we can help people to remember to do things. We are looking at one way that we think might help by sending text messages to people's mobile phone.

#### **Why have I been asked?**

We are looking at teenagers between the ages of **12 and 17 years**, who have had a brain injury. We think you might be the right age to take part.

#### **Do I have to take part?**

No, taking part is up to you. If you decide you don't want to take part it doesn't matter and no one will be upset. Any treatment you have will not be affected. If you do decide to take part we will ask you to sign a form. We will give you a copy of the form and this information sheet to keep. You can change your mind and stop doing the research at any time during the

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

project. If you do chose to stop taking part, any information you have already given us will be destroyed and will not be used in the research. Also if more people want to take part than we are able to look at you may not be able to take part.

### **What would I have to do?**

We would ask you to be involved in the study for about 8 weeks. If you choose to take part we will come and see you at your home or a local clinic. Most meetings will last about an hour.

- We will start by asking you some questions about your brain injury and your memory. We will also ask you and your parent to fill out a few short questionnaires.
- We will meet you again another day and ask you to do some tests of memory, concentration, and thinking skills.
- Another day we will give you some training about remembering to do things.
- We will ask you to try and remember to make three phone calls from a mobile phone each day to our answer machine. This will be for 3-weeks. If you don't have a mobile phone we will be able to lend you one during the study, and will pay the call charges. But we will ask you please to not use our credit for personal calls, or you might have to stop being in the study.
- We will call you quickly at the end of each day over the 3-weeks to ask about any missed phone calls, but only if you are happy with this.
- On some days we will send reminder text messages to your mobile phone, asking you to pause and think about things you are trying to remember to do that day, including the phone calls you have been asked to make.
- At the end we will ask you how you felt about the training and text messages. We will also ask you to fill out some questionnaires.

### **Is there anything to be worried about?**

Taking part will take up some of your time, because we are asking you to answer questions, attend a training session and make phone calls. We are asking you to take part for about 8 weeks. Although this is quite a lot of work, the time involved each day may be quite small, for example it may be as little as 10 minutes during the phone call task weeks. Also appointments will be arranged at times that are ok for you to fit in with your daily life. Completing tests or answering questions at the start of the study can make some people worried. But the tasks can be fun to do (e.g. like puzzles and games). You can stop at any time, and there are no right or wrong answers.

### **What are the benefits?**

We can't promise the study will help you but the information we get might help other young people with memory problems after brain injury in the future.

**Who will know what I said?**

Only the researcher (Rebecca Rous) will see your answers and the number of phone calls you make. Information about you will be kept safe and locked away. Your name and contact details and will be separate from other information about you. This means we won't ask you to write your name or address on any sheets. When the study is finished all information will be stored in a locked drawer, at the University of East Anglia for 15 years. It will then be destroyed.

With your permission we would let your GP know that you are participating in this study. If you told us something that was worrying then we might have to share it with your parents or others involved in your care, but that is the only time we will pass on information about you.

**What happens at the end of the study?**

After the study the results may be reported in an article or at meetings, but your name will not be on any reports that are written. As an important member of our team, we would be happy to send you a copy of our findings if you would like.

**Who is organising the research?**

The University of East Anglia is running and funding the study. The University will pay for the mobile phone calls you make to us, and any travelling to us you need to do. You would also get a £10 book voucher to thank you for your time.

**Who has reviewed the study?**

Before any research starts it needs to be checked that it is fair. This study has been approved by the National Research Ethics Committee.

**Further information or problems**

If you or your parents have any questions or problems, please ask me. Or contact Dr Anna Adlam (a.adlam@uea.ac.uk) at the University of East Anglia, Faculty of Health, Elizabeth Fry Building, Norwich, NR4 7TJ, Telephone: 01603 593310.



**Thank you for reading this and thinking about taking part.**

**Participant Information Sheet**  
**(12 – 15 years)**  
**Prospective Memory Research Project**

Hello! My name is Rebecca Rous and I am studying to be a clinical psychologist and I am doing a project for my course.

I would like to ask you to take part. You can choose if you want to take part. Before you choose we would like you to read this information (or ask someone to read it for you). You can ask us as many questions as you like. You don't have to decide now.

**Why are we doing this research?**

An acquired brain injury is an injury that happens to the brain after birth. It could be caused by many things such as an accident or illness. We know that brain injuries can change young people's lives and stop people from doing all the things they want.

After brain injury one thing many people have problems with is remembering to do things, like passing on a message to a teacher or meeting a friend. We are looking to find out how we can help young people to remember to do things. We are looking at one way that we think might help, by sending text messages to people's mobile phone.



**What would I have to do?**

If you and your parents choose that you would like to take part we will come and see you at home or at a clinic. We would ask you to be involved for about 8 weeks.

- We will ask you some questions and ask you to do some tests of memory concentration and thinking. These are fun (e.g. like puzzles and games), but you can stop at any time, and there are no right or wrong answers.
- Another day we will ask you to take part in some thinking skills training,
- We will also send you some text messages and ask you to remember to make phone calls to our answer machine using a mobile phone, everyday for three weeks. This would not be in school time.

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

### **Why have I been asked?**

We are looking at teenagers between the ages of **12 and 17 years**, who have had a brain injury. We think you might be the right age to take part.

### **Do I have to take part?**

You can say yes or no. It doesn't matter if you don't want to, and no one will be upset. You can change your mind and stop doing the project at any time. If you chose to stop taking part, any information you have already given us will not be used in the research.



### **Who will know what I said?**

Only the researchers will see your answers and the number of phone calls you make. The things we talk about will be kept safe and locked away.

With you and your parents' permission we would let your GP know that you are participating in this study. If you told us something that was worrying then we might have to share it with your parents, but that is the only time we would pass on information about you.

### **What happens at the end of the study?**

We will write a report to let people know what we have found. This will not have your name on it. You can have a copy of what we find out if you like.

**More information:** If you or your parents have any questions, please contact me (Rebecca Rous, [r.rous@uea.ac.uk](mailto:r.rous@uea.ac.uk)), or Dr Anna Adlam ([a.adlam@uea.ac.uk](mailto:a.adlam@uea.ac.uk)) at: The University of East Anglia, Faculty of Health, Elizabeth Fry Building, Norwich, NR4 7TJ, Telephone: 01603593310



### **Thank you for reading this!**

If you think you would like to take part we will ask you and your parents to sign a form. You can have a copy of this sheet and the form to keep.



PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Appendix C: Permission to contact form

*To be printed on UEA headed paper*

Your

name:

\_\_\_\_\_

Please tick one of the options below, and send the form back, in the freepost envelope provided. Alternatively, you can leave a message for the researcher Rebecca Rous on 01603 593310, and she will get back to you.

We are interested in taking part in the research project, please contact us	<input type="checkbox"/>
We would like to know more details before deciding, please contact us	<input type="checkbox"/>
Home Telephone Number: _____	
Mobile Telephone Number: _____	
Email Address: _____	
Postal Address: _____	
_____	
_____	

Appendix D: Media advertisement (text)

**Prospective Memory Intervention for Adolescents with an Acquired Brain Injury: A Pilot Study**

**This study is currently recruiting participants**

Sponsor: University of East Anglia, Norwich

Collaborators: The Cambridge Centre for Paediatric Neuropsychological Rehabilitation and the Medical Research Council, Cognition and Brain Sciences Unit, in Cambridge.

**Purpose**

Difficulties remembering to do things in the future are common after brain injury and can often lead to many problems in daily life for individuals who are affected. These are known as 'prospective memory' problems. The purpose of this study is to evaluate a strategy that may help improve prospective memory problems after brain injury. The strategy would involve training participants to 'stop and think' about the things they need to remember to do, and then sending several text messages to people's phones reminding them to do this.

**Inclusion Criteria:**

- Aged 12 to 17 years old
- Has an acquired brain injury, and is medically stable enough to participate in research
- English Speaking and able to read basic English
- Prospective memory problems as noticed by self or others (e.g. relative or clinician)
- Be willing to use a mobile phone for the study
- **Living in England**

**Exclusion Criteria:**

- Pre-injury diagnosis of neurological disorder diagnosis of intellectual disability, attention disorder, or a significant mental health problem
- Severe sensory motor or perceptual problems that would prevent the use of a mobile phone
- Severe amnesia

If you are interested in participating (or having your child participate in our study), or if you have any questions, please contact the research coordinator, Rebecca Rous by any of the following means and we will respond to you as soon as we can:

Email: R.Rous@uea.ac.uk Telephone: 01603 591507

Post: University of East Anglia, School of Medicine, Health Policy & Practice, Elizabeth Fry Building, University of East Anglia, Norwich, NR4 7TJ

## Appendix E: Data for study non-completers

Table A1 Demographic and injury-related characteristics of study non-completers

Case	01	02	03
Sex	F	F	M
Age at testing (years)	16.75	15..83	15.00
Age at injury (years)	13	13.41	14.00
Time since injury (months)	45	29	12
Nature of injury	Non-traumatic CVA - Infarction	Non-traumatic CVA –	Non traumatic c Infection
GCS (lowest)	-	-	-
PTA	-	-	-
LOC	-	-	-
Severity	-	-	-
Abnormal CT/MRI	Yes	Yes	No
Primary lesion side	Right, Fr	Left	-
Primary lesion site	BG; FR;	BG	-

*Note.* CVA = Cerebral vascular accident; GCS = Glasgow Coma Score; PTA = post-traumatic amnesia duration; LOC = Loss of Consciousness duration; CT = Computerised Tomography; MRI = Magnetic Resonance Imaging; OCC = Occipital; CA = Cerebral artery; CC = Corpus callosum; PWM = Periventricular white matter; TEMP-PAR = Temporal-parietal; FR = Frontal; BG = Basal ganglia; IC = Internal capsule; I = Insular; PAR = Parietal; - information unknown.

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table A2 Neurocognitive assessment data of study non-completers

Case	01	02	03
<b>Measure</b>			
FSIQ <sup>a</sup>	68	83	-
(prorated)			
<b>CMS Stories<sup>a</sup></b>			
Immediate	8	6	-
Delayed	9	6	-
Recognition	9	12	-
RBMT <sup>b</sup>	1	1	-
Appointment			
<b>BADS-C<sup>a</sup></b>			
Six Parts Test	4	4	-
<b>TEA-Ch<sup>a</sup></b>			
Walk Don't-	-	11	-
Walk			

*Note.* FSIQ = Full Scale Intelligence Quotient; CMS = Children's Memory Scale; RBMT = Rivermead Behavioural Memory Test; BADS-C = Behavioural Assessment of Executive Dysfunction in Children; TEA-Ch = Test of Everyday Attention for Children.

<sup>a</sup>Scaled score. <sup>b</sup>Profile score; - indicates missing data.

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table A3 Questionnaire and behavioural assessment of study non-completers

Case	01	02	03
<b>Measure</b>			
<b>BRIEF<sup>a</sup></b>			
BRI	81	79	68
MI	89	86	77
GEC	92	83	76
<b>PRMQ<sup>b</sup></b>			
Self-T	53	69	-
Self-P	30	35	-
Self-R	23	34	-
Parent-T	75	75	40
Parent-P	40	39	22
Parent-R	35	36	18
<b>PML<sup>c</sup></b>			
Targets achieved	0	0	-
Achieved with prompt	100	63	-
Not achieved	0	37	-

*Note.* BRIEF = Behaviour Rating Inventory of Executive Functions; BRI = Behavioural Regulation Index; MI = Metacognitive Index; GEC = General Executive Composite; PRMQ = Prospective and Retrospective Memory Questionnaire; T = Total Score; P = Prospective Memory Scale; R = Retrospective Memory Scale; PML = Prospective Memory Log.

<sup>a</sup>T-score. <sup>b</sup>Raw score. <sup>c</sup>Percentage.

- indicates missing data.

Appendix F: Severity of injury classification

Table A4 Measures of severity of TBI

	Measure		
Injury Severity	GCS (Max. 15)	Duration of PTA	Duration of LOC
Mild	12-15	< 24 hours	< 30 minutes
Moderate	9-11	1-7 days	1-24 hours
Severe	3-8	1-4 weeks	> 24 hours







*Note.* GCS= Glasgow Coma Score, Teasdale and Jennett, (1974); PTA = Post Traumatic Amnesia, Brown and Nell, (1991); LOC = Loss of Consciousness, Greenwald, Burnett & Miller, (2003).

## Appendix G: Neuro-radiology data





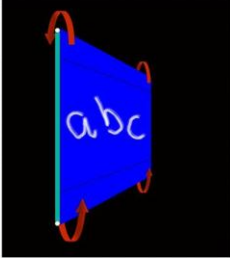

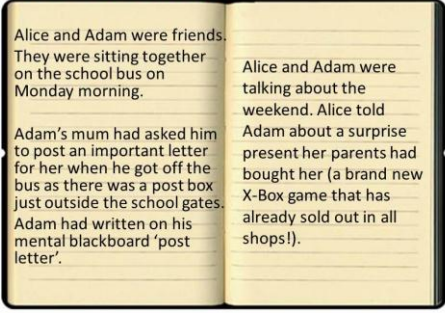

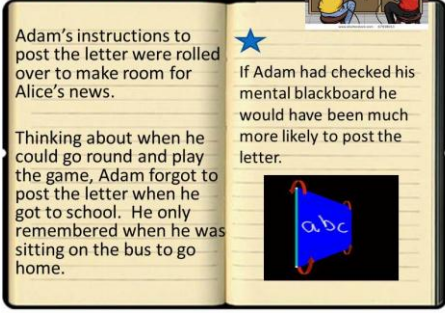


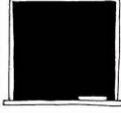
Table A5 Descriptive Neurological data for each participant (information available to researcher)

Case	Neurological case notes; CT and/or MRI results
1	Intracranial haemorrhage in occipital lobe area of brain and collection of blood between the Dura and skull on the right side of his head; Intubated and ventilated; 2 days in paediatric intensive care unit.
2	Left cerebral artery infarction, secondary to transient cerebral arteriopath; Acute infarct in left corpus callosum with smaller foci in adjacent insular and periventricular white matter
3	High signal change in left temporo-parietal region; Maturing infarct in left middle cerebral artery
4	Left middle cerebral artery infarct
5	Frontal lobe contusion; No neurosurgical intervention
6	Left middle cerebral artery infarct involving basal ganglia, internal capsule, insula, posterior left frontal lobe and much of the left parietal lobe
7	Haemorrhagic lesions in white matter of right frontal lobe and corpus callosum; Non-haemorrhagic contusion in mid brain and upper pons adjacent to the cerebellum

Appendix H: Brief GMT package: PowerPoint presentation, participant hand-outs and quiz

<h2>Goal Management Training (GMT)</h2>   <p>Adapted by R.Rous, A.Adams, &amp; M. Adams (2011) Based on Robertson I.H., Levine B. &amp; Manly, T (2005)</p>	<h2>Remembering Things</h2> <ul style="list-style-type: none"><li>• GOALS or Intentions are things we plan to do (like meet a friend or go to a party)</li><li>• Our memory for these things we want to do in the future is called 'PROSPECTIVE MEMORY'</li></ul>  
<h2>But.....</h2> <ul style="list-style-type: none"><li>• Often we don't manage to complete our goals even though we mean to.....</li><li>• Sometimes they slip from mind and get forgotten</li><li>• Or we get distracted</li><li>• Or there is just not enough time to do everything</li><li>• Or we just don't feel like doing them</li><li>• Or they are too big and we don't know where to start</li></ul>	<h2>For Example</h2> <ul style="list-style-type: none"><li>• Sometimes we might forget to take our dog for a walk even though we meant to</li><li>• Oops.....</li></ul>  <ul style="list-style-type: none"><li>• Can you think of a time when something like this happened to you?</li></ul>
<h2>Memory Mistakes</h2> <ul style="list-style-type: none"><li>• We have to remember <b>WHAT</b> we want to do and <b>WHEN</b> we want to do it</li><li>• This isn't easy and we all make mistakes</li><li>• But sometimes it can happen more often after brain injury</li><li>• Often these mistakes occur.....</li><li>• Not because you can't do it</li><li>• But because your mind was not focussing on what you were doing at the time</li></ul>	<h2>AUTOMATIC PILOT</h2> <ul style="list-style-type: none"><li>• Not paying attention to things at the time is called the <b>AUTOMATIC PILOT</b>, like a robot doing things without needing to think about them.</li><li>• Sometimes it can be helpful</li><li>• As many tasks are routine (e.g. brushing your teeth) and the automatic pilot can take care of these for us so we can think about other things.</li></ul> 



<h3>Automatic Pilot - Problems</h3> <ul style="list-style-type: none"> <li>• But it can be unhelpful because it can make us forget to do things and slip up.</li> </ul> <p>Examples of this kind of 'slip' are:</p> <ul style="list-style-type: none"> <li>• Walking to your old classroom instead of your new one at the start of a new school term</li> <li>• Helping clear the table after dinner and putting the butter in the dishwasher and a dirty plate in the fridge</li> <li>• Going into a room and forgetting what you went there for</li> <li>• Having to read something again because you weren't paying attention</li> <li>• Day dreaming instead of listening to something</li> </ul> 	<h3>The Automatic Pilot</h3> <ul style="list-style-type: none"> <li>• Can you think of a time in the last week or month when things have gone wrong because your mind wasn't really on what you were doing</li> </ul>   
<h3>Stopping the automatic pilot?</h3> <ul style="list-style-type: none"> <li>• It is hard to stop the automatic pilot mode</li> <li>• It can cause serious problems (like making us late or not doing the right thing)</li> <li>• But...</li> <li>• A good way to stop ourselves from being on autopilot is to get into the habit of checking whether we are doing the right thing we need to be...</li> <li>• <b>We can do this by telling ourselves to "STOP!" and think!</b></li> </ul>	<h3>The Mental Blackboard</h3> <ul style="list-style-type: none"> <li>• When we are doing something we have an instruction for that task in our head</li> <li>• You can imagine it like a blackboard that rolls over</li> <li>• So our short term memory is like a blackboard</li> <li>• If we get distracted the instruction gets wiped off the blackboard for a bit</li> </ul> 
<h3>Alice and Adam</h3>   <p>Alice and Adam were friends. They were sitting together on the school bus on Monday morning.</p> <p>Adam's mum had asked him to post an important letter for her when he got off the bus as there was a post box just outside the school gates. Adam had written on his mental blackboard 'post letter'.</p> <p>Alice and Adam were talking about the weekend. Alice told Adam about a surprise present her parents had bought her (a brand new X-Box game that has already sold out in all shops!).</p>	<h3>Alice and Adam</h3>   <p>Adam's instructions to post the letter were rolled over to make room for Alice's news.</p> <p>Thinking about when he could go round and play the game, Adam forgot to post the letter when he got to school. He only remembered when he was sitting on the bus to go home.</p> <p>★ If Adam had checked his mental blackboard he would have been much more likely to post the letter.</p> 
<h3>Checking The Mental Blackboard</h3> <ul style="list-style-type: none"> <li>• We can stop things from getting wiped from our mental blackboard or by going onto autopilot by:</li> <li>• Telling ourselves to <b>"STOP!"</b> and think.</li> <li>• Try and get into the habit of stopping the automatic pilot and checking whether it is the right thing to be doing...</li> <li>• To begin with it takes effort.</li> <li>• But using the <b>STOP!</b> idea to check what should be on the blackboard can help.</li> </ul>	<h3>The Mental Blackboard</h3> <ul style="list-style-type: none"> <li>• Can you think of a time in the last week or month when something slipped off your mental blackboard, but you remembered it later</li> </ul>  <p>For example:</p> <ul style="list-style-type: none"> <li>• Forgetting to take something to school</li> <li>• Forgetting to pass on a message</li> <li>• Forgetting to do homework</li> </ul> 

## Summary

- Our short-term memory is like a mental blackboard. It doesn't have much space and can easily get rolled around by distraction.
- We often forget to do things we needed to do.
- We can use the word **"STOP!"** to interrupt automatic pilot.
- We can also use the **'STOP!'** moment as a reminder to check what should be on our Mental Blackboard.
- This can help us remember what we need to be doing instead of other people reminding us.

## Exercise 1.

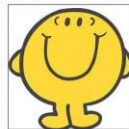
### Practice putting something on your mental blackboard

- Please try and remember to say 'Pink Elephant' in 10 minutes time.
- Imagine writing this onto your mental blackboard.
- Use an image – the odder the better – to help you remember (e.g. a clock made with elephant shaped hands pointing to the time you need to say "Pink Elephant").

## Exercise 2.

### Multitasking Activity

- Multiple tasks – trying to do **3** things in **2** minutes
- Multiple tasks – trying to do **3** things in **2** minutes with 'Stop' bleeps



## Strategy to try at home



## Stop Text Messages

- During the next 2 weeks you will receive alerting **"STOP!"** texts at random times
- These will not be sent at weekends
- This is a strategy that can help you to remind yourself rather than other people telling you



## Stop Text Messages

- When you get a text message saying **"STOP!"** you should stop what you are doing, if it is safe to do so, and think about the things you have to do that day.
- This will include making the phone call to us but also anything else you need to remember to do.
- For example you might need to meet a friend or do a piece of homework.



## Stop Text Messages

- When you get a text message ask yourself to:

**S**top S.....  
**T**hink T.....  
**O**rganise O.....  
**P**lan P.....



- You can also ask yourself these types of questions:
  - 'What have I got to do and when?'
  - 'Do I need to be concentrating?'
  - 'Do I need to do anything differently now?'
  - 'Is it ok to just carry on with what I'm doing?'
  - 'What is it I am supposed to be doing now?'

**When I get a text message saying **"STOP!"**, I should stop what I am doing if it is safe to do so, and think about the phone call to you and my other goals.**



<p>When I get a text message saying <b>"STOP!"</b>, I should stop what I am doing <u>if it is safe to do so</u>, and think about the phone call to you _____</p> <p>_____</p> 	<p>When I get a text message saying <b>"STOP!"</b>, I should stop what I am doing <u>if it is safe to do so</u>, and think about the phone call _____</p> <p>_____</p> 
<p>When I get a text message saying <b>"STOP!"</b>, I should stop what I am doing <u>if it is safe to do so</u>, and _____</p> <p>_____</p> 	<p>When I get a text message saying <b>"STOP!"</b>, I should stop what I am doing <u>if it is safe to do so</u> _____</p> <p>_____</p> 
<p>When I get a text message saying <b>"STOP!"</b>, I should stop what I am doing <u>if it is</u> _____</p> <p>_____</p> <p>Don't forget to <b>STOP, THINK, ORGANISE, PLAN</b></p> 	<p>Well done for all your hard work!!!!</p> <ul style="list-style-type: none"><li>• Any questions???</li></ul> 

### Goal Management Training (participant hand-out)

#### REMEMBERING

GOALS or intentions are things we plan to do (like meet a friend or go to a party)

'*Prospective Memory*' is our memory for these things we want to do

**But**.....

Often we don't manage to complete our goals even though we mean to

Sometimes they slip from mind and get forgotten

Or we get distracted

Or there's just not time to do everything

Or we don't really feel like doing them

Or they are too big and we don't know where to start

Or we get in a muddle



- Sometimes we might forget to take our dog out for a walk, even though we meant to
- Or we might forget to return library books and get a big fine

Do things like this ever happen to you? \_\_\_\_\_

Don't worry if they do, remembering to do things isn't easy.

We have to remember **WHAT** we want to do and **WHEN** we want to do it.

Often these mistakes occur.....

*Not* because you can't remember what you are doing

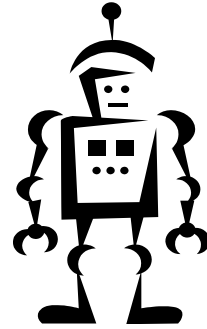
*Not* because you can't do it ... but

Because your *mind* was not focussing on what you were doing at the time.

#### **AUTOMATIC PILOT**

Not paying attention to things at the time is called the **AUTOMATIC PILOT**, like a robot doing things without needing to think about them.

Sometimes it can be helpful as many tasks are routine (e.g. brushing your teeth) and the automatic pilot takes care of these for us so we can think about other things.



### Problems

But it can be unhelpful because it can make us forget to do things and slip up.

Examples of this kind of 'slip' are:

- At the start of a new school term, walking to your old classroom instead of your new one
- Helping clear the table after dinner and putting the butter in the dishwasher and a dirty plate in the fridge
- Going into a room and forgetting what you went there for
- Having to read something again because you weren't paying attention
- Day dreaming instead of listening to something

Have there been any times when this has happened to you? \_\_\_\_\_



### Helping?

It is hard to stop the automatic pilot mode

It can cause serious problems (like making us late or not doing the right thing)

A good way to stop ourselves from being on autopilot is to

- Tell ourselves to “STOP!” and think
- Try and get into the habit of stopping the automatic pilot and checking whether it is the right thing to be doing...

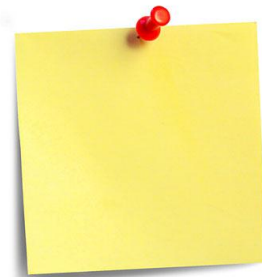
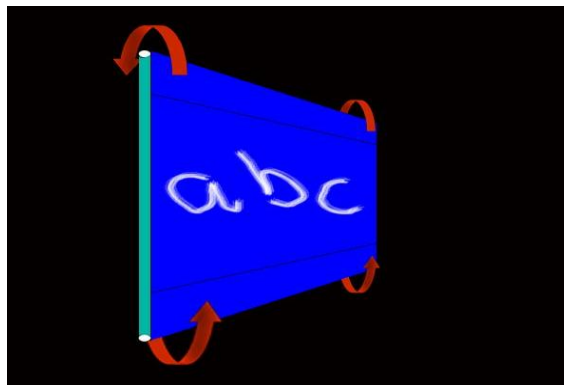
### THE MENTAL BLACKBOARD

When we are doing something - we have an instruction for that task in our head.

You can imagine it like a blackboard that rolls over.

So our short term memory is like a blackboard.....

If we are distracted, the instruction gets wiped-off the blackboard for a bit.



### Alice and Adam



Alice and Adam were friends.

They were sitting together on the school bus on Monday morning.

Adam's mum had asked him to post an important letter for her when he got off the bus as there was a post box just outside the school gates.

Adam had written on his mental blackboard 'post letter'.

Adam's instructions to post the letter were rolled over to make room for Alice's exciting news.

Thinking about when he could go round and play the game, Adam forgot to post the letter when he got to school. He only remembered when he was sitting on the bus to go home.



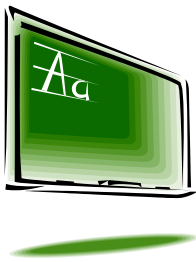
## CHECKING THE MENTAL BLACKBOARD

Can you think of a time when something slipped off your mental blackboard, but you remembered it later?

---

We can stop things from getting wiped from our mental blackboard or by going onto autopilot by:

- **Telling ourselves to “STOP!” and think.**
- Try and get into the habit of stopping the automatic pilot and checking whether it is the right thing to be doing...
- To begin with, it takes effort.
- But using the STOP! idea to check what should be on the blackboard can help.



Let's try this now

Exercise 1 – Putting something onto your mental blackboard

Exercise 2 – Multitasking Activity

- A. Multiple tasks – trying to do 3 things in 2 minutes
- B. Multiple tasks – trying to do 3 things in 2 minutes with stop bleeps

## STOP TEXT MESSAGES – Strategy to try at home

During the next 2 weeks you will receive “STOP!” texts at random times. These will not be sent at weekends.

This is a strategy that can help you to remind yourself rather than other people telling you.

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY



- When you get a text message saying “**STOP!**” you should stop what you are doing, if it is safe to do so, and think about the things you have to do that day.
- This will include making the phone call to us, but also anything else you need to remember to do.
- You might need to meet a friend or do a piece of homework.

**When you get the text message ask yourself to:**

<b>S</b> top	<b>S</b> .....
<b>T</b> hink	<b>T</b> .....
<b>O</b> rganise	<b>O</b> .....
<b>P</b> lan	<b>P</b> .....

You can also ask yourself these types of questions:

‘What have I got to do and when?’

‘Do I need to be concentrating?’

‘Do I need to do anything differently now?’

What do you think would have happened if Adam had stopped for a second to think about the things he needed to do when on the bus?.....

Please read this sentence then fill out the ones below to help you remember:

When I get a text message saying “STOP!”, I should stop what I am doing if it is safe to do so, and think about the phone call to you and my other goals.



When I get a text message saying “STOP!”, I should stop what I am doing if it is safe to do so, and think about the phone call to you and my \_\_\_\_\_ .





When I get a text message saying “STOP!”, I should stop what I am doing if it is safe to do so, and think about the phone call to you

\_\_\_\_\_.



When I get a text message saying “STOP!”, I should stop what I am doing if it is safe to do so, and think about the phone call \_\_\_\_ \_

and \_\_\_\_\_.



When I get a text message saying “STOP!”, I should stop what I am doing if it is safe to do so, and \_\_\_\_\_

\_\_\_\_\_ and \_\_\_\_\_.

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

When I get a text message saying "STOP!", I should stop what I am doing if it is safe to do, and \_\_\_\_\_ and \_\_\_\_\_.

When I get a text message saying "STOP!", I should stop what I am doing \_\_\_\_\_, and \_\_\_\_\_ the \_\_\_\_\_ and \_\_\_\_\_.



When I get a get a text message saying "STOP!!", I should \_\_\_\_\_ I am \_\_\_\_\_, and \_\_\_\_\_ the \_\_\_\_\_ and \_\_\_\_\_.



**Don't forget to STOP, THINK, ORGANISE, PLAN**

## QUIZ

1. What does STOP! stand for?

S.....  
T.....  
O.....  
P.....

2. What are you going to do when you get sent a text message reading STOP!?



3. What kind of questions can you ask yourself when you get a text message reading STOP!?

*For example 'What have I got to do and when?'.....*



4. Slips.....can you think of a time when you made a mistake because you weren't thinking about what you were doing?

*For example have you forgotten to take something with you?*

5. How might stopping to think about the things you need to do help you?

6. Can things fall off our 'mental blackboard' if we don't check them?

YES.....

NO.....

7. What are the main things you will remember from today?

Well done for all your hard work!!!!!!

Appendix I: Participant background assessment

**Prospective Memory Project – Participant Details**

Project No..... Researcher..... Assessment  
Date.....

Date of Informed Consent.....

<b>Name:</b>	<b>DoB:</b>
Address:	Email address:
Mobile tel. no:	Backup tel. no:
Own mobile phone?	
Ethnicity:	Language spoken:
GP details:	School details:
Years of education: Highest qualification:	Details of any additional support at school:
Schooling history:	
Living Situation (e.g. alone or with family)	
Parent/ Significant Other (Name & relationship) Tel nos: Email address: Contact address (if different)	
Support (Who and how much)	
Referred by:	From:

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

<p><b>Aetiology:</b> Date of onset:</p>	
<p>Details (type, location, severity):</p>	
<p>Hospital:</p>	<p>Any rehab?</p>
<p>Any pre-injury physical or developmental issues?</p>	<p>Other health problems?</p>
<p>Transport:  Driving Y/N Able to use public transport Y/N Able to access transport to appointment Y/N</p>	<p>Preferred testing location:</p>
<p>Vocational Paid work/ voluntary work Full time/ part time</p>	<p>Leisure/ Hobbies/ Interests</p>
<p>Usual method of knowing the time Watch/ mob phone clock/ other/ none? Prefers digital or analogue?</p>	
<p>Method of planning, organising, keeping track etc.:</p> <p>Are any strategies used PDA Alarms Post-its To-do lists Diary Calendar Reminded by others Other</p>	
<p>Typical daily routine: (including any regular meetings, journeys, activities, where a telephone all would be inappropriate). (A = available time slots for phone calls</p>	

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Mobile phone details: Own phone - Yes / No Type - Network - PAYG/ Contract – free minutes? Does it have vibrate mode on silent: Yes / No Normal usage – Frequent/ Sometimes/ Occasionally/ Never at present Phone charged regularly – Yes / No Phone turned on regularly – Yes / No Use text messaging: Yes / No Stop and read immediately: Yes / No  Will require access to a mobile phone for the study: Yes / No Study mobile phone number (where applicable)
Times of daily calls to be made by participant?
Willing to be contacted by phone by the researcher daily? Best method of contact?

Appendix J: PRMQ: Self and proxy ratings

Prospective and Retrospective Memory Questionnaire (PRMQ)  
Self-Rating Version

**REMEMBERING TO DO THINGS**

The following questions are about minor memory mistakes that everyone makes from time to time, but some of them happen more often than others. We would like you to tell us how often these things happen to you. Please indicate this by ticking the appropriate box. Please make sure you answer all of the questions on both sides of the sheet, even if they do not seem entirely applicable to your situation.

---

	<b>Very Often</b>	<b>Quite Often</b>	<b>Sometimes</b>	<b>Rarely</b>	<b>Never</b>	
Do you decide to do something in a few minutes' time and then forget to do it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you fail to recognise a place you have visited before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you fail to do something you were supposed to do a few minutes later even though it's there in front of you, like take a pill or turn off the kettle?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you forget something that you were told a few minutes before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you forget appointments if you are not prompted by someone else or by a reminder such as a calendar or diary?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you fail to recognise a character in a radio or television show from scene to scene?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you forget to buy something you planned to buy, like a birthday card, even when you see the shop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you fail to recall things that have happened to you in the last few days?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please Turn Over

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

	<b>Very Often</b>	<b>Quite Often</b>	<b>Sometimes</b>	<b>Rarely</b>	<b>Never</b>
Do you repeat the same story to the same person on different occasions?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you intend to take something with you, before leaving a room or going out, but minutes later leave it behind even though it's there in front of you?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you mislay something, that you have just put down, like a magazine or glasses?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you fail to mention or give something to a visitor that you were asked to pass on?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you look at something without realising you have seen it moments before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If you tried to contact a friend or relative who was out, would you forget to try again later?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you forget what you watched on television the previous day?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do you forget to tell someone something you had meant to mention a few minutes ago?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for your time**



PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Prospective and Retrospective Memory Questionnaire (PRMQ)  
Relative-Rating Version

**REMEMBERING TO DO THINGS**

The following questions are about minor memory mistakes that everyone makes from time to time, but some of them happen more often than others. We would like you to tell us how often in your opinion these things happen to the person you have chosen to rate. Please indicate this by ticking the appropriate box. Please make sure you answer all of the questions on both sides of the sheet, even if they do not seem entirely applicable to your situation.

---

	<b>Very Often</b>	<b>Quite Often</b>	<b>Sometimes</b>	<b>Rarely</b>	<b>Never</b>	
Do they decide to do something in a few minutes' time and then forget to do it?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they fail to recognise a place they have visited before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they fail to do something they were supposed to do a few minutes later even though it's there in front of them, like take a pill or turn off the kettle?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they forget something that they were told a few minutes before?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they forget appointments if they are not prompted by someone else or by a reminder such as a calendar or diary?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they fail to recognise a character in a radio or television show from scene to scene?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they forget to buy something they planned to buy, like a birthday card, even when they see the shop?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they fail to recall things that have happened to them in the last few days?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

	<b>Very</b>	<b>Quite</b>					
		<b>Often</b>	<b>Often</b>	<b>Sometimes</b>	<b>Rarely</b>	<b>Never</b>	
Do they repeat the same story to the same person on different occasions?			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they intend to take something with them, before leaving a room or going out, but minutes later leave it behind even though it's there in front of them?			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they mislay something, that they have just put down, like a magazine or glasses?			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they fail to mention or give something to a visitor that they were asked to pass on?			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they look at something without realising they have seen it moments before?			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
If they tried to contact a friend or relative who was out, would they forget to try again later?			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they forget what they watched on television the previous day?			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Do they forget to tell you something they had meant to mention a few minutes ago?			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**Thank you for your time**

Appendix K: Prospective Memory Log (PML)



**Prospective Memory Log**

**Child's Name**

**Start Date**

**End Date**

Please record your child's ability to independently remember to carry out tasks or activities over a 1 week period. Tasks may include things like remembering to complete homework, feeding a pet or taking a packed lunch PE kit to school.

Please give 2 points for successful remembering, 1 point if a prompt was needed, and 0 points if the task was forgotten completely

Date Set	Task/ Activity/ Goal	Time to be completed (e.g. am/pm)	Rating (2 = Achieved; 1 = Achieved with a prompt; 0 = Not achieved)

**Please continue over the page if necessary:**

Appendix L: Feedback for

Date

Participant ID:

Question	0 = Not at all 10 = Very
<b>Routine:</b> How easy was it to include the phone calls in your daily routine?	
<b>Taking time to think:</b> How adequately did you take time out from what you were doing to think about the phone call tasks during the day?	
<b>Autopilot:</b> To what extent were you acting on autopilot during the study?	
<b>Achievement:</b> How much of what you intended did you actually achieve over the study	
<b>Intentions:</b> How much did the training help you carry out your other goals and intentions?	
<b>Effort:</b> How hard did you try to remember to make the phone calls?	
<b>Motivation:</b> How motivated were you to make the phone calls?	
<b>Importance:</b> How important was remembering to make the phone calls to you?	
<b>Difference?</b> How much difference did the STOP strategy make to you?	

Qualitative Feedback:

What were your experiences of taking part?

How did you do the task?

How did you use the STOP STRATEGY?

What difference did you notice (if any)?

Was your phone with you most of the time?

Did you use any other prompts or reminders during the study (e.g. your parents?)

Appendix M: Cambridgeshire 4 REC approval



**National Research Ethics Service**

**Cambridgeshire 4 Research Ethics Committee**

Victoria House  
Capital Park  
Fulbourn  
Cambridge  
CB21 5XB

Telephone: 01223 597685  
Facsimile: 01223 597645

18 November 2010

Miss Rebecca Rous  
Trainee Clinical Psychologist  
School of Medicine and HPP  
Elizabeth Fry Building  
University of East Anglia, Norwich  
NR4 7TJ

Dear Miss Rous

**Study Title:** Prospective Memory Intervention for Adolescents with  
Acquired Brain Injury: A Preliminary Study  
**REC reference number:** 10/H0305/62

Thank you for your letter of 25 October 2010, responding to the Committee's request for further information on the above research, and submitting revised documentation.

The further information was considered in correspondence by a sub-committee of the REC. A list of the sub-committee members is attached.

**Confirmation of ethical opinion**

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

**Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

The favourable opinion applies to the following research site(s):

Research Site	Principal Investigator / Local Collaborator
Herchel Smith Building	Miss Rebecca Rous

**Conditions of the favourable opinion**

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

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

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## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

For NHS research sites only, management permission for research ("R&D approval") should be obtained from the relevant care organisation(s) in accordance with NHS research governance arrangements. Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

*Where the only involvement of the NHS organisation is as a Participant Identification Centre (PIC), management permission for research is not required but the R&D office should be notified of the study and agree to the organisation's involvement. Guidance on procedures for PICs is available in IRAS. Further advice should be sought from the R&D office where necessary.*

*Sponsors are not required to notify the Committee of approvals from host organisations.*

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

### Approved documents

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

Document	Version	Date
CV for Academic Supervisor	Anna Adlam	
Clinical Recruitment Site Letter	3	01 August 2010
Global Management Training Outline	3	01 August 2010
WISC-IV subtest record forms		
BADS-C Sic part test record form		
Covering Letter		13 August 2010
Summary/Synopsis	1 Flowchart	01 August 2010
Letter from Sponsor	Email from Sue Steel	11 August 2010
Investigator CV	CI Rebecca Rous	13 August 2010
Response to Request for Further Information	Rebecca Rous	25 October 2010
Participant Information Sheet: Adolescent information sheet (16 - 17 years) pilot study	4	19 October 2010
Letter of invitation to participant	1 Parent and Child Introduction Letter	01 August 2010
GP/Consultant Information Sheets	1	01 August 2010
BRIEF parent rating questionnaire		
Evidence of insurance or indemnity	Letter from UEA and Zurich Municipal Certificate	11 August 2010
Referees or other scientific critique report	from Laura Jobson	01 June 2010
Questionnaire: The Behaviour Rating Inventory of Executive Functions		
Questionnaire: Prospective Memory Log	2	01 August 2010
Advertisement	1	01 August 2010
Participant Consent Form: Parent Consent Form	3	01 August 2010
Participant Consent Form: Head Teacher Permission Form	3	01 August 2010
Questionnaire: The Prospective and Retrospective Memory Questionnaire (Self-Rating)		
Questionnaire: The Prospective and Retrospective Memory Questionnaire (Relative-Rating)		

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## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Participant Information Sheet: (13-15 years)	3	01 August 2010
Participant Information Sheet: Pilot Study (13-15 years)	3	01 August 2010
Participant Information Sheet: Parent information sheet - pilot study	4	19 October 2010
Participant Information Sheet: Participant information sheet (13 - 15 years)	4	19 October 2010
Participant Consent Form: Permission to Share Contact Details Form	3	01 August 2010
REC application		13 August 2010
Participant Information Sheet: Participant information sheet (13 15 years)	4	19 October 2010
Participant Information Sheet: Parent information sheet	4	19 October 2010
Participant Information Sheet: Participant information sheet (16 and 17 years)	4	19 October 2010
Protocol	3	01 August 2010
CV for Secondary Academic Supervisor	Professor Malcolm Adams	01 June 2010
Global Management Training Example Quiz	3	01 August 2010
CMS Stories subtest record form		
CV for Collaborator	Dr Tom Manly	
CV for Collaborator	Dr Fergus Gracey	
RBMT Appointments subtest record form		
TEA-Ch Walk Dont Walk subtest record form		
Further description of measures document		

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

Now that you have completed the application process please visit the National Research Ethics Service website > After Review

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

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

- Notifying substantial amendments
- Adding new sites and investigators
- Progress and safety reports
- Notifying the end of the study

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

We would also like to inform you that we consult regularly with stakeholders to improve our service. If you would like to join our Reference Group please email

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PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

referencegroup@nres.npsa.nhs.uk.

10/H0305/62

Please quote this number on all correspondence

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

Yours sincerely

RP. N Storey

Dr Leslie Gelling  
Chair

Email: Nicky.Storey@eoe.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

*"After ethical review – guidance for researchers"*

Copy to: Tracy Moulton  
Research, Enterprise & Engagement Office  
The Registry  
University of East Anglia  
Norwich  
NR4 7TJ

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**National Research Ethics Service**  
**Cambridgeshire 4 Research Ethics Committee**

Victoria House  
 Capital Park  
 Fulbourn  
 Cambridge  
 CB21 5XB

Tel: 01223 597656  
 Fax: 01223 597645

14 December 2010

Miss Rebecca Rous  
 Trainee Clinical Psychologist  
 School of Medicine and HPP  
 Elizabeth Fry Building  
 University of East Anglia, Norwich  
 NR4 7TJ

Dear Miss Rous

**Study title:** Prospective Memory Intervention for Adolescents with Acquired Brain Injury: A Preliminary Study  
**REC reference:** 10/H0305/62  
**Amendment number:** Amendment 1  
**Amendment date:** 06 December 2010  
**Summary:** Lowering the age group of the study from 13 to 12.

The above amendment was reviewed on 16 December 2010 by the Sub-Committee in correspondence.

**Ethical opinion**

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

**Approved documents**

The documents reviewed and approved at the meeting were:

Document	Version	Date
Participant Information Sheet: Adolescent information sheet (16 - 17 years)	5	06 December 2010
Participant Information Sheet: Adolescent information sheet (12 - 15 years)	5	06 December 2010
Participant Information Sheet: Parent information sheet - pilot study	5	06 December 2010
Participant Information Sheet: Adolescent information sheet - pilot study (16 - 17 years)	5	06 December 2010
Participant Information Sheet: Adolescent information sheet - pilot study (12 - 15 years)	5	06 December 2010
Protocol	4	06 December 2010
Notice of Substantial Amendment (non-CTIMPs)	Amendment 1	06 December 2010
Permission in principle from Sponsor (UEA)		06 December 2010

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## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Recruitment site letter	4	06 December 2010
media advertisement (text content)	2	06 December 2010
Head teacher permission form	4	06 December 2010
Participant Information Sheet: parent information sheet	5	06 December 2010

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### R&D approval

All investigators and research collaborators in the NHS should notify the R&D office for the relevant NHS care organisation of this amendment and check whether it affects R&D approval of the research.

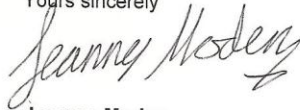
### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H0305/62:

Please quote this number on all correspondence

Yours sincerely



**Leanne Moden**  
Assistant Co-ordinator

E-mail: [leanne.moden@eoe.nhs.uk](mailto:leanne.moden@eoe.nhs.uk)

Enclosures: *List of names and professions of members who took part in the review*

Copy to: *Tracy Moulton  
The Registry  
University of East Anglia  
Norwich  
NR4 7TJ*



National Research Ethics Service

Cambridgeshire 4 Research Ethics Committee

Victoria House  
Capital Park  
Fulbourn  
Cambridge  
CB21 5XB

Tel: 01223 597653  
Fax: 01223 597645

15 March 2011

Miss Rebecca Rous  
Trainee Clinical Psychologist  
University of East Anglia  
School of Medicine and HPP  
Elizabeth Fry Building  
University of East Anglia, Norwich  
NR4 7TJ

Dear Miss Rous

**Study title:** Prospective Memory Intervention for Adolescents with Acquired Brain Injury: A Preliminary Study  
**REC reference:** 10/H0305/62  
**Amendment number:** Amendment 2  
**Amendment date:** 11 March 2011

Thank you for your letter of 11 March 2011, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

Document	Version	Date
Advertisement	3	11 March 2011
Protocol	5	11 March 2011
Notification of a Minor Amendment (email from R Rous)	Amendment 2	11 March 2011

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# PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

## Statement of compliance

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10/H0305/62:

Please quote this number on all correspondence

Yours sincerely

  
  
**Miss Susan Davies**  
**Committee Co-ordinator**

E-mail: susan.davies@eoe.nhs.uk

Copy to:

Mrs Tracey Moulton  
Research Office  
University of East Anglia  
Norwich  
Norfolk  
NR4 7TJ

Anna Adlam  
Clinical Lecturer  
University of East Anglia  
Norwich  
NR4 7TJ

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**National Research Ethics Service**  
NRES Committee East of England - Cambridge South

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Cambridge  
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02 August 2011

Miss Rebecca Rous  
Trainee Clinical Psychologist  
University of East Anglia  
School of Medicine and HPP  
Elizabeth Fry Building  
University of East Anglia, Norwich  
NR4 7TJ

Dear Miss Rous

**Study title:** Prospective Memory Intervention for Adolescents with Acquired Brain Injury: A Preliminary Study  
**REC reference:** 10/H0305/62  
**Amendment number:** Amendment # 3 (minor)  
**Amendment date:** 01 August 2011  
**Amendment summary:** The researchers would like to extend the end date of the study to 31 December 2011.

Thank you for your letter of 01 August 2011, notifying the Committee of the above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment	Amendment # 3 (minor)	01 August 2011

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for

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NRES Committee East of England - Cambridge South

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13 September 2011

Miss Rebecca Rous  
Trainee Clinical Psychologist  
University of East Anglia  
School of Medicine and HPP  
Elizabeth Fry Building  
University of East Anglia, Norwich  
NR4 7TJ

Dear Miss Rous

**Study title:** Prospective Memory Intervention for Adolescents  
with Acquired Brain Injury: A Preliminary Study  
**REC reference:** 10/H0305/62  
**Amendment number:** amendment # 4 (minor)  
**Amendment date:** 13 September 2011  
**Amendment summary:** The CI would like to add Miss Emily Drake to the  
project as a research assistant.

Thank you for your letter of 13 September 2011, notifying the Committee of the  
above amendment.

The Committee does not consider this to be a "substantial amendment" as defined in the  
Standard Operating Procedures for Research Ethics Committees. The amendment does  
not therefore require an ethical opinion from the Committee and may be implemented  
immediately, provided that it does not affect the approval for the research given by the R&D  
office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

Document	Version	Date
Notification of a Minor Amendment – email dated 13 September 2011	amendment # 4 (minor)	13 September 2011

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for

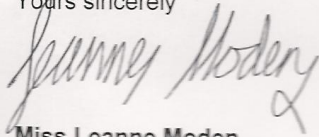
PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

10/H0305/62:

Please quote this number on all correspondence

Yours sincerely



**Miss Leanne Moden**  
**Assistant Coordinator**

E-mail: [leanne.moden@eoe.nhs.uk](mailto:leanne.moden@eoe.nhs.uk)

Copy to: Mrs Tracey Moulton  
Research Office  
University of East Anglia  
Norwich  
Norfolk  
NR4 7TJ

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Appendix N: R&D Approval

Cambridgeshire and Peterborough 

NHS Foundation Trust

*Understanding mental health, understanding people*

**CPFT R&D Department**

Box 277  
Addenbrooke's Hospital  
Hills Road  
Cambridge  
CB2 0QQ

17 December 2010

R&D Ref: M00415

[www.cpft.nhs.uk/Aboutus](http://www.cpft.nhs.uk/Aboutus)  
[r&d@cpft.nhs.uk](mailto:r&d@cpft.nhs.uk)

Miss Rebecca Rous  
University of East Anglia  
Trainee Clinical Psychologist  
School of Medicine and HPP  
Elizabeth Fry Building  
Norwich  
NR4 7TJ

Dear Miss Rous

**Study title: 10/H0305/62 Prospective Memory Intervention for Adolescents with Acquired Brain Injury: A preliminary study**

Further to reviewing your application for NHS permission to conduct the above named project, we are pleased to confirm that the research as described in the application form, protocol and supporting documentation has been approved.

A site specific assessment has also been conducted by R&D based on the information provided on the site specific information.

Any changes to the above research should be communicated to this Trust and to the relevant Ethics Committee, and protocols followed accordingly.

**Honorary Research Contracts (HRC)**

All researchers with no contractual relationship with any NHS body, who are to interact with NHS patients in a way that directly affects the quality of their care, should hold honorary NHS contracts (Access Letter or Research Passport). For more information on whether you or any of your research team will require an HRC please liaise with the R&D office. **It is your responsibility to inform us if any of your team does not hold NHS contracts.** Any additional researchers who join the study at a later stage must also hold a suitable contract.

**Risk and Incident Reporting**


Much effort goes into designing and planning high quality research, which reduces risk; however untoward incidents or unexpected events (i.e. not noted in the protocol) may occur in any research project. Where these events take place on trust premises, or involve trust service users, carers or staff, you must report the incident within 48 hours via the Trust incident reporting system on [www.cpft.nhs.uk](http://www.cpft.nhs.uk). Alternatively, you may contact the R&D department for further guidance.



HQ Elizabeth House, Fulbourn Hospital, Cambridge CB21 5EF  
T 01223 726789 F 01480 398501 [www.cpft.nhs.uk](http://www.cpft.nhs.uk)

V1 November 2010  
In partnership with the University of Cambridge



Cambridgeshire Community Services   
NHS Trust

Please reply to:  
R&D Office  
NHS Cambridgeshire  
Lockton House  
Clarendon Road  
Cambridge  
Cambridgeshire  
CB2 8FH

25/10/11

Miss Rebecca Rous  
School of Medicine, and HPP  
Elizabeth Fry Building  
University of East Anglia, Norwich  
NR4 7TJ

Direct Number: 01223 725466  
Email: [Vivienne.shaw@cambridgeshire.nhs.uk](mailto:Vivienne.shaw@cambridgeshire.nhs.uk)

Dear Miss Rous

**Re: Amendments 2, 3 & 4**

**Re: L001098 Prospective Memory Intervention for Adolescents with Acquired Brain Injury: A Preliminary Study**

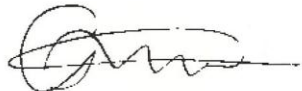
**Re: 10/H0305/62**

The amendment for the above research project has been reviewed for Cambridgeshire Community Services NHS Trust in accordance with the Department of Health Research Governance Framework.

Please accept this letter as confirmation of the Trust's positive governance review to continue to act as a patient identification centre (PIC).

We would welcome feedback about your experience of this review process to help us improve our systems. May we take this opportunity to wish you well with your research and we look forward to hearing the outcomes.

Yours Sincerely



Graham Nice  
Lead Nurse & Assistant Director Clinical Governance  
Cambridgeshire Community Services NHS Trust

cc: Miss Tracy Moulton

Cambridge University Hospitals NHS Foundation Trust

Research and Development Department

Box 277  
Addenbrooke's Hospital  
Hills Road  
Cambridge  
CB2 0QQ

R&D ref: A092253  
24<sup>th</sup> June 2011

Dr Amos Burke  
Consultant Oncologist  
Addenbrooke's Hospital  
Paediatric Oncology  
Ward C2  
Box 5

Direct Dial: 01223 348468 (Ext 58468)  
Switchboard: 01223 245151  
E-mail: [amos.burke@addenbrookes.nhs.uk](mailto:amos.burke@addenbrookes.nhs.uk)  
[rd@enquiries@addenbrookes.nhs.uk](mailto:rd@enquiries@addenbrookes.nhs.uk)  
[www.addn.org.uk](http://www.addn.org.uk)

Dear Dr Burke

Re: 10/H030562 Prospective memory intervention for adolescents with acquired brain injury: a preliminary study

In accordance with the Department of Health's Research Governance Framework for Health and Social Care, all research projects taking place within the Trust must receive a favourable opinion from an ethics committee and approval from the Department of Research and Development (R&D) prior to commencement.

I am pleased to confirm that Cambridge University Hospitals NHS Foundation Trust has reviewed the above study and agree to act as a Participant Identification Centre (PIC) referring potential participants to the relevant research team.

Please note that as a PIC the Trust does not provide indemnity for this study.

Sponsor: University of East Anglia

End date: 30/09/2011

Protocol: Version 5, dated 06/12/2010

The project must follow the agreed protocol and be conducted in accordance with all Trust Policies and Procedures especially those relating to research and data management.

Please ensure that you are aware of your responsibilities in relation to: The Data Protection Act 1998, NHS Confidentiality Code of Practice, NHS Caldicott Report and Caldicott Guardians, the Human Tissue Act 2004, Good Clinical Practice, the NHS Research Governance Framework for Health and Social Care, Second Edition April 2005 and any further legislation released during the time of this study.

Members of the research team must have appropriate substantive or honorary contracts with the Trust prior to the study commencing. Any additional researchers who join the study at a later stage must also hold a suitable contract.

If the project is a clinical trial under the European Union Clinical Trials Directive the following must also be complied with:

the EU Directive on Clinical Trials (Directive 2001/20/EC) and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Regulations 2004;

the EU Directive on Principles and Guidelines for Good Clinical Practice (EU Commission Directive 2005/28/EC); and UK's implementation of the Directive: The Medicines for Human Use (Clinical Trials) Amendment Regulations 2006;

Amendments

Please ensure that you submit a copy of any amendments made to this study to the R&D Department.

Annual Report

It is obligatory that an annual report is submitted by the Chief Investigator to the research ethics committee, and we ask that a copy is sent to the R&D Department. The yearly period commences from the date of receiving a favourable opinion from the ethics committee.

Please refer to our website [www.cuh.org.uk/research](http://www.cuh.org.uk/research) for all information relating to R&D including honorary contract forms, policies and procedures and data protection.

Should you require any further information please do not hesitate to contact us.

Yours sincerely

Louise Stockley  
Research Governance Manager

VS Feb 09

Addenbrooke's Hospital | Royal Hospital

Innovation and excellence in health and care

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

**Subject:** RE: [Fwd: RE: 10-H0305-62]  
**From:** "Carolyn Dunford" <cdunford@thechildrenstrust.org.uk>  
**Date:** Wed, June 15, 2011 7:46 am  
**To:** "R.Rous@uea.ac.uk" <R.Rous@uea.ac.uk>  
**Cc:** "Fiona Adcock" <fadcock@thechildrenstrust.org.uk> ([more](#))  
**Priority:** Normal  
**Options:** [View Full Header](#) | [View Printable Version](#) | [Download this as a file](#) | [View Message details](#)

Dear Becky,

Yes this is all that we need at our end. I will ask the clinicians to start handing out the packs and hope you get some more participants for your study. We look forward to hearing all about your study once it has been completed.

Good luck!

Carolyn

-----Original Message-----

From: [R.Rous@uea.ac.uk](mailto:R.Rous@uea.ac.uk) [mailto:[R.Rous@uea.ac.uk](mailto:R.Rous@uea.ac.uk)]  
Sent: 14 June 2011 21:02  
To: Carolyn Dunford  
Subject: [Fwd: RE: 10-H0305-62]

Dear Carolyn

I have been in touch with my ethics committee to inform them about using Tadworth as a patient identification site. However, they are unable to put anything formal in writing about this.

Below is my email correspondence. They have said that the ethics committee does not need to be informed about this. They have also cited relevant REC documentation to confirm this.

Is this enough for you at your end?

Thanks for your time  
Best Wishes

Becky

----- Original Message -----

Subject: RE: 10-H0305-62  
From: "Bailey Charis" <[Charis.Bailey@eoe.nhs.uk](mailto:Charis.Bailey@eoe.nhs.uk)>  
Date: Tue, June 14, 2011 2:57 pm  
To: "'[R.Rous@uea.ac.uk](mailto:R.Rous@uea.ac.uk)'" <[R.Rous@uea.ac.uk](mailto:R.Rous@uea.ac.uk)>  
Cc: "Davies Susan" <[Susan.Davies@eoe.nhs.uk](mailto:Susan.Davies@eoe.nhs.uk)>

Hi Becky

I cannot do that as, since the Committee don't need to know - as

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

per the information  
in my previous e-mail - they have not been informed.

If you want something in writing from the Committee, your request will have to go to the Chair who can respond on behalf of the Committee. However, this may take a little time, depending on his availability and other matters for him to review.

Please let me know how you would like to proceed.

With kind regards  
Charis

-----Original Message-----

From: [R.Rous@uea.ac.uk](mailto:R.Rous@uea.ac.uk) [mailto:[R.Rous@uea.ac.uk](mailto:R.Rous@uea.ac.uk)]  
Sent: 14 June 2011 12:49  
To: Bailey Charis  
Subject: RE: 10-H0305-62

Hi Charis  
Thanks so much.  
Would it be possible to just say in some kind of written format that your ethics committee is aware that I will be using the Tadworth Childrens Trust as a patient identificaiton site and that there are no problems with this?

Best Wishes  
Becky

> Hi Becky  
>  
> Here is the relevant reference I have found for you: -  
>  
>  
> "Management permission or approval must be obtained from each host  
> organisation prior to the start of the study at the site concerned.  
>  
> Management permission ("R&D approval") should be sought from all NHS  
> organisation(s) involved in the study in accordance with NHS research  
> governance arrangements. Guidance on applying for NHS permission for  
> research is available in the Integrated Research Application System  
> (IRAS) or at <http://www.rdforum.nhs.uk>.  
>  
> Where a NHS organisation's role in the study is limited to identifying  
> and referring potential participants to research sites ("participant  
> identification centre"), guidance should be sought from the R&D office  
> on the information it requires to give permission for this activity.

Appendix O: Parent consent form

**PARENT CONSENT FORM**

**LREC Reference Number:**

**Title of Project: Prospective Memory**

**Name of Researcher: Rebecca Rous (Trainee Clinical Psychologist)**

**Please put your initials in the boxes below**

1. I confirm that I have read and understand the information sheet dated 20/05/2010 (version 2) for the above study and have had the opportunity to ask questions.

Initials here

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

Initials here

3. I am satisfied that the information I give will be kept confidential, and I understand that data collected during the study will be looked at by the researchers, and that any reports that are written will not include any personally identifiable details of the people who take part in the study.

Initials here

4. I agree to completing some questionnaires at set points in the study

Initials here

5. I agree that my child may take part in the above study.

Initials here

I want my child.....(write name here)..... to participate in this study

-----  
Name of Parent/Guardian

-----  
Date

-----  
Signature

-----  
Name of researcher taking consent

-----  
Date

-----  
Signature

Appendix P: Adolescent assent form

**ADOLESCENT ASSENT FORM**

**Title of Project: Prospective Memory**

**Name of Researcher: Rebecca Rous (Trainee Clinical Psychologist)**

**LREC Reference Number:**

**Please circle YES or NO**

- |   |         |
|---|---------|
| 1. Have you read (or had read to you) about this project?           | YES/ NO |
| 2. Has the researcher (Rebecca Rous) explained this project to you? | YES/ NO |
| 3. Do you understand what this project is about?                    | YES/ NO |
| 4. Have you asked all the questions you want?                       | YES/ NO |
| 5. Have you had your questions answered in a way you understand?    | YES/ NO |
| 6. Do you understand it's OK to stop taking part at any time?       | YES/ NO |
| 7. Are you happy to take part?                                      | YES/ NO |

***If any answers are 'no' or you don't want to take part, don't sign your name!***

If you **do** want to take part, you can write your name below:

Your  
name.....  
Sign.....  
Date.....

Name of the researcher who explained this project to you and let you ask questions:

----- Name of researcher taking consent	----- Date	----- Signature
---	---------------	--------------------

Name of your parent or guardian:

----- Name of Parent/Guardian	----- Date	----- Signature
----------------------------------	---------------	--------------------

Appendix Q: Adolescent consent form

**ADOLESCENT CONSENT FORM**

**Title: Prospective Memory Research Project**

**Name of Researcher: Rebecca Rous (Trainee Clinical Psychologist)**

**Please initial boxes**

1. I have read and understood the information sheet for this study and have been able to ask questions.
2. I understand that my participation is voluntary and that it is ok to stop taking part at any time, without giving any reason, and without my health care being affected.
3. I give permission for the research team to look at sections of my medical records to help them find some information about me for this project.
4. I am happy for the research team to contact my GP to tell them that I am taking part in this project.
5. I agree to complete some questionnaires during the study
6. I agree that I want to take part in this study.
7. I would like to be sent a summary of the results when the project has finished.
8. In the future I am happy to be contacted by Dr Anna Adlam (UEA) and the research team about other research studies, and I understand that this does not mean I would have to take part.

-----  
Name of Participant

-----  
Date

-----  
Signature

-----  
Name of Researcher

-----  
Date

-----  
Signature

Appendix R: Written record of call times

*Please try to remember to make a phone call to us on:*

**01223 273737**

*at the following times every day except weekends.*

- 
- 
- 
  
- Please leave your name and which phone call of the day it is (e.g. your first call)
- If you forget to make a call, please make it as soon as you remember about it, even if it is very late
- If the call is late, please give a reason e.g. 'I forgot' or 'I was meeting a friend'
- Just for this study please do not use any reminders like alarms, or asking someone to help you remember to make these calls.
- Thank you

*If you have any questions or problems relating to the study, please contact Becky Rous on 07758 235215 or email [R.Rous@uea.ac.uk](mailto:R.Rous@uea.ac.uk)*

**Thank you very much for taking the time to help us with our research**



Appendix S: Pilot study information sheets

**Parent Information Sheet**

**Prospective Memory Research Project – PILOT STUDY**

My name is Rebecca Rous, and I am a trainee clinical psychologist at the University of East Anglia (UEA). We would like to invite your child to take part in a research study evaluating a strategy that may help young people remember to do things in the future. It would involve your child taking part in thinking skills training, receiving text messages and making phone calls to a researcher on a mobile phone. This would not be during school time.

**Please read on if you are interested and would like to find out more**

Please take time to read the following information. Before you agree for your child to take part you must be clear about what the project involves. You do not have to decide today, and can talk to others about the study if you wish. Please ask if anything is not clear, or if you would like more information.

**What is prospective memory?**

Prospective memory is remembering to do something in the future, like passing on a message or attending an appointment.

**What is the purpose of the study?**

An acquired brain injury is an injury that happens to the brain after birth. It could be caused by many things such as an accident or illness. After brain injury people often have problems with prospective memory, and struggle to plan, organise and remember to do things in the future. This can be disabling and can interfere with the lives of those affected. We are interested in finding out we can help improve people's ability to remember and carry out things they intended to do. This study is looking at one promising strategy that involves sending text messages to participants' mobile phones to remind them to pause and review their goals.

**Why has my child been chosen?**

We are looking at teenagers between the ages of **12 and 17 years**, and we think your child may be the right age to take part. We are carrying out a test study in preparation for larger project with adolescents who have sustained a brain injury. This test study will help guide our research.

**Does my child have to take part?**

No, it is up to you and your child to decide whether to take part. If you decide not to take part we will respect your decision, and it will not affect any future healthcare that your child may receive. If you and your child do decide to take part, we will ask you to sign a consent

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

form before your child begins the project. We will give you a copy of the form and this information sheet to keep. You are free to change your minds and not take part at any time without giving a reason. If you chose to withdraw the information you and your child have already provided will be destroyed and not used in the research.

### **What will happen if my child takes part in the study?**

If your child wishes to participate, and you give consent for them to do so, we would ask you to be involved in the study for about 4 weeks. We will come and see you at your home or a local clinic. Most meetings will last about an hour.

- We will arrange a meeting and will ask you and your child to fill out some short questionnaires.
- We will ask your child to try and remember to make three mobile phone calls a day to our answering machine. This will be for 3-weeks. Calls will not be during school hours and we will discuss call times with you and your child.
- The researcher will also telephone your child quickly at the end of each day over the 3-week period to review any missed phone calls, but if you are happy with this.
- If your child doesn't have a mobile phone we will lend them one during the study, and will pay the call charges. But we will ask that they please don't use our credit for personal calls, or they might have to stop being in the study.
- After one week, we will give your child some training about remembering to do things.
- Then, on some days we will send reminder text messages to your child's mobile phone, asking them to use the training strategy to try and remember to do the things they need to that day, including the phone calls you have been asked to make.
- At the end we will ask you and your child how you felt about the training and text messages. We will also ask you to fill out some questionnaires.

### **Expenses and payments**

We are unable to provide any expenses or payments for taking part in this research.

However, your child will receive a £10 book voucher to thank them. Costs incurred including mobile phone calls will be covered, and we ask that credit is used responsibly.

Unfortunately, extensive misuse of our phone credit may result in exclusion from the study.

### **Are there any risks to my child?**

The main disadvantage is the amount of time it will require, as the project involves attending assessments, training sessions and making phone calls, and we are asking you and your child to commit to the project for a few weeks. Although this is quite a lot of work, the time involved each day will typically be quite small, for example perhaps as little as 10 minutes

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

during the phone call task weeks. Also all appointments will be arranged at times that are convenient for you and your child. If your child became tired, stressed or upset in anyway, the study would be stopped immediately.

### **What are the potential benefits?**

Although the study hopes to identify effective strategies to help teenagers remember to do something in the future, we do not know yet whether these strategies are useful for younger people. Therefore, it may be best not to assume that involvement in the study will benefit you or your child personally. In the future, the information we get might help young people with memory problems after brain injury.

### **Will my child's taking part be kept confidential?**

Information collected about you and your child during the study will be kept anonymous and safe. This means we won't write your child's name or address on any questionnaires.

Information will be stored by the researcher in a locked cabinet, or on a password protected computer. When the study is finished all information will be stored in a locked drawer, at the University of East Anglia for 15 years. It will then be destroyed.

With your permission we would let your child's GP know that your child is participating in this study. The only other time we would disclose any of the information that you have given us, would be if criminal or other inappropriate behaviour was made known.

### **What will happen to the results of the study?**

After the study the results may be reported in an article or at meetings, but your child's name will not be on any reports that are written. We would be happy to send you and your child a copy of our findings if you would like.

### **Who is organising the research?**

The University of East Anglia is running and funding the study.

### **Who has reviewed the study?**

To protect your interests, before any research starts it needs to be checked that it is fair. This study has been reviewed and approved by the Cambridge 4 Research Ethics Committee.

### **What if there is a problem?**

If you have any questions or experience any difficulties please contact me (Rebecca Rous), or Dr Anna Adlam. Our contact details are:

University of East Anglia, School of Medicine, Health Policy & Practice, Norwich, NR4 7TJ

Telephone number: 01603 593310.

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

### **Further information and contact details**

For further information about the project please contact Rebecca Rous ([r.rous@uea.ac.uk](mailto:r.rous@uea.ac.uk)) or Dr Anna Adlam ([a.adlam@uea.ac.uk](mailto:a.adlam@uea.ac.uk)) at the University of East Anglia, on Faculty of Health, Elizabeth Fry Building, Norwich, NR4 7TJ, Telephone: 01603 593310. We will be happy to discuss any questions you might have.

**Thank you for taking time to read this sheet.**

**Adolescent Information Sheet (16-17 years)**  
**Prospective Memory Research Project – PILOT STUDY**

Hello! My name is Rebecca Rous. I am studying to be a clinical psychologist and I am doing a project for my course.

I would like to ask you to take part. It would involve doing some thinking skills training, getting sent some text messages and making phone calls to me from a mobile phone. This would not be in school time. We are doing this to try to help teenagers remember to do things they need to.

You can choose if you want to take part. Before you choose we would like you to read this information (or ask someone to read it for you). You can discuss this with your family, friends, doctor or nurse if you want. You can ask us as many questions as you like. You don't have to decide right now.



**Please read on if you are interested**

**and would like to find out more**



**Why are we doing this research?**

An acquired brain injury is an injury that happens to the brain after birth. It could be caused by many things such as an accident or illness. We know that brain injuries can change young people's lives and stop people from doing all the things they want.

After brain injury one thing many people have problems with is remembering to do things like passing on a message to a teacher or meeting a friend. We want to find out how we can help people to remember to do things. We are looking at one way that we think might help by sending text messages to people's mobile phone.

**Why have I been asked?**

We are looking at teenagers between the ages of **12 and 17 years**. We think you might be the right age to take part.

**Do I have to take part?**

No, taking part is up to you. If you decide you don't want to take part it doesn't matter and no one will be upset. Any treatment you have will not be affected. If you do decide to take part we will ask you to sign a form. We will give you a copy of the form and this information sheet

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

to keep. You can change your mind and stop doing the research at any time during the project. If you do chose to stop taking part, any information you have already given us will be destroyed and will not be used in the research.

### **What would I have to do?**

We would ask you to be involved in the study for about 4 weeks. If you choose to take part we will come and see you at your home or a local clinic. Most meetings will last about an hour.

- We will start by asking you and your parent to fill out a few short questionnaires.
- Another day we will give you some training about remembering to do things.
- We will ask you to try and remember to make three phone calls from a mobile phone each day to our answer machine. This will be for 3-weeks. If you don't have a mobile phone we will be able to lend you one during the study, and will pay the call charges. But we will ask you please to not use our credit for personal calls, or you might have to stop being in the study.
- We will call you quickly at the end of each day over the 3-weeks to ask about any missed phone calls, but only if you are happy with this.
- On some days we will send reminder text messages to your mobile phone, asking you to pause and think about things you are trying to remember to do that day, including the phone calls you have been asked to make.
- At the end we will ask you how you felt about the training and text messages. We will also ask you to fill out some questionnaires.

### **Is there anything to be worried about?**

Taking part will take up some of your time, because we are asking you to answer questions, attend a training session and make phone calls. We are asking you to take part for about 8 weeks. Although this is quite a lot of work, the time involved each day may be quite small, for example it may be as little as 10 minutes during the phone call task weeks. Also appointments will be arranged at times that are ok for you to fit in with your daily life.

### **What are the benefits?**

We can't promise the study will help you but the information we get might help other young people with memory problems after brain injury in the future.

### **Who will know what I said?**

Only the researcher (Rebecca Rous) will see your answers and the number of phone calls you make. Information about you will be kept safe and locked away. Your name and contact details and will be separate from other information about you. This means we won't ask you to write your name or address on any sheets. When the study is finished all

## PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

information will be stored in a locked drawer, at the University of East Anglia for 15 years. It will then be destroyed.

With your permission we would let your GP know that you are participating in this study. If you told us something that was worrying then we might have to share it with your parents or others involved in your care, but that is the only time we will pass on information about you.

### **What happens at the end of the study?**

After the study the results may be reported in an article or at meetings, but your name will not be on any reports that are written. As an important member of our team, we would be happy to send you a copy of our findings if you would like.

### **Who is organising the research?**

The University of East Anglia is running and funding the study. The University will pay for the mobile phone calls you make to us, and any travelling to us you need to do. You would also get a £10 book voucher to thank you for your time

### **Who has reviewed the study?**

Before any research starts it needs to be checked that it is fair. This study has been approved by the National Research Ethics Committee.

### **Further information or problems**

If you or your parents have any questions or problems, please ask me. Or contact Dr Anna Adlam ([a.adlam@uea.ac.uk](mailto:a.adlam@uea.ac.uk)) at the University of East Anglia, Faculty of Health, Elizabeth Fry Building, Norwich, NR4 7TJ, Telephone: 01603 593310.



**Thank you for reading this and thinking about taking part.**

**Participant Information Sheet (12 – 15 years)**  
**Prospective Memory Research Project – PILOT STUDY**

Hello! My name is Rebecca Rous and I am studying to be a clinical psychologist and I am doing a project for my course.

I would like to ask you to take part. You can choose if you want to take part. Before you choose we would like you to read this information (or ask someone to read it for you). You can ask us as many questions as you like. You don't have to decide now.

**Why are we doing this research?**

An acquired brain injury is an injury that happens to the brain after birth. It could be caused by many things such as an accident or illness. We know that brain injuries can change young people's lives and stop people from doing all the things they want.

After brain injury one thing many people have problems with is remembering to do things, like passing on a message to a teacher or meeting a friend. We are looking to find out how we can help young people to remember to do things. We are looking at one way that we think might help, by sending text messages to people's mobile phone.



**What would I have to do?**

If you and your parents choose that you would like to take part we will come and see you at home or at a clinic. We would ask you to be involved for about 4 weeks.

- We will meet you and a parent to ask some questions.
- Another day we will ask you to take part in some thinking skills training,
- We will also send you some text messages and ask you to remember to make phone calls to our answer machine using a mobile phone. This would be everyday for three weeks, but would not be in school time.
- At the end we will ask you how you felt about having the training and text messages.



**Why have I been asked?**

We are looking at teenagers between the ages of **12 and 17** years. We think you might be the right age to take part.

**Do I have to take part?**

You can say yes or no. It doesn't matter if you don't want to, and no one will be upset. You can change your mind and stop doing the project at any time. If you chose to stop taking part, any information you have already given us will not be used in the research.



**Who will know what I said?**

Only the researchers will see your answers and the number of phone calls you make. The things we talk about will be kept safe and locked away.

With you and your parents' permission we would let your GP know that you are participating in this study. If you told us something that was worrying then we might have to share it with your parents, but that is the only time we would pass on information about you.

**What happens at the end of the study?**

We will write a report to let people know what we have found. This will not have your name on it. You can have a copy of what we find out if you like.

**More information:** If you or your parents have any questions, please contact me (Rebecca Rous, [r.rous@uea.ac.uk](mailto:r.rous@uea.ac.uk)), or Dr Anna Adlam ([a.adlam@uea.ac.uk](mailto:a.adlam@uea.ac.uk)) at: University of East Anglia, Faculty of Health, Elizabeth Fry Building, Norwich, NR4 7TJ, Telephone: 01603 593310.



**Thank you for reading this!**

If you think you would like to take part we will ask you and your parents to sign a form. You can have a copy of this sheet and the form to keep.

Appendix T: Pilot study summary

Table A6. Summary of pilot study data for each neurologically healthy participant

Participant Details	Data
<p>Pilot Case 1: 54 year old female Involvement: Piloted full telephone task procedure (3 weeks of calls plus GMT)</p>	<p>Week 1: Percentage of calls achieved = 93%; Average daily composite score = 12.8 Cued days: Percentage of calls achieved = 100%; Average daily composite score = 15.2 Un-cued days: Percentage of calls achieved = 100%; Average daily composite score = 8.8</p>
<p>Pilot Case 2: 17 year old female Involvement: Piloted full telephone task procedure (3 weeks of calls plus GMT)</p>	<p>Week 1: Percentage of calls achieved = 66%; Average daily composite score = 5.4 Cued days: Percentage of calls achieved = 60%; Average daily composite score = 4.8 Un-cued days: Percentage of calls achieved = 73%; Average daily composite score = 7.8</p>
<p>Pilot 3: 12 year old male Involvement participated in GMT session</p>	<p>Feedback: Typical everyday PM tasks include music practice, passing on a telephone message, remembering to feed pet. 'The training made sense. The quiz was easy'.</p>

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Appendix U: Distribution statistics for cued and un-cued data

Table A7 Data distribution statistics for mean proportion and composite scores across cued and un-cued telephone task conditions at a single-case and group level

	Cued				Uncued			
	N	Skewness	Kurtosis	S-W	N	Skewness	Kurtosis	S-W
<b>Proportion score</b>								
Participant 1	5	2.24	2.44	< <b>.01</b>	5	-.48	-.72	.32
Participant 2	5	0.61	-3.33	< <b>.01</b>	5	0.61	-3.33	< <b>.01</b>
Participant 3	5	-2.24	5.00	< <b>.01</b>	5	-1.72	2.71	<b>.02</b>
Participant 4	5	-0.54	-0.54	.32	5	-0.41	-0.24	.81
Participant 5	5	-1.02	-9.65	<b>.05</b>	5	-0.06	2.00	.33
Participant 6	5	2.24	5.00	< <b>.01</b>	5	2.24	5.00	< <b>.01</b>
Participant 7	5	0.61	-3.33	<b>.01</b>	5	0.06	2.00	.33
Group	7	1.17	1.84	.27	7	0.60	-1.08	.49
<b>Composite score</b>								
Participant 1	5	1.01	2.55	.20	5	1.54	1.95	.09
Participant 2	5	0.48	-1.08	.66	5	-0.48	0.09	.88
Participant 3	5	0.61	-1.60	.59	5	0.14	-1.67	.34
Participant 4	5	1.07	1.13	.50	5	-0.54	-0.59	.70
Participant 5	5	0.83	0.59	.82	5	-0.36	-2.41	.50
Participant 6	5	-0.61	-3.33	<b>.01</b>	5	0.81	-1.54	.20
Participant 7	5	-0.48	1.22	.78	5	1.41	1.33	.12
Group	7	-0.60	0.16	.91	7	0.27	-1.85	.40

*Note.* S-W = Shapiro-Wilk test; Bold typeface represents a significant deviation from a normal data distribution.

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Table A8 Levene's test for homogeneity of variance for mean proportion and composite telephone task scores at a single-case level.

Proportion score	Levene statistic	df1	df2	Significance
Participant 1	2.14	1	8	.18
Participant 2	0.04	1	8	.84
Participant 3	3.29	1	8	.11
Participant 4	0.58	1	8	.47
Participant 5	0.82	1	8	.39
Participant 6	< 0.00	1	8	.96
Participant 7	0.08	1	8	.79
Composite score				
Participant 1	1.00	1	8	.35
Participant 2	0.28	1	8	.61
Participant 3	5.75	1	8	<b>.04</b>
Participant 4	0.11	1	8	.75
Participant 5	0.71	1	8	.42
Participant 6	0.46	1	8	.52
Participant 7	0.12	1	8	.74

*Note.* df = degrees of freedom; bold typeface represents a significant difference between the variance of cued and uncued scores.

PROSPECTIVE MEMORY IN PAEDIATRIC ACQUIRED BRAIN INJURY

Appendix V: Rater agreement for phone-call task omissions

Table A9 Rater agreement for phone call omissions

No.	Reason for late or missed phone call	R1	R2	R3
1	Taking part in a memory training session with the researcher	1	1	1
2	Attending a doctor's appointment	1	1	1
3	Attending a hospital appointment	1	1	1
4	Being in the bath	0	0	0
5	Having surgery in hospital	1	1	1
6	Feeling unwell	0	0	0
7	Revising for exams	0	0	0
8	Playing football	0	0	0
19	Playing on an x-box	0	0	0
10	Falling asleep for a nap after school	0	0	0
11	Being busy	0	0	0
12	Spending the day with your grandparents	0	0	0
13	Going on a picnic in woods with no phone reception	1	1	1
14	Your mum taking away your phone because you were 'naughty'	1	1	1
15	Being at the gym	0	0	0
16	Watching TV	0	0	0
	Total agreement	100%		

*Note. 1 = valid reason for omission to be excluded from data analysis; 0 = non-valid reason for omission to be included in data analysis.*